THE UNIVERSITY *of York*

S | P | R | U

SOCIAL POLICY RESEARCH UNIT

A Review of the Research Evidence Surrounding Risk Perceptions, Risk Management Strategies and their Consequences in Adult Social Care for Different Groups of Service Users

Wendy Mitchell and Caroline Glendinning

A CIP catalogue record for this report is available from the British Library.

Further copies of this report or any other Social Policy Research Unit publication can be freely obtained by visiting our website:

www.york.ac.uk/spru

Paper copies can be obtained from:

The Publications Office
Social Policy Research Unit
University of York
Heslington
York
YO10 5DD

Contents

List of tables

Acknowledgements

Executive Summary

This summary reports the results of a review of the research evidence on the perceptions and management of risk amongst adult social care service users conducted by researchers at the Social Policy Research Unit, University of York. The summary is divided into four sections; the first outlines the aims, scope and methods of the review, the second section presents an overview of the evidence base; the third summarises key findings from the evidence reviewed and the fourth section, identifies gaps and areas for future research.

Aims, scope and methods of the review

Key aims:
- 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, including the impact of corporate and organisational factors on the behaviour of front line staff.
- To identify gaps on the perceptions and management of risk within and between different groups of adult social care service users and professional staff.

Recognising the complex and extremely large and diverse literature surrounding 'risk' and adult social care, clear study criteria and boundaries were established.

The review identified and reported:
- Recent data from 1990 onwards.
- Concentrated on empirically based research conducted in the UK, largely England.
- A range of services provided by public, private, formal/voluntary and informal sectors and also user-directed support services.
- Research involving different groups of service users, specifically, older people, disabled people, drug and alcohol service users, black and ethnic minority people, young people moving from child to adult services and informal carers.
- Evidence from a range of academic disciplines, especially, social policy, sociology and psychology.

The review excluded the following research:
- Unpublished or 'grey' (soon to be published was included).
- Acute mental health service users and their families.
- Conducted in clinical settings or with a primary focus on health care.
- Discussing or evaluating specific risk management tools or policies.

- Calculating statistical probabilities of risks occurring in health or social care settings

The researchers employed a range of search strategies. Seven key databases and four relevant websites were searched, 31 academics and risk researchers were consulted and a small number of key journals were hand searched. A list of potential search terms was developed and initial literature searches identified a large number of references (1,309) which were entered onto Endnote. However, it was clear that many of these did not fall within the study's criteria. The researches thus employed a three stage process of inclusion and exclusion, 151 references were finally included in the review. These references were read and relevant information from each was entered onto an Access database.

Evidence base – its scope and characteristics

Within the 151 references identified, 92 were classified as original empirical research, 13 were literature reviews (largely empirical evidence), 42 were scholarly discussions (literature reviews and author commentary) and two were project reports. Ninety-four references (empirical and project reports) focused solely on reporting empirical research.

The evidence surrounding risk and adult social care was not evenly balanced in terms of either the type of social care services or participants involved. Research focused largely on three groups of service users; older people (46 references out of 151), disability (22) and mental health (19). A general overview of different types of services was provided by 44 references, however, these also concentrated on the above three service areas. In addition, 20 out of the 22 disability related studies focused on learning disabilities. The review only identified a very small number of studies specifically on risk and black and ethnic minority people (3), young people in transition to adult services (12) and people who misuse substances (3). In addition, a third of studies (32) focused solely on the views of practitioners, the views of only service users (5) and informal carers (2) were noticeably absent. Service users' views were more likely to be presented when they complimented or contested the views of practitioners or informal carers.

The review also demonstrated that the vast majority of empirical research was qualitatively based (80 out of 94 references), frequently small scale exploratory or case studies drawing on specific samples and based in limited geographical and care locations. Only two studies were quantitative, 12 studies employed both qualitative and quantitative methods, usually a mix of interviews and questionnaires.

Literature overview

Although 151 references were identified and reviewed, only 94 were actually empirically based studies and some also discussed the same study. Furthermore, many of the 57 literature reviews and scholarly discussions included in the study reviewed these same empirical studies. The actual evidence base surrounding risk and adult social care that currently exists is thus smaller and more limited than the number of identified references would suggest. Themes and issues emerging from the three key areas of research evidence identified; namely, perceptions of risk and its management in mental health, older age and disability are summarised in this executive summary. The summary also only focuses on references identified as primary empirical research.

Mental health
The majority of studies concentrated on risk and 'danger'. Mental health service users were presented as a 'danger' to others, both family members and community participants.

- Research focused largely on the views of mental health practitioners, particularly in relation to how practitioners and staff assess the degree of 'danger' that mental health service users pose and the management strategies employed or regarded as most appropriate to employ.
- The importance of the wider socio-economic context was noted, especially with regard to litigation fears and issues of blame for practitioners arising from public inquiries or 'scandals'. Practioners were also very aware of their 'duty of care' both to service users and their families and also to the wider public.
- Research also noted the issue of racism with associations of 'black' and 'dangerousness' (especially young black males) drawing on racial and cultural stereotypes.

In contrast, there was an absence of research exploring mental health service users' views and experiences.

- Only a very small body of research explored service users experiences of risk and the danger of self-harm or injury, social stigma and/or isolation in the community within which service users lived, increased surveillance from others, particularly practitioners and the potential negative effects of medication.

There was also less focus on perceptions of risk and the management practices employed by informal carers compared to research on other types of social care.

Older people
The majority of studies identified concentrated on everyday risks older people encountered when returning home or seeking to remain in their own home.

- Research focused on the physical risks that older people could encounter, especially 'slips, trips and falls'.
- The importance of risk taking for older people was explored, particularly the idea of older people weighing up the costs and benefits of taking risks. Research demonstrated that risk taking activities could be 'covertly' undertaken by older people unbeknown to carers or practitioners supporting them. Some of the benefits were discussed in terms of psychosocial effects such as, feelings of well-being associated with greater independence, control and a sense of 'normality'. There was less research on risk and damage to psychological well-being.
- Research also focused on the process of risk assessment during hospital discharge, in particular, how risk was viewed and the process of assessment experienced by different groups such as, service users and practitioners.

The evidence base surrounding older people included a range of perspectives and experiences. Views of risk and different management strategies prioritised and adopted by service users, informal carers and practitioners were all explored. Research also demonstrated the importance of placing what is viewed as 'risky behaviour' and how it could/should be managed in the context of everyday life for both service users and their carers.

- Risk and the importance of service user and carers' subjective ideas and interpretations were apparent. These could conflict with or challenge practitioner ideas and practices.
- The importance of seeking a 'normal' life or as 'normal as possible' was also important. Normality was frequently redefined by both service users and carers as life circumstances (physical/social) changed.

Disability

As noted above, empirical research focused predominately on risk and adults with learning disabilities, there was a noticeably absence of research on adults with other or multiple impairments, such as physical or sensory impairments.

- Much of the research evidence was grounded in the theoretical framework of normalisation. Risk and risk taking was viewed as part of everyday life with a positive potential in terms of personal self-development and learning, especially for adults with learning disabilities.
- Studies highlighted that staff and practitioners working with adults with learning disabilities frequently recognised and often promoted these normalisation ideas. However, research also demonstrated that staff and practitioners ideas and suggested normalisation practices/policies could conflict with parents/carers views of risk, the everyday dangers that adults with learning disabilities could face and how these risks should be managed.

The evidence base identified explored the views of different parties (service users, parents/carers and practitioners).

- The risks associated with pursing a 'normal' life were a key focus, for example, gaining independence, household tasks and meeting other people, especially members of the opposite sex and sexuality.
- However, the views of parents/carers were often reported in greater depth compared to those of adults with learning disabilities.
- It was also clear that parents/carers adopted different risk strategies depending on how they viewed risk and its acceptability or inevitability in their son/daughter's everyday life experiences. Some parents sought to avoid risk, whereas others prioritised risk management rather than complete avoidance.

Gaps in the evidence base and areas for future research

Reviewing the literature surrounding perceptions of risk and its management in adult social care has indicated that there are a number of gaps in the evidence base where more research would be advantageous. These can be summarised as follows:

Mental health
- Voice and perspective of mental health service users and their informal carers.

Disability
- Perceptions and management of risk by different groups of disabled people, especially those with physical, sensory or multiple impairments and also those who experience fluctuating levels of impairment or health conditions.
- Exploring risk and disability from a broader theoretical framework, in particular, the social model of disability and the idea of risk and a disabling society.

Wider socio-economic circumstances
- Impact of gender on risk and its management, both in terms of gender of service users and also, the gender of practitioners and/or informal carers.
- Impact of ethnic and cultural diversity on risk and its management, in particular, service users' ethnicity and/or cultural practices or preferences and similarly, practitioners and informal carers' ethnicity and/or culture.
- Effects on risk taking and its management on access to different types and levels of social and material resources, especially the different types and levels of access experienced by service users and informal carers.

Psychological well-being
- Particularly how risks to psychological well-being are managed by service users and also others (service users, informal carers and practitioners).

New developments: technology and self-directed support arrangements.

- Impact of 'smart' technology (such as electronic alarm systems) on the risk views, experiences and management strategies adopted by different groups (service users, informal carers and practitioners).
- Potential risks emerging for direct payment and individual budget users and their employees/helpers.

Methods
- Research conducted using quantative methods, drawing on larger, more diverse samples and conducted in a range of geographical and care locations.

Chapter 1   Introduction

1.1   Aims and objectives of the study

The aim of the scoping study was to identify and review research evidence on definitions of risk and on risk-related practice within the field of adult social care. The concept of 'risk' is an extremely broad and complex area with many potential dimensions that could be explored. Indeed, in late modern society, 'risk' has become a term frequently used as a short-hand in a wide range of areas and disciplines but with very different meanings and interpretations. Hence, some of the subtleties surrounding 'risk' and its use as a term may be ignored or glossed over.

Recognising the importance of this diversity but also the necessity and practicality of defining and establishing conceptual boundaries, it was decided that this review would focus on perceptions and definitions of 'risk'; in particular, the different ways that risk is perceived, understood and managed in different social contexts by different people. Risk as a statistical concept, particularly in the context of establishing or actually calculating the probability or likelihood of an event occurring, was not included in this study. Risk in the context of social ideas, their meaning, interpretation and practice within adult social care was prioritised.

This study thus had a particular focus on identifying different perceptions of risk and identifying and documenting these differences in perception within and between different groups of adult service users and service providers. Moving beyond perceptions, the study also sought to explore how these differences were subsequently negotiated and managed in practice.

Within this broad aim, the review thus had two key objectives:
- To review research evidence on the perceptions and management of risk within and between different groups of adult social care service users and professional staff, including the impact of corporate and organisational factors on the behaviour of front line staff.
- To identify gaps in evidence on the perceptions and management of risk within and between different groups of adult social care service users and professional staff.

1.2   Scope and limitations of the review

Study criteria and boundaries were discussed by the researchers and the Department of Health (DoH) and it was decided that the review would cover only

recent (1990 onwards) UK based literature. In light of the differences in legislative frameworks, institutional and cultural arrangements, the review focused primarily on research carried out in England. More specifically, the review centred on perceptions of risk and their negotiation and management in front-line practice in relation to the full range of social care services and other support arrangements, including services provided by the public, private, formal/voluntary and informal sectors (Knapp *et al.*, 2004), user-directed support, direct payments and other mechanisms to facilitate independent living. However, the review largely excluded acutely mentally ill people and services for them because of the significantly different and often quite specific concerns surrounding risk and fears of risk amongst this group, at both individual and societal levels. Apart from this exception, the review thus included research on older people, those with dementia or cognitive impairments, people with physical, sensory and learning disabilities, including young people moving to adult services, men and women, members of black and ethnic minority communities, drug and alcohol service users and carers. Although the focus of the review was on risk in the context of social care services, and their practitioners and providers, important interfaces and transitions between health and social care were also included, such as hospital discharge and intermediate care and the transition from children's to adult services for young people with ongoing support needs.

Recognising the complexity of risk taking and risk assessment within the field of adult social care and the different academic disciplines that have contributed to the knowledge base, the review included research evidence from a number of relevant disciplines, including social policy, sociology, psychology (especially social psychology), economics and media studies. These are all broad disciplines which are likely to include substantial bodies of literature on many different aspects of risk. In light of this, it was decided that the review would focus on empirical research on perceptions of risk by the groups and in the services, as specified above. 'Grey' (or unpublished) literature, although an important source of information, was not included in this review, as it would have been difficult within the review's limited timescale and resources to assess its quality. However, as and when appropriate, unpublished project reports were included. In addition, relevant literature that was soon to be published and/or had been accepted for publication, especially in peer reviewed journals, was included. Finally, the review was limited to empirical research; theoretical papers, opinion pieces and policy and practice guidelines were excluded unless they contained a significant element of empirical research.

In recent years there has been a proliferation of 'scoping reviews'. This is partly a result of the increasing importance and prominence given in government policy and professional practice to developing empirical knowledge and establishing a theoretical and functional base upon which professionals can ground their practice. Scoping reviews can help to develop this empirical base as they aim to 'map rapidly the key concepts underpinning a research area and the main sources and types of evidence available' (Arksey and O'Malley, 2005: 21). Analysis of scoping reviews has

demonstrated that they can take many different forms. Arksey and O'Malley (2005: 21) suggest that there are essentially four broad types of review that seek to:

- explore the 'extent, range and nature of the research activity'; these are frequently rapid reviews designed to 'map' rather than describe in detail the available literature
- 'determine the value of undertaking a full systematic review'; these are largely pilot studies
- 'summarise and disseminate research findings', thus providing a more in-depth description and overview
- 'to identify research gaps in the existing literature'; here, the review moves beyond description to present conclusions and suggestions.

Although this review was time and resource limited, it sought to move beyond the first two models in order to summarise and disseminate key research findings surrounding different perceptions of risk and risk management strategies employed by different service users and practitioners in the field of adult social care. It also aimed to summarise the literature as a whole, identify key gaps and areas for future research. However, it must be noted that the review was not a systematic review of all relevant or available research but was rather a review of the evidence base within clearly specified parameters.

Scoping reviews can sometimes employ consultation exercises with key informants and this, as Arksey and O'Malley (2005) note, can provide a valuable and additional source of information and a more practically based focus particularly relevant for policy makers. In this review, limited time and resources prevented direct consultation with service users or professionals. However, a range of key academics and researchers within the field of risk and adult social care were consulted in order to ensure that recent relevant research, especially soon to be published research, had been included in the review.

Chapter 2   Methods

2.1   Identifying relevant literature

A key aim of any scoping study that seeks to review the evidence base is to be rigorous, consistent and transparent. Electronic databases were the main mechanism used to search the potential evidence base, as they provide a quick and effective search tool. However, before a search can be undertaken, key search terms need to be established and then tested and confirmed in order to ensure consistent parameters across the evidence base, in particular, consistency (as far as possible) across the different databases searched.

A range of potential search terms were initially discussed by both researchers. As noted above, the concept of 'risk' is extremely broad and so developing a range of relevant terms which were both generic but also specific was essential. A list of key search terms was drawn up and then tested on two electronic databases: Applied Social Sciences Index and Abstracts (ASSIA) and Sociological Abstracts and Social Services Abstracts (CSA). This resulted in an extremely large number of references being identified, many clearly beyond the remit of this study. The lead researcher discussed the search terms initially used with the second reviewer and together the researchers modified some of the terms; for example, some search terms had clearly been too broad and thus required a more specific definition, such as, 'hospital' or 'hospital care' were narrowed to 'leaving hospital'. A revised list of search terms was subsequently drawn up (see Table 2.1).

As Table 2.1 highlights, terms were divided into three broad categories: client group; the setting; and dimensions of risk. Appropriate Boolean search terms and conventions were employed as dictated by each database and their specific search criteria.

Table 2.1   Keywords used for searching electronic databases

Client group	Setting	Dimensions of risk
Adult(s)	Care/caring	Perceptions of risk(s)/risk(y) perception(s)
Young adult(s)	Family care/care-giving	Risk(y) assess(ments/ing)
Young person/people	Informal care/caring	Risk(y) manag(ement/ing)
Dementia	Domiciliary care/caring	Risk-taking/taking risk(s)
Old/Older people	Community care/caring	Risk(y) decision(s)/risk(y) decision mak(ing/ers)
Elder/elderly people	Social care	Risk(y) negotiat(ion/ors)
Disab(led) people	Social work	Risk(y) behaviour(s)
Learning disability	Social context(s)	Risk(y) control(ing)
Service user(s)	Direct payment(s)	Risk(y) communicat(ion/s/ors)
Informal/family carer(s)	Self-directed support(s)	Risk-based regulation/risk(y) regulat(ing/ors/ion)
Impairment(s)	Person-centred support(s)	Risk avers(e/ion)
	Home care	Risk(y) decision(s)
	Hospital discharg(e/ing)	
	Leaving hospital	
	Intermediate care/caring	

Seven electronic databases were searched, these were:
- Sociological abstracts and social services abstracts (CSA)
- Applied social sciences index and abstracts (ASSIA
- International bibliography of the social sciences (IBSS)
- Zetoc[1]
- PsychINFO
- Medline
- Health management information consortium (HMIC).

These databases cover literature from a number of key disciplines including social policy, sociology, social psychology, politics, law and economics. A separate electronic search of the literature was conducted for each category, i.e. one for client group, one for setting and one for risk processes and then the results of each were combined in order to produce a list that contained references falling into all three

categories. However, not all the databases (i.e. Zetoc) allowed separate searches to be combined; in this case, one joint search was conducted for all three categories.

In addition, four relevant websites were searched:
- Social care online which is part of the Social Care Institute for Excellence (SCIE) - http://www.scie.org.uk/
- Society Today which is part of the Economic and Social Research Council (ESRC), in particular 'Social Contexts and Responses to Risk' (SCARR) - http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/index.aspx
- Joseph Rowntree Foundation (JRF) - http://www.jrf.org.uk/
- National Centre for Independent Living (NCIL) - http://www.ncil.org.uk/default.asp.

Each of these websites has its own database of either published literature and/or (in the case of the SCIE and the ESRC), recently completed and ongoing research. The latter thus provided a means to identify potentially relevant 'research in progress'. However, as one would expect, the complexity and number of key words that these website based databases allowed the researcher to employ were more limited than the other databases searched. In a similar manner to the Zetoc database search, the researcher thus focused on the concepts and key words with widest applicability, for example: adult, disabled, community care, family care, risk management and risk taking. With these website based searches it was frequently a matter of trial and error, building and refining a specific and relevant search strategy for each one.

Key word searches are inevitably partial, as not every potential keyword can practically be included and use of key words and their meaning is invariably somewhat subjective. For example, some relevant articles may not use the key words chosen by this review; indeed, some authors may not use the term 'risk', although, 'risk' in a variety of guises may be discussed and thus be a central issue. In order to begin to address this, the key journal 'Health, Risk and Society' was hand searched from 1999 onwards (when it went online) and lists of references from key articles were scanned for additional relevant articles; these were subsequently followed up.

Electronic databases, although providing a systematic and comprehensive tool, are time limited in the sense that references have to be identified and entered onto the database; hence a time delay can occur. In order to try to address this problem, as noted above, a range of academics and researchers in the field of risk and adult social care were identified. Fourteen leading academics were initially contacted; these 14 academics then suggested others in the field. Ultimately, 31 academics and researchers and three PhD students were contacted. Each respondent was sent a personal e-mail explaining the project, its aims, focus and scope and then asked if

---

[1] Zetoc is the British Library's table of contents service, indexing journal articles and conference papers.

they could provide information about relevant, recently completed or current research, and/or recently published or soon to be published research. Twenty-eight replied and a range of information was supplied. Overall, just over half of respondents (16) said that they either did not know of any relevant, current or soon to be published research, and amongst those who did provide information, not all was relevant or met our search criteria. However, the consultation process did highlight a number of recently completed research projects and soon to be published results which had been accepted by peer reviewed journals and of which the authors sent advance copies.

In addition to this direct contact, a general e-mail requesting information (once again on recently completed/ongoing and/or soon to be published research) was sent to the British Sociological Association (BSA) 'Risk and Society' study group and the Joint Universities' Council Social Policy and Social Work email lists. This was not as successful, resulting in only five replies, one of which was relevant. However, this response rate reflects the fact that the majority of these two groups' members had already been contacted personally as key academics/researchers.

The final search strategy employed to highlight research in progress or recently completed research was viewing the abstracts of a forthcoming (September 2006) BSA conference, 'Health, Risk and Society'. Once again, all relevant studies apart from one had been previously identified. The software package, 'Endnote' was used for bibliographic management.

2.2 Results of the literature search

Table 2.2   Results of the literature search

Method of identification (database name)	Initial results	Number of duplicates	Number of references after de-duplication
Sociological abstracts & social services abstracts (CSA)	281	24	264
Applied social sciences index and abstracts (ASSIA)	176	21	155
PsycINFO	135	14	121
Zetoc	418	46	378
Medline	51	3	48
International bibliography of the social sciences (IBSS)	70	2	68
Social care online (SCIE)	119	8	111
Health management information consortium (HMIC)	64	19	45
Hand searched *	116	6	110
Joseph Rowntree Foundation (JRF)	9	0	9
Total	**1,430**	**143**	**1,309**

* Hand searched included references gleaned from academic/researcher consultation and journal hand searches.

Table 2.2 charts the results of the literature searches undertaken using the different databases, a large number of potential references (1,430) were identified by the key search terms. After de-duplication this was reduced to 1,309 references. All of the electronic data bases highlighted potential references, with CSA (281) and Zetoc (418) highlighting the largest numbers. Medline and HMIC highlighted relatively few, as this review and its key search terms focused on the context of social care rather than health care. The process of hand searching resulted in a relatively substantial number of potential references (110).

2.3   The process of inclusion and exclusion

A process of inclusion and exclusion was subsequently employed in order to ensure that only literature relevant to this study was included. This process involved two stages. The first stage focused on deciding which articles appeared to be relevant, these articles would then be retrieved and read. The second stage entailed reading each article and then making a final decision whether to include or exclude from the review.

The first stage involved the lead researcher reading the summarised details from each of the database searches. For most potential references, the details included key words and an abstract. The following criteria were employed by the researcher to decide whether to include each reference:

- literature from the 1990's onwards
- research conducted in the UK, primarily England
- empirically based research
- perceptions of risk and/or management strategies employed by adult social care service users, carers and support service providers and practitioners
- important interfaces between health and social care, especially hospital discharge, intermediate care and the transition from child to adult services.

All potential articles to be included in the review were highlighted by the lead reviewer and then checked by the second reviewer. The lead reviewer marked the articles which clearly fell beyond the review's inclusion criteria, however, as one would expect, there were a number of references which were harder to assess. Both reviewers discussed these references and a decision was made drawing on the following exclusion criteria:

- acute mental health service users
- context of health care as the primary or only focus, e.g. clinical risk and hospital care
- discussion or evaluation of specific risk management tools or policies (not empirically based)
- policy discussions (not empirically based)
- calculating the statistical probability of a particular risk occurring in a health or social care setting.

A significant number of articles were excluded by the two criteria of not based in the UK and calculating risk as a statistical probability. When reading the abstracts of potential references it became apparent that many were not UK based, the majority of these being North American or Australian. Risk as a statistical probability and the process of calculating an incidence of risk were clearly identified by the study's search terms but, as the researchers decided, were beyond the scope of this review. Discussions of statistical risk focused largely on economic calculations/evaluations rather than perceptions of risk, the focus of this review.

Table 2.3 presents the results of the inclusion/exclusion process. The results of the first phase inclusion process are reported in the 'potentially relevant' column. At the end of the first phase, a total of 239 references were classified as 'potentially relevant' from the 1,309 references initially identified by the database searches.

All of these 239 references were retrieved from four key sources:

- downloaded electronically (117)

- libraries (university or inter-library loans 111)
- other (e.g. author sent copy) (10).

Once received, the lead reviewer read each[2] and made a final decision, re. inclusion/exclusion, this lead to a further (85) being excluded, according to the criteria listed above.

Although the reviewers sought to be as consistent as possible in applying the inclusion/exclusion criteria, there is inevitably an element of subjectivity. For example, excluding acute mental health service users was not always easy as boundaries are frequently blurred and definitions can vary. However, in applying this criterion, the focus was primarily on less severe mental health problems (i.e. depression, anxiety, stress).

The research focus was on the UK, with particular emphasis on England. Thirteen studies were included from Wales (3), Scotland (3) and Northern Ireland (7). Most of these studies drew their sample from the UK as a whole, only a very small number focused solely on Wales, Scotland or Northern Ireland.

At the end of phase two of the inclusion/exclusion process, 151 references were selected to be included in the study (see Table 2.3, 'included in the review column'). Although a large number of references were initially highlighted by the large electronic databases such as CSA, ASSIA, PsycINFO and Zetoc (975 from all four), ultimately, the number of references actually included in the review from these four databases was very small (39). The rate of exclusion was even more pronounced in relation to Medline and IBSS, as no references from these databases were finally included in the study. In contrast, all the references hand searched or collected from the JRF website were included.

---

[2] The lead reviewer read at least the introduction and conclusion of each reference, in the vast majority of cases, the whole article or chapter was read in order to ensure an informed understanding and overview were gained.

Table 2.3   Literature initially and finally included in the study

Method of identification (name of database)	Number of results after de-duplication	References potentially relevant	References finally included in the review
Sociological abstracts & Social Services Abstracts (CSA)	281	16	9
ASSIA	155	34	15
PsycINFO	121	17	11
Zetoc	418	6	4
Medline	48	0	0
International bibliography of the social sciences (IBSS)	68	5	0
Social care online (SCIE)	111	30	19
Health management information consortium (HMIC)	45	9	5
Hand searched *	110	111	79
Joseph Rowntree Foundation (JRF)	9	9	9
Total	**1,430**	**239**	**151**

* Hand searched included references gleaned from academic/researcher consultation and journal hand searches.

2.4   Charting the data

As noted above, each reference was read and relevant information was entered onto an Access database. Access was chosen as it provided a means to input key data efficiently in a uniform and concise manner, identifying key themes and issues and then charting these across the literature. Drawing on past literature reviews and scoping studies and also the expertise developed in SPRU (Arksey *et al.*, 2003, 2005), a comprehensive list of key information areas was developed, this acted as both a guide and template for data extraction. As the authors' developed their knowledge of the area, a range of key themes were identified and the Access database template was refined. In order to aid consistency, previously entered studies were revised to ensure this information was similarly charted onto the Access database. In this way, key themes could be charted and comparisons drawn across the literature both as a whole and also between different user groups (such as older people, disabled people and mental health service users) and also different groups of people (such as service users, carers and practitioners).

Different types of literature employ different methods and are subject to different types of review; these are key issues surrounding the concept of 'quality'. In light of this complexity, this study did not have the time or resources to perform an in-depth evaluation of the 'quality' of literature reviewed. However, appreciating its importance, as noted in Arksey (2003, 2005) and Croucher *et al.*'s (2003) previous reviews, each reference in this study was categorised according to its source and key study methods and sample details were noted (see Appendix 1 for Access template).

The key areas of information entered onto Access can be summarised as:
- Endnote reference number
- Bibliographic details
- Research type
- Research methods employed
- Key themes of study
- Perceptions of risk (whose perspective and effects)
- Risk management strategies (whose strategy and effects)
- Other comments or issues.

Chapter 3   The scope and characteristics of the literature

This chapter outlines the scope of the literature ultimately selected for inclusion within the project in terms of the types of literature identified; the areas of adult social care covered; the perspective taken (i.e. service user, informal carer, practitioner/staff); and geographical area.

3.1   Type of literature identified

As noted in Chapter 2, the process of literature searching and applying our key inclusion/exclusion criteria led to the identification of 151 references. These references were categorised into four broad types of literature:

- Original empirical research: this consisted of empirically based journal articles, book chapters and project summaries published by organisations such as Joseph Rowntree Foundation.
- Literature reviews: reviews of other people's work (largely empirical) rather than the author's own empirical research.
- Scholarly or discussion pieces: these usually combined a review of the surrounding literature with the author's own ideas/suggestions and/or past empirical research. These pieces were often chapters from books such as, general guides/introductions to 'risk', text or handbooks or edited collections.
- Project reports: largely end of project reports which were not published but were usually available to the public.

Table 3.1   Type of literature identified (n=151)

Type	Number of references
Original empirical	92
Literature review	14
Scholarly discussion	43
Project reports	2
Total	**151**

Table 3.1 demonstrates that over 60 per cent of the literature reviewed (original empirical and project reports) focused on specific empirical studies. A substantial number (28 per cent) of the references included scholarly discussions, although not specifically focusing on one empirical study; these discussions frequently drew on the authors' previous empirical research of risk perceptions, risk assessment and/or

management strategies and were thus empirically grounded. A small number of literature reviews was identified and included within the project. They provided an overview of many different areas of the risk literature and its corresponding empirical research.

Original empirical research was classified very broadly as qualitative, quantitative or mixed methods (i.e. qualitative and quantitative). Table 3.2 presents the proportion of original empirical references falling into each category.[3]

Table 3.2 General research approach employed by empirical research* (n=94)

Research approach	Number of references
Qualitative	80
Quantitative	2
Mixed – qualitative and quantitative	12
Total	**94**

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

Within the 80 qualitative studies four were evaluations of small scale pilot projects and nine described themselves as case studies; most of these case studies involved a small number of specific cases. The remaining studies largely used interviews, either individual or group based. Only two studies employed quantitative methods, however, slightly more studies (12) employed a mix of qualitative and quantitative methods. This was usually in the form of qualitative interviews or focus groups combined with a questionnaire administered to a larger sample.

A comprehensive assessment of the 'quality' of the empirical research reviewed was beyond the scope of this project. This was largely due to time and resource restraints.

Although many of the studies reviewed were relatively small scale and frequently involved specific samples of adult social care users, informal carers and/or practitioners from a limited range of geographical locations, this does not automatically invalidate the research. However, the researchers did consider the appropriateness of the methods used to the research aims/questions and to the conclusions which were drawn from the results. The vast majority of empirical studies summarised the research approach and methods that they had employed. Out of 94 original empirical references, the researcher only noted 11 references as being vague in relation to one or more of the following: research tools employed, sample

---

[3] Only original empirical data has been presented here, as these references could be categorised more clearly and accurately compared to literature reviews or scholarly/discussion pieces (the latter two types discussed many different studies rather than one specific study).

population or data analysis. Some authors noted that study methods were discussed/described in other articles.

3.2 Areas of adult social care researched

As previously discussed, it was decided that this review would search for literature within the fields of older people, including those with dementia; disabled people, including those with learning, physical, sensory and multiple disabilities; mental health needs (excluding acute mental health); young people moving to adult services; members of black and ethnic minority communities and substance misuse. The database searches highlighted a range of studies in these areas, however, as Table 3.3 demonstrates, the literature was not equitably spread:

Table 3.3 Areas of research focus (n=151)

Area	Number of studies
Older people	46
Disability	22
(specifically learning disabilities)	20
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**

Almost a third of the references included in the review focused on older people. The definition of 'older' and the age range studied varied, however, it was frequently those 65 to 70 years plus. Furthermore, amongst the literature on older people, out of the 46 references, 12 discussed issues of risk specifically in relation to older people with dementia. In contrast, only two studies explored risk and dementia amongst younger adults (i.e. those under 65 years of age). The two other areas most frequently discussed were 'risk' in relation to disabled adults (22 references) and mental health service users (19 references).

Within the studies of risk and disability, the vast majority (20 out of 22) focused on people with learning disabilities. Study participants frequently had additional

impairments; however, learning disabilities was the key issue under consideration, largely due to the important but complex debate surrounding risk and normalisation. This is a central theme within the literature and will be explored in the results chapter (see Chapter 4).

The parameters of this study largely excluded literature exploring risk and acute mental health, however, as Chapter 2 noted, defining and drawing a distinction between 'less severe' mental health problems and severe mental illness was not always easy or clear cut. Some studies included a range of mental health service users, from those viewed as 'depressed' to those diagnosed as 'psychotic' and legally sectioned. However, it must be noted that the definition of 'mental health' was often left ambiguous, the key factor frequently appeared to be that sample participants were mental health service users. Furthermore, it was often difficult not to include 'acute' mental health service users, their informal carers or the practitioners who worked with them, as this is the group most usually defined as 'at risk' or 'a risk to others' and thus has been the focus of much research.

Twelve studies explored 'risk' in the context of young adults moving from child to adult social care. Of these 12 studies, nine focused on disabled young people and the transition to adult services. Once again, many studies focused on people with learning disabilities; however, many of the young people in these studies had additional physical or sensory impairments and some complex health conditions. Table 3.4 demonstrates that the review identified very few studies focusing specifically on people from black and ethnic minority communities or people who misused alcohol or drugs. Issues relating to culture, religion and ethnicity were discussed in some studies (as will be reported later in the report) but in a largely peripheral manner. The three key studies identified here were diverse, addressing risk and ethnicity in relation to older people, issues of mental health and the transition to adult services. Two of the three studies exploring substance misuse focused on alcohol and one on 'hard' drug use (heroin).

It must also be noted that almost a third of the studies included in this review discussed the concept and management of 'risk' in a number of different settings or from different perspectives, for example, comparing ideas and practices of service users, informal carers or practitioners in relation to older people, disability and mental health. These more general overviews tended to fall into the category of literature reviews or scholarly/discussion pieces rather than original empirical studies.

3.3 Risk perceptions: users, informal carers and practitioners

Amongst the literature identified, especially the original empirical research reviewed (n=94), studies focused on a range of perspectives including those of service users, informal carers and practitioners.

Table 3.4 The balance of user, informal carer and practitioner perspectives within the original empirical references* (n=94)

Perspective	Number of references
Service users	5
Service users and informal carers	10
Service users and practitioners	20
Service users, informal carers and practitioners	16
Informal carers	2
Informal carers and practitioners	8
Practitioners	32
Total	**93****

* References categorised as 'original empirical' and 'project reports'.
** One of the studies focused on an evaluation of media outputs, such as newspaper and television reports rather than the perspective of users, informal carers or practitioners and thus has not been included in this table.

A third (32) of the original empirical studies reviewed concentrated predominately on the views of practitioners (i.e. managers, professionals or formal carers). In contrast, only a very small number of studies focused solely on the views of service users (5) or informal carers (2). These specific studies of users and carers perspectives focused on a range of social care service areas. The five studies exploring users' perspectives were divided as follows: two studies focused on substance misuse, two on young people's transition to adult services and one discussed the perspectives of ethnic minority service users. The two studies focusing on carers' experiences were located in the areas of mental health and older people with dementia.[4] The views of service users were more frequently presented (35 studies in total) when they complemented or contested those of either practitioners or informal carers.

---

[4] It must be noted that although this study of informal carers of older people was a separate study, the carers' sample was drawn from a wider project based on randomised controlled trials involving practitioners.

3.4 Geographical location

The review focused on research conducted in the UK. Within this, there was a particular emphasis on England and this was reflected in the scope of the literature reviewed. Of the 151 references for inclusion, the vast majority focused on England. Indeed, only 13 (out of 94) of the original empirical references included Wales (three studies), Scotland (three studies) or Northern Ireland (seven studies) in their sampling frames. Two of these studies focused specifically on Scotland and six of the seven Irish studies discussed risk only in the context of Northern Ireland. Amongst the references categorised as literature reviews or scholarly/discussion pieces, UK literature was discussed, there was some discussion or signposting of internationally based empirical work; however, this literature was not included in the review.

Chapter 4   Results

This chapter explores seven themes that have emerged from our review of recent research on risk.

The themes are:
- Risk and the search for a 'normal life'
- Risk and the importance of socially perceived competence
- Risk and strategies to gain or maintain control
- Risk in different organisational contexts
- Risk and the importance of knowledge and experience
- Risk and wider socio-economic factors
- Risk and the role of technology.

These themes are used as an analytical framework to structure the discussion. Each of the following sections outlines the overall scope of the research evidence; compares the evidence on different perceptions of risk in daily life and/or professional practice; and compare different approaches to assessing and/or managing risk that are used by or for different groups of social care users and their families

Although these seven themes are used to structure the discussion of research evidence, in practice the evidence frequently interacts and overlaps between the themes.

4.1   Risk and the search for a 'normal' life: Developing and applying normalisation ideas and strategies

This section will examine the research evidence on risk in the context of pursuing a 'normal' (or what is perceived as a 'normal') life by different groups of service users and/or carers.[5] It will examine how a number of 'everyday' risks are viewed, the normalisation strategies that are actively developed and the potential consequences of these.

Forty-nine references (out of 151 identified) discussed the theme of 'normalisation', albeit in differing degrees of depth. However, as Table 4.1 shows, much of this literature focused on older people and people with learning disabilities.

---

[5] In this report, the term 'carers' refers to family and other unpaid care-givers.

Table 4.1 References discussing the theme of risk and 'normalisation' by subject area* (n=49)

Subject area	Number of references discussing risk and 'normalisation'
Disability	16
(specifically learning disability)	13
Older people	17
General**	10
Young adults	5
Mental health	1
Total	**49**

* A number of these references either discussed the same study or refer to different papers/chapters/books that report different aspects of the same study.
** 'General' references focus on more than one group of service users - most commonly older people, people with learning disabilities and mental health service users.

The focus on learning disabilities is not surprising, as the concept of 'normalisation' originated from disability theorists such as Wolfensberger (1972) and O'Brien (1992). The concept refers to creating 'as normal a life as possible' for disabled people, in which risk and risk-taking are part and parcel of everyday life. These ideas have been extended to other groups such as older people and increasingly underpin policies of community care and community-based supported living.

4.1.1 Risk, normalisation and adults with learning disabilities

If people with learning disabilities are to be encouraged and supported to lead a 'normal' life in the community within which they live, they need to be both aided and given the opportunity to take risks in a supported and positive environment. Indeed, Clarke *et al.* (2005) highlight the importance of working towards a 'model of social coherence' for people with learning disabilities, one which moves beyond a simple dichotomy premised on inclusion/exclusion. Drawing on qualitative interviews with 27 adults with learning disabilities, and, in some cases a key family member (35 people were interviewed in total); Clarke *et al.* explored how service users and their families wished to work with practitioners when assessing need. The importance of discussing and planning for risk and risk taking opportunities was recognised and the authors found that families wanted these discussions to be conducted in a supportive and holistic manner. This would mean practitioners had knowledge of their client's wishes, were responsive to these and also took account of wider family circumstances and preferences.

In the articles/chapters presenting a more general overview of the current literature (see Table 4.1), five out of the ten references (Alaszewski and Alaszewski, 2000b; Alaszewski *et al*., 1998a; Manthorpe and Alaszewski *et al*., 2000; Stalker, 2003; Waterson, 1999) recognised the general importance of underlying normalisation theory and its key principles for practitioners working with people with learning disabilities. More specifically, Alaszewski and colleagues (1998a) drawing upon previous empirical research found that nurses in the field of learning disability were aware of the importance of normalisation theory as a guiding principle. Indeed, drawing on interviews with 72 nurses and 20 additional personal diary records of nurses working in the field of learning disability, mental health and older people, Alaszewski *et al*. (1998a) found that amongst the three groups of nurses, those working with adults with learning disabilities were more likely than nurses from mental health or older people's services to recognise the potential positive aspects of risk, in particular, risk as an opportunity for clients to learn from everyday risk taking in the pursuit of 'as normal a life' as possible.

However, as noted above by Clark *et al*. (2005), supported personal risk taking takes time, effort and resources. The pursuit of choice and supporting normal activities depends on the availability of resources, two factors which, as Sellars (2002) in her general discussion of literature and personal clinical experience of risk assessment for people with learning disabilities notes, are frequently limited or unavailable.

In contrast to the views of practitioners, the research evidence demonstrates that parents/carers of adults with learning disabilities are often less likely to view everyday risk taking as a positive, empowering experience. Indeed, both Alaszewski *et al*. (1999) and Heyman and Huckle's (1993a, 1993b) studies of everyday risk taking by adults with learning disabilities found that parents were generally more reluctant to see risk taking as a positive act compared to staff. In Alaszewski *et al*.'s (1999) study, two focus group discussions with parents/carers whose son/daughter used residential or community based services were held, each with four to 12 participants; the study also included two focus groups of adults with learning disabilities and one group of staff, similarly with four to 12 participants. Heyman and Huckle (1993a, 1993b, 1995) conducted interviews with the carers of 20 adults with learning disabilities attending adult training centres; Heyman and Huckle also interviewed the adults themselves and eight members of staff. Both studies revealed that although parents recognised that everyday life was beset with risk, risk was largely something which, if possible, parents thought should be avoided. The degree to which risk should be avoided could differ amongst parents; however, there was a general association of risk with danger and risk taking was often feared by parents.

Over half (7 out of 13) of the references focusing on risk and 'normalisation' focused specifically on risk and relationships, particularly romantic or sexual relationships (Alaszewski and Alaszewski, 2002; Alaszewski *et al*., 1999; Banim *et al*., 1999; Heyman and Huckle, 1993a, 1993b, 1995; Thompson, 2000). However, five of these

references discussed only two studies, i.e. Alaszewski *et al.*'s (1999) and Heyman and Huckle's studies (1993a, 1993b, 1995), as noted above, both of which explored the ideas of service users, carers and practitioners. In contrast, Banim *et al.*'s (1999) study of sexual health information explored the views of 73 disabled people attending day centres and 24 staff; carers were not consulted. However, Banim *et al.*'s study drew on a wider sample of disabled people compared to the other studies; their sample included both physically disabled participants and those with learning disabilities. In contrast, Thomson's (2000) study was more focused and specific, as he explored the issue of adults with learning disabilities as potential sexual abusers. Specific details of his sample are rather vague, although it appears he consulted the staff associated with or supporting ten men with learning disabilities who had sexually abused others or were regarded as having displayed inappropriate sexual behaviour. Whether the men with learning disabilities were themselves directly consulted is not clear. Although a diverse group of studies, the views of practitioners/staff were included in each study and service users were also consulted in four out of the five studies. In Heyman and Huckle and Alaszewski *et al.*'s studies, users' ideas were reported in less depth than those of parents and staff. However, this reflects the fact that risk is an abstract concept and as both sets of authors note, the adults with learning disabilities frequently had a limited understanding of risk as a concept.

Within the sphere of learning disabilities, the issue of sexuality is, as Banim *et al.* (1999) observe, generally viewed in society as potentially problematic and 'dangerous'. Three key issues come to the fore:

- Fear, often voiced by parents of adults with learning disabilities that their adult child is potentially 'vulnerable' and naïve and thus open to sexual exploitation by others (noted by Banim *et al.* (1997) in their previous work).
- The danger of unintended consequences, such unplanned pregnancy or sexually transmitted diseases.
- A common social assumption, as discussed by Shakespeare *et al.* (1997) that people with learning disabilities are often asexual and/or not interested in sexuality.

These fears were clearly demonstrated by Heyman and Huckle's (1993a, 1993b, 1995) aforementioned study. Parents regarded meeting members of the opposite sex as potentially risky and dangerous for their son/daughter. For some parents, as Heyman and Huckle note, this was a 'hazard' that should be avoided at all costs. For others, it was a risk that needed to be carefully managed but not completely dismissed; there was parent/carer recognition that risk taking was part of everyday life. In addition, Heyman and Huckle's interviews also demonstrated that adults with learning disabilities frequently adopted similar ideas to their parents/carers and therefore viewed everyday activities, such as meeting members of the opposite sex alone, as 'risky' and potentially dangerous. Indeed, as the authors' note, when sexuality was discussed, it was largely viewed as something for others and not for them; the importance of self-control was also highlighted. In this instance, it appears

that carers' views may exert a significant influence over the perceptions of risk among disabled people themselves. Although Heyman and Huckle observed that conflict between adults with learning difficulties and carers could exist, it was not a key finding in their research.

4.1.2 Risk, normalisation and older people

Older people's views

The voice and views of older people, especially those with dementia, were evident in three empirical studies (Clark *et al.*, 1996a, 1996b, 1998; Wilson, 1994). A common theme identified in this research was how older people try to manage everyday risks in order to lead as 'normal' a life as possible. For the majority of older people in these studies, this meant continuing or returning to live in one's own home as independently as possible. However, this aspiration entailed a complex and often lengthy process of redefinition and adaptation to physical and/or psychological changes arising from ageing and/or dementia. Clark *et al.* (1996a, 1996b) studied the process of hospital discharge from two hospital trusts amongst two cohorts of older people (the first cohort of 30 people were discharged and then followed up, the second cohort of 20 older people had all been discharged in the previous 18 months). They found that a period of personal re-adjustment and life re-assessment frequently followed discharge. Interviews revealed this process often involved each older person rationalising the physical and psychological changes they faced; re-assessing what was now possible; deciding what additional resources (e.g. equipment, aids) were necessary or acceptable; and identifying the activities or tasks that must be given up as they were not feasible or regarded as 'not worth the risk'.

Drawing on interviews with older people aged 75 years plus[6], Wilson (1994) suggests that these processes entail three discreet, but interwoven, practices:
- developing new strategies for everyday living that reduce risks but maintain independence; for example, an older person going downstairs on his/her bottom
- reallocating time to accommodate the increasing time taken for some activities; for example, lunch may take all morning to prepare
- avoiding some risks altogether; such using local shops if crossing a road or catching a bus was viewed as 'too risky'.

These examples illustrate how the older people in Wilson *et al.*'s study recognised activities that they considered risky or that could threaten their continuing ability to live in their own homes; instead, they actively and positively adapted everyday life patterns and preferences to accommodate their changed circumstances.

Adaptation can either be individual or may involve accepting the support of others. Clark *et al.* (1998) conducted in-depth interviews with 51 older people, one-third of whom were interviewed two or three times in order to chart how ideas changed or were adapted as circumstances altered. Participants valued what they termed, 'low level support' (i.e. domestic or practical help within the home) from paid care workers. This support enabled them to keep a 'well-maintained' home, which was important to their sense of self-worth and continued social standing in the wider community. Significantly, as Clark *et al.* stress, this support was often not regarded as 'care', but was 'normalised' as help with 'housework'. Both Clark *et al.* and Wilson's research demonstrates that concepts of risk are thus individual and subjective.

The importance of viewing older people's behaviour in terms of both their past and their current biographical contexts was noted in four studies (Clark *et al.*, 1996a, 1996b, 1998; Wilson, 1994); and Pugh and Keady's (2003) scholarly discussion of older people with dementia. Although Pugh and Keady report only three case studies, they demonstrate clearly that risk assessments must be located in the context of both the older person and their carer's biographies and personal priorities. For example, in one of the case studies, a woman with dementia followed her carer husband around the house all day, leaving her husband no privacy or personal space. Pugh and Keady argue that using standardised textbook definitions many community mental health nurses would initially define this behaviour as 'challenging' and 'intrusive' for the carer. However, when the behaviour of the older person was viewed in context and the older person and their carer were invited to explain the reasons for their behaviour, Pugh and Keady found that it was not regarded as 'challenging' or 'intrusive' by either party. Indeed, it was valued by the husband/carer as a risk management strategy. He kept 'an eye' on his wife and made sure she was safe. This provided the husband with peace of mind and enabled his wife a degree of independence, as she had chosen to follow him around.

Taking account of personal biographies can however be problematic and raise potential areas of tension for practitioners. For example, in their literature review, Reed *et al.* (2004) provide a hypothetical example of the tensions that a rug can bring in the area of 'slips, trips and falls' during risk assessments. For the authors, this example highlights the different interpretations of 'risk' held by older people and practitioners. For the older person, a rug can be symbolically important, as it may have personal memories/associations or may make the house more 'homely'. However, for practitioners it increases potential 'risks' of falling and is thus a 'danger'. Recognising these different interpretations and meanings, Reed *et al.* conclude that practitioners must weigh up their professional 'duty of care' against the promotion of psycho-social well being for service users via a sense of personal control and self-identity.

---

[6] Specific details of the study's sample and methods are not given in this article; Wilson merely states that she draws on recent work with service managers and a longitudinal study of older people and notes that methods are discussed in other papers. Placing this study in context is thus difficult.

Clark et al. (1996a, 1996b) note that risk assessments are often static and episodic events rather than ongoing processes. As demonstrated above, the older people in Clark et al.'s study were continually re-assessing risk and adapting their lives to take account of the physical and psychological changes of ageing. Discussions with practitioners assessing the older people during hospital discharge revealed that although many were aware that older people's support needs and views of risk altered over time, especially as they regained confidence living at home, it was often not possible to update risk assessments due to limited time and resources. Having time to regularly visit was regarded by practitioners as a luxury that they did not have and could not give their clients. Hence, Clarke warns that many risk assessments do not acknowledge the dynamic nature of older people's on-going adjustments and re-evaluations of risk. They are often static documents, out of sync with clients and their needs. This is an important issue and as the authors note, can have very real consequences for the risks identified and prioritised in older people's lives, and the relevance of management strategies advocated by practitioners.

Preserving or re-defining choice, independence, respect and personal self-esteem are pivotal in older people's strategies for managing risk in order to maintain a 'normal' life. A literature review (Help the Aged, National Care Forum and The National Care Homes Research and Development Forum 2006) concluded that definitions of 'quality of life' for older people should include:
- maintaining a positive self-identity and sense of worth
- listening to older people and what is important to them
- helping people to define and meet their own goals/ambitions
- maintaining an individual contribution to life patterns (e.g. getting dressed)
- participation in meaningful social activities
- maintaining social relationships and bonds
- having one's ethnic and cultural needs respected and met.

The review acknowledged that although risks may arise in the course of pursuing these goals, they are nevertheless outweighed by the quality of life and associated psycho-social well-being that results.

Similarly, the importance of wider community support has been noted by Gilmour et al. (2003) in their Northern Irish study of ten older people, their carers and associated practitioners. Community knowledge of the normal practices and routines of older neighbours and 'community surveillance' (i.e. neighbours looking out for older people) helped older participants to continue living in their own homes.

Carers' views
Out of the 17 references specifically discussing risk in relation to a 'normal life' context for older people, four empirical studies (Buri and Dawson, 2000; Clarke, 1999, 2000; Clarke and Heyman, 1998) and one literature review; (Manthorpe, 2004)

examined this from the perspective of informal carers. A key theme in these latter studies was the importance that carers attached to 'normalising' patterns of everyday life with the person they supported, especially if s/he was a spouse or partner. Retaining a sense of 'normality' was important in making sense of their current situation and enabled many carers to sustain feelings of personal control and self-identity. As with the strategies of older people (see above) what was perceived as 'normal' was continually being re-defined and renegotiated by these carers to incorporate the support needs and priorities of the person they were caring for. Moreover, this process of 'normalisation' was influenced and shaped by the histories of the personal and emotional relationship between the carers and the people they supported.

Clarke (1999, 2000; Clarke and Heyman, 1998) studied 23 primary informal carers of older people with dementia. All 23 carers were interviewed and nine also kept diaries of their caring experiences (health and social care practitioners working with these carers were also interviewed or completed a questionnaire, 85 in total). The study provides an in-depth analysis of how carers use the following strategies to 'normalise' their everyday care-giving experiences and reduce the risks to their own physical and/or mental health and the health of the person they supported:

- 'pacing' – strategies to limit physical and emotional contact with or exposure to the person receiving care
- 'confiding' – for example, 'off-loading' feelings to practitioners but at a time and in a manner chosen by the carer
- 'rationalising' – drawing selectively on information provided by practitioners.

Together, these three processes helped carers to balance their own needs, those of the person they were supporting, and the maintenance of a 'normal' life. Consequently, carers were prepared to allow the person they were supporting to continue doing things for him/herself, even if this was regarded as 'risky' by a practitioner, if it preserved the carer's sense of a 'normal' life or if any risks were outweighed by the benefits of maintaining the older person's sense of control and self-worth, the carer's relationship with the older person or potentially, wider family relationships as well.

Both Clarke (Clarke, 1999, 2000 and Clarke and Heyman, 1998) and Buri and Dawson (2000) identified how the relationship between carers and older people shaped carers' approaches to managing risk and maintaining a 'normal' life. Both studies showed how these strategies were underpinned by longstanding relationships and identities of both carers and older people and by the desire to sustain co-residence. These findings have implications for practitioners and professionals' relationships with carers and for the types of services that are acceptable. For example, as Clarke and Heyman's (1998) interviews with carers demonstrated, the offer of a service such as respite care or short break may be perceived by a carer as incurring significant risks to the 'normal' relationship they

have built up with the person they are supporting. Indeed, Clarke (2000) and Clarke and Heyman (1998) found that carers and practitioners drew on very different types of knowledge and implicit assumptions. Carers prioritised the particular history and current relationship with the older person; in contrast, practitioners drew on generalised medical and technical knowledge which presumed pathology and the need for professional intervention. Given these different knowledge bases, Clarke (2000) and Clarke and Heyman (1998) identified the potential for tension, misunderstanding and conflict between practitioners and informal carers.

4.1.3 Risk, normalisation and young disabled people

Similar contrasts between professional views of risk and the strategies of service users to create and maintain a 'normal' life were identified in four studies (Atkin and Ahmad, 2000; Hendey and Pascall, 2001; Morris, 1999; Schur *et al.*, 1999) of young people with disabilities or chronic health problems. However, here the priorities of the young people focused on conforming to peer group norms and pressures rather than maintaining identity and self-esteem.

Two studies focused on young disabled people and their aim to live independently from their parents. Hendey and Pascall (2001) conducted a qualitative study of 72 disabled young people with a range of physical impairments and learning difficulties; Morris (1999) conducted a literature review and interviews with 14 young people with complex impairments and health needs in their transition from child to adult services. In both studies, the disabled young people were aware of the potential dangers that living independently of their parents could bring, such as coping with illness on their own, weakened emotional bonds with parents or social isolation. However these risks were contrasted with socially valued peer norms and expectations; as one young person noted: 'I can't stay [living with my father] forever and I've got my own life to lead and I want to get on with it. I'm 21 now and time's ticking on' (Morris, 1999: 72). Indeed, some of the young people in Hendey and Pascall's study viewed living with one's parents as 'failure' and thus potentially damaging to their identity and positive self-worth. They were aware that, in the eyes of their peers, living at home had strong associations of dependency. Not surprisingly, parents did not always agree with their son/daughter's assessment of the benefits of independent living; for them ensuring safety and minimising risk frequently remained major concerns.

For young people living with chronic illnesses, 'fitting in' with peer norms and lifestyles was pivotal in their attitudes towards risk and risk management behaviours. For example, in Atkin and Ahmad's (2000) study of 25 young people with

thalassaemia major[7] and Schur *et al.*'s (1999) interviews with eight young people with Type 1 diabetes, risk and 'difference' were central themes. For many of the young people, there were potentially serious dangers associated with denying their medical condition or need for treatment. However, presenting themselves as 'normal' teenagers, 'similar to' rather than 'different from' their peers, were key concerns. Minimising any differences was imperative and anything that set the young people apart was often viewed negatively as it made them feel vulnerable, open to ridicule and social stigma and could have negative impacts on their self-esteem and social inclusion.

Although based on a small and specific group of young people, Atkin and Ahmad (2000) point out that young people's non-compliance with medical treatment (e.g. not using their pump for as long or as frequently as required) needs to be understood within this social context. What may appear to constitute irrational and 'risky' behaviour is nevertheless understandable when viewed in a wider social context and set against other priorities such as gaining respect from friends and engaging in valued social activities. Moreover, the potential benefits of social inclusion and psychological well-being were frequently felt to outweigh the potential dangers of medical non-compliance and ensuing risks to health (e.g. physical weakness and future complications such as, diabetes or heart problems).

Avoiding social stigma was also highlighted in Schur *et al.*'s (1999) small study of interviews with eight young people with diabetes. The authors found that some of the young people were reluctant to inject themselves in public in order to minimise any 'difference' from their peers. Interwoven within this evidence on risk, normalisation and young people are wider issues concerning competence and age; these will be discussed in more detail below. The studies reviewed here draw attention to the potential trade-offs between the various costs and benefits associated with risk – specifically the potential benefits of optimal health and care against the risks to self-esteem and social inclusion.

4.2   Risk and the importance of socially perceived 'competence'

This section focuses on research in which risk is described or explained in terms of the perceived 'competence' of particular groups of adult service users. It will examine how issues of perceived competence appear to influence both perceptions of risk and its management by different groups of people (adult service users, informal carers and practitioners). The research suggests that perceptions of competence (or its

---

[7] Thalassaemia Major – very broadly, thalassaemia can bring a danger of excessive iron to the body. In its major form, this is often treated with injections of the drug desferrioxamine through a battery operated pump. Treatment can be between eight to 12 hours per need for five to seven nights a week. Thalassaemia is often found amongst Cypriot, South Asian, Chinese peoples but it can also be amongst African-Caribbean and some indigenous white British.

absence) are often not based on individual assessments but may be derived from generalised stereotypes, prejudices and fears. These stereotypes are likely to affect the availability of opportunities to participate in decisions about 'risk' or engage in 'risk-related' behaviours.

Table 4.2 indicates that 54 references referred to 'competence', or 'incompetence'. These references fell into three groups: research with or about people with learning disabilities (12 references); older people, particularly those with dementia (13 references); and people with mental health difficulties. Although this might suggest that the issue of competence was less prominent in research on young adults, black and ethnic minority service users and substance misusers, there were far fewer studies in general on these latter groups.

Table 4.2 References discussing the theme of risk and 'competence' by subject area* (n=54)

Subject area	Number of references discussing risk and 'competence'
Disability	14
(specifically learning disability)	12
Older people	13
Mental health	12
Young adults	4
General**	8
Ethnicity	2
Substance misuse	1
Total	**54**

* It is important to note that a number of the references in the literature reviewed and identified as discussing competence issues, either discussed the same study or the study's authors have written more than one article/chapter/book discussing aspects of the same study.
** 'General' refers to those references discussing more than one area, often older people, those with learning disabilities and mental health service users.

4.2.1 Risk, competence and older people

Five studies (Alaszewski and Manthorpe, 2000; Ballinger and Payne, 2002; Healey and Yarrow, 1998; Horton and Arber, 2004; Stevenson, 1999) point to wider social attitudes towards older people, the potential for ageism and the consequent implications for the perceived competence of older people. Ageism and consequent perceptions of competence were also noted in two reviews of the literature surrounding risk and older people (Manthorpe, 2004; Parsloe, 1999); Parsloe (1999) notes that ageist social ideas and assumptions are often interwoven with the concept

of competence, in particular, with ideas of 'vulnerability' and 'diminished responsibility'. Underlying these ideas, as Parsloe suggests, are beliefs that older people need to be protected; they are 'at risk' and lack the mental capacity to make reasoned risk evaluations and personal decisions. Conditions such as dementia are further assumed to compromise capacity for rational thought and reasoning. However, as Manthorpe (2004) highlights in her review of the literature, dementia is not a static condition and the mental capacity of people with dementia can ebb and flow, particularly in the early stages of dementia. Despite this, Manthorpe argues that blanket assumptions surrounding 'dementia' are frequently made and this in turn can have a profound effect on how an older person is perceived and treated by others, regardless of their actual capabilities.

The effects of labelling people, especially older people with conditions such as dementia is discussed by Iliffe and Manthorpe (2004) in relation to the early recognition and diagnosis of dementia. Iliffe and Manthorpe suggest that providing an early diagnosis and labelling an older person as a person with dementia can have important effects on the older person's self-esteem and identity. For Iliffe and Manthorpe, there is a very real danger that early diagnosis risks devaluing the mental capacity of the older person and introduces unwarranted assumptions of reduced competence; there is also the danger that the older person may come to question his/her own mental capacity.

Ballinger and Payne (2002) explored how hospital staff managed the environment of older people in order to prevent risk and ensure safety. This study also demonstrates the impact of stereotypes and assumptions. Drawing on interviews with 15 older patients and participant observation of a range of staff (such as doctors, nurses and occupational therapists), the authors found that staff continually controlled the environment of the older people in order to prevent risks, especially falling. For example, a policy such as administering medicine to all patients and locking pills away was based on presumptions of older people being incapable of taking medication correctly. Amongst the patients themselves, interviews demonstrated that some of the younger older patients or those using the hospital for rehabilitation felt that staff treated all patients the same, irrespective of their mental capacity. This could have implications for their personal sense of identity as a competent person, so they made a distinction between themselves and 'others'. Although this study is only based on data from one hospital it illustrates how assumptions of competence, both of the physical environment patients experience and their own self-identity for older people, especially those with dementia.

Some research has examined the different perceptions and understandings of practitioners and older people concerning the assumed competence of older service users. Three studies (Huby *et al.*, 2004; Pugh and Keady, 2003; Vallelly *et al.*, 2006) demonstrated that when behaviour or actions initially regarded as irrational, meaningless or dangerous are actually viewed in context from the perspective of the

older person, what appears to reflect lack of competence may actually be a competent and meaningful act. In Vallelly *et al.*'s (2006) large scale study of older people with dementia living in 'extra care' supported housing, the authors drew on both qualitative and quantative methods to explore how risk was experienced and managed by both residents and staff. Sixty residents completed questionnaires every six months over a three year period and six residential settings were chosen as case studies. From the case studies, 30 residents were interviewed alongside a range of staff and family members. Data revealed that care staff frequently viewed some residents' tendency to 'wander' (i.e. walk around the grounds and local residential environment) as 'risky' and dangerous as it put them at 'risk' of falling and getting lost. However, interviews with the older people themselves demonstrated that for those who 'wandered', this 'wandering' had meaning and purpose; it was a means to take physical exercise and provided an opportunity to get out and meet others.

The importance of recognising and respecting the subjective meanings that older people place on their behaviour and of placing their actions and ideas in the context of their personal lives was similarly demonstrated in Huby *et al.*'s (2004) study of older patients' participation in planning their discharge from hospital. Based on interviews with 22 patients and a range of hospital staff (consultants, nurses, social workers) Huby *et al.* demonstrated that practitioners frequently found older people unwilling to participate in the process of planning their hospital discharge and generally disinterested in considering issues of risk. This was often interpreted by practitioners as signifying a lack of ability to engage in risk discussions and the process of discharge planning. However, interviews with the older people revealed that this presumption was misplaced; patients were often competent, and non-participation was based on rational decisions and evaluations. For example, non-participation for some patients was an active and meaningful strategy to encourage their families, especially potential informal carers, to become more involved in their care when returning home. The older people had therefore acknowledged potential risks and identified their own preferred potential personal solutions. Although this study focused on only one hospital and the authors' themselves note was a pilot study, it demonstrates the need for practitioners to listen to patients and begin, as Huby *et al.* argue, to 'trust patients' competence'.

The importance of practitioners listening to service users and their families and placing behaviour in context was also noted by Pugh and Keady (2003). Drawing on a small number of case studies (three), the authors' discuss the behaviour of older people that had been regarded as challenging and risky by community mental health nurses. When viewed in context however, this behaviour could actually be understood as a means of coping with reduced physical and mental capacity. For example, Pugh and Keady cite the case of an older man who wanted to sleep in his clothes rather than pyjamas. This seemed irrational behaviour, challenging social norms and demonstrating a limited grasp of social conventions, all of which demonstrated reduced reasoning for practitioners. For the older man's wife, there

was a fear that this behaviour called into question her caring capacity (i.e. it demonstrated neglect). However, for the older man it was an important means to exert choice and control over his life, other choices had been removed. Challenging normal social conventions, as the authors suggest, cannot always be interpreted as a lack of competence. Practitioners' understanding and empathy are important within risk assessments and planning with service users and their families, this will be discussed further in Section 4.5: Risk and the importance of knowledge and experience.

4.2.2 Risk, competence and learning disabilities

Seven studies examined the assumed (lack of) competence on the part of adults with learning disabilities (Alaszewski and Alaszewski, 2002; Alaszewski *et al.*, 1999; Banim *et al.*, 1999; Heyman and Huckle, 1995; McConkey and Smyth, 2003; Sellars, 2000; Thompson, 2002). Two discussion pieces (Manthorpe and Alaszewski, 2000; Manthorpe and Stanley, 1999) also noted the assumed lack of competence on the part of this group of service users. For example, although adults with learning disabilities may be chronological adults, cognitively they are regarded and frequently treated as children or, as Manthorpe and Alaszewski (2000) suggest, a 'child in an adult body'. Research shows how this characterisation has implications for perceptions of risk and its management among people with learning disabilities.

This raises a number of important and complex issues for all those involved, service users, informal carers and practitioners. In the case of practitioners there are important tensions between recognising the need to protect potentially vulnerable clients and viewing risk taking as an everyday activity. This was demonstrated in Alaszewski *et al.*'s (1999) study of adults with learning disabilities, their parents/carers and the staff who worked with them in residential settings. Drawing on data from focus group interviews with practitioners from five English and Welsh locations, Alaszewski *et al.* found that practitioners were aware of the potential tensions surrounding risk and competence for their clients. Staff recognised parents' concerns that their son/daughter was vulnerable and often 'unknowing' and thus risk taking was potentially dangerous, indeed, staff were also very aware of their own 'duty of care' to clients. However, staff also recognised that risk taking could be a positive learning experience for clients, providing an opportunity to develop personal competence. Balancing these competing demands was, as the authors note, complex and difficult for staff.

Recognition of risk as empowering is further complicated, as suggested by Sellars (2002) in her review of the literature and current policy guidance surrounding risk assessment for people with learning disabilities not to 'overburden' people with learning disabilities. Asking or expecting people with learning disabilities to make complex risk decisions which can in turn have important future implications for and

effects (both positive and negative) on their life. This can be both daunting and threatening. For Sellars, being realistic and appreciating that some people will not be able to make 'informed decisions' are crucial.

Perceptions of competence can vary. Although based on one specific special school, Carnaby and Lewis' (2000) study of disabled young people's transition meetings as they prepared to leave school found that the verbal abilities of young people with learning disabilities frequently determined their involvement in personal assessments. Drawing on observations of transitions meetings for 15 young people with learning disabilities, the authors found that those with more complex disabilities and communication impairments were assumed to lack competence and were more likely to be excluded than those with less pronounced learning disabilities and those who could communicate verbally. In light of their findings, Carnaby and Lewis suggested that the school drew on alternative modes of non-verbal communication and spent time preparing students for their meeting in order to involve them and reduce the risk of exclusion. Revisiting the school four years later, observations of a further 12 young people's transition meetings demonstrated that those with communication impairments could be included and their views sought. Although a very small and specific study, Carnaby and Lewis demonstrate that competence does not always rest on verbal ability and a lack of competence cannot be presumed by a lack of participation if communication barriers exist. Hence, the authors emphasise the need for staff and practitioners to listen to young people in ways that are appropriate for each student.

The assumptions of others, especially parents, about the competence of people with learning disabilities may not correspond to those of people with learning difficulties themselves. This was demonstrated in McConkey and Smyth's (2003) study of young people with 'pronounced' learning disabilities who had recently left two special schools in Belfast. Thirty-four young people were interviewed separately from their parents. From the interviews with young people, McConkey and Smyth found that they considered themselves more 'competent' than their parents did; they felt able to do more activities/things in life (such as going out alone, domestic tasks) and manage everyday risks than their parents gave them credit for. Despite this, under half of the parents interviewed were prepared 'to take the risk' of teaching their son/daughter to manage everyday risks, presuming that they could not learn how to do everyday tasks such as crossing the road or cooking, or that they had no need to learn to do these things. However, as the authors note, when young people demonstrated their ability to learn or successfully did everyday tasks, this could set a 'virtuous circle' in motion and encourage future/new risks. Although a relatively small scale and specific study, it is important as it actively seeks to explore young people with learning disabilities' own ideas about their competence.

In a number of the studies relating to competence and risk for people with learning disabilities, sexuality, sexual relationships and sexual behaviour emerged as key

preoccupations of study participants. Indeed, over half of the studies that examined issues of risk and adults with learning disabilities included risks relating to sexuality. As noted previously (Banim *et al.*, 1999; Heyman and Huckle, 1993a, 1993b, 1995), this preoccupation is usually grounded in the belief that people with learning disabilities lack the competence to prevent sexually associated dangers or take appropriate action to protect themselves in relation to risks such as, unwanted pregnancy, sexually transmitted diseases or the unwanted attentions/advances of others.

Parents' views of their son/daughter as vulnerable due to a lack of understanding and thus in need of protection were clearly demonstrated in Heyman and Huckle's (1993a, 1993b, 1995) study of parents of adults with learning disabilities and the risk management strategies they adopted. Drawing on a sample of 20 adults with learning disabilities who attended two adult training centres in Northern England, interviews were conducted with service users, their informal carers/parents and centre staff. Data from the parents' interviews demonstrated that everyday activities, such as going out alone or meeting people of the opposite sex, were viewed as 'hazards' and dangerous. However, Heyman and Huckle found that although parents viewed hazards and risk taking as dangerous and something to be feared, there were differences between parents in their approach to and management of risk. The authors noted two risk management approaches:

- Risk taking as a danger to be avoided at all costs; here, young people's opportunities for personal autonomy and risk taking were severely limited.
- Limited risk taking; risk taking was feared and seen as potentially dangerous but for these parents there was also recognition that risk taking could potentially be a positive learning experience for their son/daughter.

In the latter view, there is some recognition by parents that their son/daughter could learn and develop from risk taking opportunities, i.e. they have the competence to learn.

The risks of adults with learning disabilities, especially males, being potential sexual abusers was infrequently discussed, only three articles discussed this issue (Brown *et al.*, 1994; Manthorpe and Stanley, 1999; Thompson, 2000). However, they raise a number of important and complex issues surrounding sexual risk and competence, especially the issue of whether people with learning disabilities are aware and/or knowing of their actions, both in terms of social appropriateness and the effects that their behaviour can have on others. In their discussion of the literature, Manthorpe and Stanley (1999) highlight the dual and often conflicting status of people with learning disabilities as both 'deviant' and/or 'innocent', 'victims' and/or 'villains'. This frequently 'muddies the waters' surrounding how they are viewed and treated by others, particularly staff.

This ambiguity with regard to competence was demonstrated in Thompson's (2000) small qualitative study of ten adults with learning disabilities who had sexually abused or presented sexually inappropriate/'unacceptable' behaviour towards others (including fellow service users and staff). Within this article it was not clear who had been interviewed, however, details of methods are given in Brown and Thompson (1997)[8] indicating that Thompson reports the views of staff working with the adults with learning disabilities. In his case studies, he found, as Manthorpe and Stanley (1999) suggest, that staff often felt the status of these men, as sexual perpetrators and/or unknowing and innocent was unclear and confusing. In addition, Thompson argues, the whole area of sexuality was viewed as difficult to address and manage by staff, as it was often viewed as a private area. Overall, he found a lack of guidance for staff and no clear information or guidance for people with learning disabilities about what is acceptable or unacceptable. Thompson argues that the question; how far should a person with learning disabilities be allowed to take responsibility for their actions, raises complex issues for staff. Staff need to balance their duty of care to protect potentially unknowing service users lacking competency from inappropriate actions against the right of adults with learning disabilities to make choices and learn from mistakes, i.e. to treat as competent individuals. For Thompson 'good risk management' involves staff taking account of both identities of 'victim' and 'villain'.

Murphy *et al.*'s (1995) Dynamic Risk Assessment and Management (DRAMS) model of active risk management presents an interesting approach to risk management, as it presumes that adults with learning disabilities can learn from their behaviour and develop their personal level of competence. Murphy *et al.*'s study presents an in-house evaluation of the DRAMS pilot project developed in a high security hospital for people with learning disabilities, predominately male patients. Ten members of staff completed a questionnaire about their experiences of using DRAMS.

DRAMS is a traffic light system attached to risky or unacceptable behaviour (i.e. with red as unacceptable and green as acceptable behaviour at either end of a continuum) with the aim of presenting a visually meaningful portrayal of what is acceptable/unacceptable behaviour to people with learning disabilities. The authors found that staff generally regarded DRAMS as helpful, as it enabled them to focus on patient behaviour and real issues. For example, if behaviour coded as 'red' was undertaken by service users, staff felt the traffic light system helped patients to recognise and understand that their actions had consequences and that sanctions would be taken by staff. Although based on a small scale pilot, this model clearly links risk, behaviour and competence together as it is premised on a more positive presentation of risk, underpinned by the potentially empowering idea that people with learning disabilities can develop 'competence' around and knowledge of their

---

[8] Brown and Thompson (1997) a small scale qualitative case study and action research project interviewing ten men with learning disabilities who had been involved in inappropriate or challenging sexual behaviour/activities. Consultations with managers and care staff who worked with the men were also held.

behaviour (i.e. what is acceptable and unacceptable) and if transgressions occur, lessons can be learnt from these mistakes.

4.2.3 Risk, competence and mental health

In the literature, the issue of 'competence' on the part of people with mental health difficulties was inextricably linked to widespread perceptions of their status as 'dangerous' individuals. Eleven empirical studies or discussions of previously conducted empirical work (Godin, 2004; Hird and Cash, 2000; Kelly and McKenna, 2004; Langan and Lindow, 2000, 2005; Newbigging and Lowe, 2004; Ryan, 2000, 2002; Stanley and Manthorpe, 1997; Warner, 2006; Warner and Gabe, 2004) were identified relating to risk, competence and 'dangerousness' among people with mental health problems. Five review articles (Alaszewski, 2002; Langan, 1999; Manthorpe and Alaszewski, 2000; Manthorpe and Stanley, 1999; Parsloe, 1999) also focused on risk in the context of competence and danger among people with mental health problems.

Amongst the literature, the general theme that people with mental health problems were dangerous to society predominated, particularly ideas about mental health service users lacking the competence to think or act rationally. Warner's (2006) interviews with 39 mental health social workers and managers highlights the important role that high profile mental health inquiry reports can play shaping practitioners ideas about people with mental health problems and also their practice toward managing the risks users present. Discussions with social workers demonstrated that inquiry reports often mirrored wider social presumptions about people with mental health problems as 'dangerous', irrational and unpredictable and also helped to reinforce these presumptions and fears. Social workers were also aware of these social ideas and wider fears and the implications that this brought for their practice of potential litigation, scapegoating and being blamed. As Warner (2006) argues, they are 'active' documents in the sense that they helped to guide and influence practitioners' ideas and practice about 'who' was viewed as dangerous and thus a risk to society.

However, the role played by the media in creating and sustaining popular beliefs about risk, danger and lack of competence on the part of people with mental health problems is complex. Although Petts *et al.*'s (2001) study draws on a wide range of risk issues and fears presented in the media, the 18 discussion groups they held with a large and varied sample of 145 people demonstrated the importance of personal ideas and experiences. To be feared, 'risk' had to be viewed as personally relevant to each individual and their life; people did not merely accept media presentations and ideas in an unthinking manner. As Petts *et al.* note, how the public views and interprets 'risk' is a complex, active and subjective process; one cannot presume that all members of the public automatically accept media representations.

Complex attitudes and evaluations were similarly demonstrated in Warner and Gabe's (2004) research with practitioners working with mental health service users, especially their views of users' competence and capacity for rational thought. Drawing on interviews with 39 mental health social workers from one inner city social services district, Warner and Gabe found that social workers frequently applied a binary categorisation for many mentally ill clients, based on the idea of the 'mad' and the 'bad'. A key characteristic of the 'mad' is the idea that their mental illness lies at the heart of their actions; if they are a danger to the community is it due to their illness rather than some innate evil tendency. Hence, the individual is not felt to be morally accountable for their actions, their competency is questioned due to their 'illness'. In contrast, those categorised as 'bad' are usually viewed as having a degree of responsibility. This binary categorisation is, as Warner and Gabe suggest, clearly a moral evaluation, a divide between the 'deserving' and the 'undeserving', which can in turn have important implications for service users in terms of the services and support they receive and how they are treated by practitioners (and others in society). The 'competence' of both groups (mad and bad) is also compromised in the fact that they are, as the authors note, socially marginalised and their capacity for rational thought is questioned.

However, for those service users whose mental health problems may be less pronounced or who are not obviously 'mad' or 'bad', Warner and Gabe's interviews with social workers indicated that they frequently assigned 'hard to place' people with mental health problems, especially those living on the streets, a 'liminal' status. For Warner and Gabe, drawing on the work of Lupton (1999), people with mental health problems are 'liminal' in the sense that they occupy an in-between place, neither part of the community nor clearly beyond the community. It is an unknown place and thus feared and associated with danger and unpredictability. More specifically, the authors' found that their social workers drew on ideas of 'otherness' to make sense of clients. Clients assigned a 'liminal' status were frequently viewed as 'shadowy' figures, peripheral to or, detached from mainstream society. This characteristic of 'otherness' has also been noted by Godin (2004) in his study of 20 community mental health nurses. For Warner and Gabe, this association of 'otherness' and 'liminality' can also contribute to the idea that people with mental health problems constitute a potential threat to social order. By assigning some mental health service users a 'liminal' status, it becomes, as Warner and Gabe suggest, easier to separate them from 'normal' life. 'Liminal' mental health service users become a 'risky' category in themselves; their competence is implicitly compromised and it becomes 'risky' for practitioners to allow them to engage in risk-related decisions or activities. Indeed, as the authors suggest, it may be easier and socially more acceptable to increase surveillance and deny risk-taking opportunities in the name of 'safety' and protection, both for the user and for society.

Warner and Gabe's research has clearly demonstrated the power of negative labels and associated stigma as a means to marginalise and exclude mental health service

users, either defined as 'mad', 'bad' or the 'other'. The use of negative labels was also noted by Langan and Lindow (2000) drawing on data from a workshop conducted with 30 mental health service users and practitioners from a range of settings, including, statutory and voluntary services and the police. Group discussions revealed that practitioners used the term 'no insight' as a short-hand to dismiss mental health service users' competence to assess what constitutes 'risk' and/or their preferred management strategies.

In addition, the literature reviewed suggests that 'dangerousness', race and ethnicity are interwoven, frequently premised on biological and cultural presumptions of 'difference'. Four studies highlighted the prevalence of racism in mental health and the popular cultural stereotype of black mental health service users as 'dangerous' (Browne, 1995; Langan and Lindow, 2000; Warner, 2006; Warner and Gabe, 2004). Warner and Gabe (2004) found that amongst the social workers they interviewed there was awareness of racial stereotypes, with black young male mental health service users viewed as particularly dangerous. Warner and Gabe suggest that being 'black' and a mental health service user are two forms of 'otherness' often presented as two sides of the same coin and mutually reinforcing. Browne's (1995) discussion of black mental health users argues that this perception of risk, danger and being black impacts on professional ideas and practices. Reporting the ideas of a range of staff and practitioners from two psychiatric hospitals, Browne found that three quarters of staff viewed black patients as more dangerous than white patients. Black mental heath users were frequently treated more harshly, with restraint routinely used and more likely to be administered medication as a sedative compared to white patients. Issues of risk and ethnicity will be discussed further in Section 4.6: Risk and wider socio-economic factors.

In the research on risk and competence, the perspectives of mental health service users themselves are largely absent. Only four references (empirical studies or discussions drawing on previous empirical work) were found that examine risk and competence from the perspective of service users (Alasewski *et al.*, 1998a; Hird and Cash, 2000; Kelly and McKenna, 2004; Ryan, 2000). These studies draw attention to some of the potential risks faced by people with mental health problems themselves, including self harm (from self injury to suicide); negative side-effects of prescribed medication; and social isolation and victimisation in the communities within which they live. Kelly and McKenna (2004) argue that such potentially negative consequences of community care policies are frequently ignored or dismissed.

4.2.4 Risk, competence and young people

Three studies (Atkin and Ahmad, 2000; Morris, 1999; Stanley *et al.*, 2004) and one review/discussion article (Bridge, 1997) were found that examined issues of 'competence' in relation to young people and the transition from child to adult status.

The literature discussed issues of parents being overprotective and acceptable levels of parental participation in decision making were also central.

Adolescence is frequently presented as separate phase in the life-course, a period in-between childhood and adulthood but, as Stanley *et al.* (2004) and Bridge (1997) highlight in their study and literature review respectively, it is also often presented as a time of social and emotional confusion and potential rebellion from adult social norms. This presentation of adolescence as 'troubled' and a time of 'self-discovery' can, as Bridge (1997) suggests, have important implications for the perceived competence. Social stereotypes of young people as irrational, rebellious and confused can lead to a questioning of their perceived competence to make rational, informed choices about risk taking and their ability to manage risky situations.

The popular social idea of young people as 'risk takers', engaging in risky action with little regard to potential consequences, especially in terms of personal health, was demonstrated in Atkin and Ahmad's (2000) study of medical non-compliance among 25 young people with thalassaemia major (see Section 4.1: Risk and normalisation for details of the study's methods). From their discussions with young people, Atkin and Ahmad found that the young people most likely to engage in medical non-compliance (i.e. turning off or using their pump less frequently than treatment required) were those aged 13 to 16 years; an age group very clearly associated with adolescence and potential rebellion. Young people below 13 years and above 17 were frequently more compliant, viewing medical 'non-compliance' less positively; older young people in particular, were more willing to acknowledge the future health risks and dangers attached to non-compliance.

The authors also found that young people, especially those aged 13 to 16 years, felt that their parents were often over protective and did not allow them to do things such as staying overnight with friends or doing sports because of their illness and treatment routine. For young people, as Aktin and Ahmad note, non-compliance was thus a means to assert their independence and personal autonomy, to take control of their lives and make decisions. The negative consequences of medical compliance may suggest that young people's non-compliance actions are irrational; however, as Atkin and Ahmad highlight, they were regarded by the young people themselves as rational and meaningful acts. The young people felt that they were competent to make decisions regarding their treatment, even if parents viewed their behaviour as misguided and lacking understanding.

As noted above, issues of competence and adolescence can be further complicated when a young person's mental health is called into question. In her review and subsequent discussion of the literature and a number of past high profile cases, Bridge (1997) explores how young people with mental health problems raise complex issues for practitioners. She argues that issues of 'competence' regarding young people with mental health problems are often ambiguous and unclear, a situation not

aided by the current legal ambiguity surrounding their role in the decision making process. Bridge stresses that although participation may be advocated in current policies and legislation such as, the Children Act (1989), UN Convention on the Rights of the Child and test cases such as Gillick vs West Norfolk and Wisbech Area Health Authority (1985), there is still much confusion and ambiguity, a situation which has led to different interpretations of 'sufficient' understanding and intelligence amongst between professionals and their practice.

From her review of the literature and previous test cases, Bridge suggests that in the past, practitioners have largely focused on mental health issues and tended to ignore the issue of adolescence and its potential impact on young people's behaviours. Focusing specifically on young people refusing medical treatment, Bridge suggests a typology of three potential scenarios that mental health practitioners working with young people should consider:
- 'competent young person' – refuses treatment the same as any other adult would
- 'mentally ill young person' – treatment is refused as a result of mental health problems/misconceptions
- 'rebellious teenager' – refuses treatment due to adolescent experiences, such as rebellious 'teenage angst' rather than mental health issues.

Within this typology, Bridge highlights the importance of placing teenage behaviour in context, i.e. 'teenage angst'. What may be viewed as potentially problematic, anti-social or 'strange' behaviour by concerned family members may be more to do with young people pursuing adolescent patterns of risk taking behaviour such as, experimenting with drugs or establishing/re-establishing their role and status in society. Bridge concludes by suggesting that when conducting assessments practitioners need to consider the role of adolescence in the life of each young person and the potential impact it may have/be having on their personal behaviour and decisions made (i.e. whether to accept treatment or not). Bridge argues that if practitioners adopt a more socio-culturally aware perspective, a more informed understanding of young people will be possible, one that does not automatically assume or question young people's competence and ability to make rational and informed decisions regarding personal treatment. Although Bridge does not present empirical evidence, her discussion and resulting typology raises a number of important issues in an extremely complex area.

The final issue raised by the literature surrounds adolescence, adult status and working with parents, especially in the context of a young person's right to confidentiality. This was clearly demonstrated in Stanley *et al.*'s (2004) study of 30 GPs exploring how they would manage parental concern for a son/daughter who they viewed as at risk of suicide. In a telephone interview, each GP was asked how s/he would approach the following fictional case of Ben, a 20 year old student who had returned home from university and was under weight, reclusive and uncommunicative. The GPs were asked to discuss how they would manage two potential scenarios: the

first; with Ben's mother seeking help from the GP but Ben unwilling to see the doctor and the second, with Ben attending the meeting and also acknowledging previous suicidal thoughts and treatment with anti-depressants whilst at university. Stanley *et al.* found that GPs' perceptions of risk can differ, i.e. whether Ben was seen as 'high risk' or not. Telephone interviews demonstrated that most GPs recognised parents' fears and concerns and also their desire for information and wish to be kept continually informed. However, GPs were also aware of young people's right to confidentiality and also their own professional 'duty of care'.

With regard to action taken, a small number of GPs stood at two extremes, those who would not take any action without the young person's consent and those who would either visit the young person at home or have him brought to surgery by his parents without consent. Most GPs sought a middle ground, making contact with the young person, listening to them and respecting confidentiality, whilst also listening to parents concerns and keeping them informed, as far as possible. Although this study draws on a small group of GPs (purposively selected rather than random) and fictional scenarios, limitations which the authors themselves note, it highlights a number of tensions and ambiguities surrounding young people's perceived competence and right to confidentiality and professional practice. As Stanley *et al.* note, GPs were aware of the need to balance parents' views of their son/daughter's competence and ability to make a rational and informed decision (to see the GP or not); the wider question of whether they are mentally ill and at risk of suicide; and the young persons' wish for confidentiality, respecting this confidentiality and assessing their competence to make rational decisions in the context of their own professional obligations and a duty to care.

4.3 Risk and strategies to gain or maintain 'control'

This section focuses on approaches to managing and controlling risk – whether from the perspective of service users about their own circumstances and activities of practitioners concerned to manage the risk-taking behaviours of others – than on definitions of and attitudes towards risk itself. 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, informal carers and practitioners may involve negotiating or re-negotiating the boundaries of what is 'acceptable', 'unacceptable', 'appropriate' or 'inappropriate'. Such strategies can

have important effects on the lives and experiences of both service users and informal carers.

Table 4.3 documents the research identified on control and the management of risk. Most of the relevant empirical research focuses on older people; in addition, a relatively large number of references were retrieved that consisted of literature reviews or discussion pieces. Significantly, only one piece of empirical research was identified that examined control and the management of risk within the context of mental health services; there appeared to be no such research examining the perspectives of, or practice with minority ethnic adult service users.

Table 4.3 References discussing the theme of risk and gaining or maintaining 'control' by subject area* (n=38)

Subject area	Number of references discussing 'risk and control'
Older people	13
General**	14
Disability	5
(specifically learning disability	3)
Young adults	3
Substance misuse	2
Mental health	1
Total	**38**

* It is important to note that a number of the references in the literature reviewed and identified as discussing issues of risk and control, either discussed the same study or the study's authors have written more than one article/chapter/book discussing aspects of the same study.
** 'General' refers to those references discussing more than one area, often older people, those with learning disabilities and mental health service users.

4.3.1 Risk, control and service user strategies

As noted above, there appears little research on how mental health service users or adults with learning disabilities gain or maintain control over everyday risks; any such evidence appears to be largely derived from the perspectives of informal carers or practitioners. Seven studies examined how direct payments (i.e. service users managing, organising or co-ordinating their social care support and services through direct payment provision, as opposed to services being directly provided by statutory, voluntary or private organisations) allowed disabled people to exercise greater control over how, when and by whom their social care support and services were provided and thereby reduce risk; these studies will be discussed in the following section, Section 4.4: Risk and different social settings.

Nine references focused specifically on the control-related strategies used by service users; of these, seven (Atkin and Ahmad, 2000; Clark and Hartman, 1996; Clark *et al.*, 1996a, 1996b; Schur *et al.*, 1999; Turning Point, 2006; Warburton *et al.*, 2005) described how service users actively withheld information about their actions or behaviour. Despite focusing on different groups of service users (older people in Clark and Hartman (1996) and Clark *et al.*'s (1996a, 1996b) work; people who misuse substances, particularly alcohol, in Turning Point (2006) and heroin in Warburton *et al.*'s (2005) study, young people in Atkin and Ahmad (2000) and Schur *et al.*'s (1999) studies), in all seven studies there was general recognition that some activities were regarded as 'risky' by informal carers or practitioners. Nevertheless, the service users in these studies had made a definite choice to either begin or continue pursuing these 'risky' activities. This was largely due to the fact that, in contrast to their carers or practitioners, whilst recognising that their behaviour/actions was in some ways risky and could have negative consequences for them (e.g. falling for older people or compromising current and/or future health for the young people) they either felt that they could manage or control these risks, or, alternatively, felt that the potential positive benefits which ensued from their risky actions outweighed any potential negative effects. For example, benefits such as an increased sense of emotional well-being, self-identity and independence and sustaining normal, every-day life and social participation, were identified.

Weighing up these potential costs and benefits was demonstrated in Clark *et al.*'s (1996a, 1996b) study which interviewed 50 older people with dementia leaving two hospitals and returning home (interviews were also conducted with practitioners and carers and reported in Section 4.1: Risk and normalisation). One participant described how she regularly showered alone, unbeknown to her care worker, in between her twice-weekly care visits when she was bathed by the care worker. The older person recognised the risk of falling and took care to avoid injury by placing cushions around the shower to break her fall if she did slip. Explaining the situation, the older person felt that the personal sense of enhanced control, confidence and independence the additional showers provided were worth the risk of falling.

Where service users were aware that their actions could be viewed as risky, they were keen to keep these hidden from informal carers or practitioners, as 'discovery' could have negative consequences. For example, in Clark *et al.*'s (1996a, 1996b) study, interviews with carers demonstrated that older people did not want to cause their informal carers undue anxiety and stress, be a 'burden' to their families or put paid care workers in a potentially awkward position. With regard to the latter issue, the older people recognised that practitioners could feel 'duty bound' to take preventative action or report their actions to senior managers. As Clarke *et al.* note, the older people in turn recognised that this could have negative ramifications, in terms of being able to continue with the perceived 'risky' behaviour or, indeed, continuing to live in their own home. The authors demonstrate that the older people they interviewed were aware of their reliance on others; indeed, they recognised both

the existence and importance of the power dynamics that lay between themselves and informal carers and/or paid care staff, especially the latter. Covert strategies to regain or maintain control were clearly important to many of the older people interviewed and helped to facilitate an increased sense of well-being and continuing independence. However, it was also apparent from Clarke's interviews that pursuing these covert risky acts was stressful, as it brought an ever-present fear of 'being found out' and negative sanctions. Atkin and Ahmad (2000) also found in their discussions with 25 young people with thalassaemia that covert action, in this case, medical non-compliance, led some young people to feel guilty when they deceived their parents by turning off their pump or hiding unused syringes. The young people, as the authors' note, were aware that their behaviour would/did cause their parents anxiety and this knowledge of the extra stress they brought parents accentuated their feelings of guilt.

By taking risky actions in a covert manner, both the older people and young people risked the danger of 'being found' out and if 'found out' this could lead to increased monitoring and surveillance and thus paradoxically less opportunities for independent action, especially future risk taking. This was demonstrated in Atkin and Ahmad's (2000) study. Discussions with those young people whose medical non-compliance and deception to their parents had 'been found out' revealed situations where their parents now took more control over their medical treatment, either administering injections or controlling the pump. As the authors suggest, the young people felt they had lost control and personal autonomy. A paradox thus emerges: in searching for more independence and a sense of 'control' with opportunities to take risks, users' covert 'controlling' strategies may actually limit the risk taking opportunities that they have or control that they can exert in everyday life. Covert risk taking is clearly doubled edged.

Reviewing past literature surrounding doctor and patient consultations discussing risky health behaviour, Misselbrook and Armstrong (2002) demonstrate how patients may agree with doctors whilst in the consultation room but in everyday life they continue to take risks and pursue previous life patterns. The authors suggest that some patients recognise the important of 'playing the game', outwardly accepting and complying with professional definitions of risk and management strategies for 'appropriate' action, whilst subjectively re-defining 'risk' and modifying these strategies in practice.

'Playing the game' was similarly noted in Heyman (2005) and Heyman *et al.*'s (2002) research exploring the idea of 'health risk escalators'. In Heyman *et al.* (2002), the authors focused on one hospital for offenders with mental health problems and within this, 11 patients and the staff working with them. Heyman (2005) reports the results of a further case study in a hospital involving prenatal chromosomal screening (in this article Heyman also report on his previous work with offenders with mental health problems). Although the data draws on specific case studies of disparate groups of

service users both were consistent in demonstrating a 'health risk escalator'. With regard to mental health, Heyman (2002, 2005) argues that in the 'health risk escalator', service users either move 'up' the escalator towards greater autonomy and opportunities for risk taking behaviour or, conversely, 'down' the escalator with an emphasis of increasing danger and thus the need for safety and risk avoidance. Discussions with service users demonstrated that they could, and frequently did take control of their direction of travel, either by compliance and 'playing the game' if they felt comfortable with the direction in which they were moving or, if they did not like the direction and/or speed of travel, then deliberately 'fouling up'. This could involve doing something viewed as 'dangerous' or 'challenging' by others and lead to the user being moved back 'up' the escalator.

Research has also shown how some service users sought to reduce others' perceptions of risk by carefully managing their presentation of self. In Warburton *et al.*'s (2005) study of 174 (51 interviewees, 123 questionnaire respondents), semi-dependent or 'controlled'[9] heroin users, presenting themselves to others, especially family and friends, as being 'in control' was of primary importance. Users frequently drew on their knowledge of how much heroin they could 'safely' take and controlled the social context of where and with whom they took heroin, in order to present themselves as 'in control' and able to maintain normal routines and obligations to others. For these users, it was imperative to avoid associations of being 'out of control' and therefore 'at risk'. Indeed, Warburton *et al.*'s study demonstrates another form of 'othering' (as noted previously by Warner and Gabe's study of liminality) with users distancing themselves from 'them' – 'the druggies', out of control – and 'me' – a user, who is 'in control'. This risk management strategy was ongoing, albeit based on a fragile and precarious balancing act.

The importance of presenting oneself as 'in control' was also demonstrated by Turning Point's (2006) study of children and parents affected by alcohol misuse. Recognising the risk that the children of alcoholic mothers might be defined as 'at risk' and in need of professional intervention, Turning Point's study showed that many mothers deny their alcoholic status and try to present a façade of normal life by controlling the information given to others. Here, complex issues of risk, rights and responsibility are raised.

4.3.2 Risk, control and informal carer strategies

Ten references were identified that examined the strategies employed by informal carers to control either the physical or social circumstances of the person they cared for (Buri and Dawson, 2000; Clarke, 1999, 2000; Clarke and Heyman, 1998; Daker-

---

[9] 'Controlled' heroin users – this was based on the users' own self-evaluation of their use and dependence; they essentially saw themselves in control of their use of heroin.

White *et al.*, 2002; Heyman, 1995; Heyman and Huckle, 1993a, 1993b; Manthorpe, 2004; Stalker, 2003). Situations or actions viewed as 'risky' were either avoided or modified/adapted to try and minimise danger and ensure greater safety. These activities were often undertaken covertly by informal carers, or not openly discussed with the person they were caring for, as carers acknowledged that the latter might not concur with the carers' perception of 'risk' and what is or is not appropriate behaviour. For example, in Buri and Dawson's (2000) exploratory study of six relatives caring for older people with dementia, in order to reduce risks of falling, carers frequently re-arranged the physical layout of the older person's home; furniture was moved into 'safer' places; dangers which could be tripped over were removed. In Daker-White *et al.*'s (2002) study of 20 informal carers[10], mainly of younger people with dementia (i.e. under 65 years); some carers regarded driving as a particularly 'risky' activity for the person with dementia. Covert actions such as hiding car keys were therefore carried out. The authors of both these studies suggest that the informal carers interviewed sought to manage and control risk through covert strategies which did not directly threaten the sense of independence of the person being supported. The carers recognised the importance of the older person they supported feeling that they had retained some control and autonomy in their life.

Carers' covert risk management also raised the issue of unintended consequences. Research demonstrated that carers' covert strategies to control risk may unintentionally increase them. Interviews with carers in Buri and Dawson's study (2000) showed how re-arranging the physical layout of the home could reduce carers' anxieties but paradoxically could also increase the actual risk of falling for older people, for example, if an older person is not used to the new layout of a room, becomes confused, overlooks obstacles and thus falls. Carers' covert strategies to control risk could also cause conflict with practitioners who may view these as unethical and potentially disempowering for the person being supported. Potential conflict between informal carers and practitioners has also been noted in Clarke's studies of older people with dementia (Clarke, 1999, 2000; Clarke and Heyman, 1998) (see Section 4.1: Risk and normalisation). This evolved from carers' strategies to make sense of and manage risk in the life of the person they cared for and their own life. As Clarke demonstrated, carers' normalisation strategies were frequently a means to try and control their (and the older person they supported) current life situation and the support offered by service providers.

Studies of carers of people with learning disabilities, in contrast, suggest that these carers may take a more direct approach to controlling the physical and social environment in order to reduce risk. The parents of adults with learning disabilities in Heyman and Huckle's (1993a, 1993b, 1995) study actively tried to control the degree

---

[10] Daker-White's *et al.*'s study also involved interviews with service users and practitioners and a wider postal questionnaire of practitioners.

of freedom their son/daughter had, especially in relationships with the opposite sex, although the level of control exercised by parents varied.

4.3.3 Risk, control and practitioner strategies

Nine references focused on the role of practitioners in controlling information to adult service users, informal carers and their families in order to manage risk (Adams, 2001; Ballinger and Payne, 2002; Banim *et al.*, 1999; Heyman and Huckle, 1995; Iliffe and Manthorpe, 2004; Redfern *et al.*, 2006; Pritchard, 2001; Stanley *et al.*, 2004; Tan and Killimach, 2004). Eight of these references are empirical studies and one provides a review of the literature (Iliffe and Manthorpe, 2004). The empirical studies are all qualitative and the majority focus on limited geographical settings, either one or two locations. The samples vary in size but two in particular draw on small samples; Tan and Killimach (2004) interviewed only eight disabled young people and their parents and Pritchard (2001) discusses five case studies. The studies focus on different groups of service users, particularly mental health service users, older people and disabled people.

Four of the empirical studies (Ballinger and Payne, 2002; Banim *et al.*, 1999; Heyman and Huckle, 1995; Redfern *et al.*, 2006) noted that some practitioners routinely did not share information about risk and potential risk-related activities with service users, leaving the latter frequently ill informed. For example, in Redfern *et al.*'s (2006) study observing consultation meetings between doctors and patients and/or patients and a nurse in two hospital clinics seeking to reduce the risk of further strokes occurring, observations demonstrated that doctors did not routinely share information or explain to patients about potential risks they faced or how to prevent a further stroke. In addition, when they did give information, this was often in medical or technically based language, which patients frequently did not understand. In contrast, the nurse used more accessible lay language and encouraged a more participatory dialogue between herself and patients, encouraging patients to ask questions. Indeed, Redfern *et al.*, found that the nurse often spent time explaining the doctor's technical language to patients and answering their questions from previous consultations with doctors. Although this is a small scale study (68 patient consultations in two outpatient clinics with six doctors and only one nurse), it illustrates how different groups of professionals can have different approaches towards the provision of information about risk (see also Alaszewski and Horlick-Jones, 2003; Edwards, 2003; Edwards *et al.*, 2002; Paling, 2003).

Other research on professionals' control of information relating to risk has examined the problematic balance between risk and confidentiality. Stanley *et al.*'s (2004) study of 30 GPs and young people regarded as 'at risk' of suicide by their parents (see Section 4.2: Risk and competence for details of the study and its methods) showed the tensions that GPs encountered trying to balance their 'duty of care' with the

young people's 'right' to confidentiality and with parents' desire for information. In the context of multi-agency working, Pritchard (2001), in her review and subsequent discussion of the literature and personal experiences of social work practice, argues that social workers can face complex ethical dilemmas as clients may have given them personal information without realising that social workers may routinely share this information with colleagues or, if there are questions of potential harm, with practitioners from other agencies. This can raise complex ethical questions for social workers seeking to balance individual client rights, risks to wider society and their own professional 'duty of care' and associated legal obligations. Pritchard thus argues that clearer guidance needs to be established for individual practitioners in order to support and guide their everyday practice.

In their review of current literature and policy directives, Iliffe and Manthorpe (2004) discuss the potential benefits and risks associated with early diagnosis of dementia (see Section 4.2: Risk and competence). Offering an early diagnosis of dementia and giving information to older people and their carers are currently advocated in practice guidance. However, Iliffe and Manthorpe argue that early diagnosis and information provision can be a negative experience for the older people involved and have an important impact on both their sense of 'self' and wider social status in society. In particular, it can lead to a redefinition of routine daily activities previously viewed as acceptable being re-defined as unacceptably risky. Iliffe and Manthorpe therefore question the presumption that early diagnosis is necessarily desirable and suggest that consideration needs to be given to when and what information is given to older people and their families.

However, information is not always controlled by practitioners; moreover defining, assessing and managing risk can be a dialogue rather than a monologue. This was highlighted in Adams' (2001) study of discussions about risk between 24 community psychiatric nurses (CPNs) and informal carers of older people with dementia. Adams explored how the process of defining and managing risk developed through a complex exchange of ideas between both parties:

- The first stage, 'fishing', was usually CPN-led, with the nurse providing the carer with opportunities to discuss their concerns.
- During the second stage, 'identification', the carer could identify situations they viewed as 'risky'.
- The third stage, 'assessment' enabled both the practitioner and the carer to engage in further discussion of 'what is risk'. Although both parties are involved, it was apparent that the nurse frequently controlled the outcome of this stage and future direction of the risk discourse and its subsequent management. For example, the CPN may decide that no further action was required (i.e. the level of perceived risk was not regarded as requiring action or concern) or that action needs to be taken. If the latter decision is made by the CPN, discussions then progress to the fourth stage.

- The final stage, 'addressing and managing risk' was planned and agreed by both parties.

Although a small and very specific study (one group of practitioners and one user group), Adams' observations of consultation meetings demonstrates that control of information is not always practitioner led. Information provision and developing knowledge is, as Adams notes, a complex and dynamic process between different parties, in this case practitioners and informal carers.

4.4 Risk in different contexts

This section will explore how different contexts impact on both how 'risk' is viewed and subsequently managed by service users, informal carers and practitioners. It will explore two contexts that the literature has focused on: the organisational contexts within which different practitioners work, their ethos and procedures; and providing care and support in domestic or informal settings, such as service users' homes.

The importance of contextual issues was noted in just under a third (48) of the references reviewed. As Table 4.4 demonstrates, there were more references discussing risk in relation to issues of context in terms of more than one client group (i.e. those classified as 'general). Many of these studies focused on the development and/or evaluation of direct payments across a range of client groups or compared the different organisations settings that different groups of practitioners working within.

Table 4.4 References discussing the theme of risk in different social settings or organisational contexts by subject area* (n=48)

Subject area	Number of references discussing risk and different contexts
General**	26
Older people	9
Disability	6
(specifically learning disability)	4
Mental health	3
Young adults	2
Substance misuse	2
Total	**48**

* It is important to note that a number of the references in the literature reviewed and identified as discussing risk and different organisational contexts, either discussed the same study or the study's authors have written more than one article/chapter/book discussing aspects of the same study.
** 'General' refers to those references discussing more than one area, often older people, those with learning disabilities and mental health service users.

4.4.1 Interpreting and managing risk in different organisational contexts

Ten references noted the importance of different organisational contexts (Alaszewski, 2002; Alaszewski and Manthorpe, 1998a; 1998b; Alaszewski *et al.*, 1995; Manthorpe, 2003; Manthorpe and Stanley, 1999; Parsloe, 1999; Ryan, 1996; Thom and Blair, 1998), however, within these references three studies conducted by Alaszewski and colleagues were frequently discussed. The three empirical studies were Alaszewski and Manthorpe (1998a) and Alaszewski *et al.* (1998a, 1999).

Alaszewski *et al.*'s (1998a) study explores the ideas and experiences of practitioners, their perceptions of risk, the management strategies they employ and how 'risk' is taught to student practitioners, with a key focus on nurses. The study also explored the ideas and experiences of service users and their informal carers. Data was gleaned using a number of different qualitative methods, including interviews, diaries and group discussions and focused on a range of nursing participants from lecturers to students, interviewing in total 72 participants. The sample and methods employed in this study are thus relatively broad compared to others. Nurse participants worked with older people, adults with learning disabilities or clients with mental health problems.

The second (Alaszewski and Manthorpe, 1998a) and third (Alaszewski *et al.*, 1999) studies both explored the organisational context of different agencies. The Alaszewski and Manthorpe (1998a) study examined the policy guidelines and practice guidance accompanying risk assessment and management in 42 statutory and voluntary agencies providing care for vulnerable children and adults. Of the 42 agencies, 15 were defined as 'multi-purpose', 21 supported people with learning disabilities and six provided care for vulnerable children. Although reporting results from a range of agencies, the authors themselves note the study's poor response rate (38%) as 110 agencies were initially contacted. The Alaszewski *et al.* (1999) study explored both agencies' and practitioners' risk management approaches and also the ideas and experiences of service users and carers. The authors conducted focus groups and individual interviews in five locations in England and Wales with staff working with people with learning disabilities, service users and their carers. A total of 31 telephone interviews were conducted with staff from a range of agencies (statutory, voluntary and private) from all five locations. Agencies were asked to provide any documentation supporting risk assessment and management. This study focused on one specific client group, i.e. adults with learning disabilities; however, it drew on a range of different agency providers (statutory, voluntary and private) in different geographical locations.

Ideal type models present a useful means to identify organisational similarities and differences surrounding key themes. Drawing on the ideas of Weber, Hood *et al.*'s

(1992)[11] typology of risk and organisations and King *et al.*'s (1971) typology of child care agencies, Alaszewski and Manthorpe (1998a) have developed a typology of the different approaches agencies can take to risk. This is largely based on whether they adopt a narrow or a broad approach in three key areas:

- participation in decision making – a narrow approach emphasises expert judgements and technical expertise, whereas a broader approach seeks to include lay opinions and experiences in any definition or assessment of risk
- 'internal incentive systems' – here a narrow approach focuses on individual accountability and blame with clear sanctions for staff, a broader approach seeks to protect staff if 'true' mistakes are made, to share information and to learn (as an organisation) from mistakes
- 'managing the environment' – trying to control the environment in order to take preventative action lies at the heart of a narrow response, whereas a broader approach seeks to be responsive to risks, as the environment is unpredictable.

Parsloe (1999) in her review of the literature similarly noted the importance of asking three key questions with regard to how organisations react to risk:

- Does the organisation support staff making difficult decisions?
- Does it support staff if things 'go wrong'?
- Does it encourage shared learning?

Alaszewski and Manthorpe (1998a) used their typology to analyse the data gained from interviews with practitioners and their examination of a range of risk related documentation (i.e. guidance, policies) provided by the 42 participating voluntary and statutory agencies. Practitioner interviews and documentary analysis led Alaszewski and Manthorpe to conclude that most agencies were defensive and narrow in their approach to risk. They were most defensive in terms of seeking to manage the environment; the ideal was clearly to take preventative action before risk occurred. However, elements of a broader approach were noted in respect to lay participation, as some practitioners were aware of the importance of involving users and carers in risk assessments. Similarly, in their 1999 study drawing on data from 31 interviews with staff working with adults with learning disabilities from a range of agencies, Alaszewski *et al.* found that overall most agencies took a narrow protectionist perspective and wanted staff to be proactive in predicting and preventing risk rather than reactive.

As the authors (Alaszewski and Manthorpe, 1998a) note, if staff experience a closed environment and one that seeks to apportion blame to individuals, this does not facilitate or encourage staff to voice concerns surrounding risk to colleagues. Taking this one step further, Manthorpe and Stanley (1999) have noted, that individual

---

[11] For this review, Hood *et al.*'s three most important dimensions were whether an organisation prioritised: narrow vs broad participation, assigning blame vs absolving and anticipation vs rapid response to risk.

'whistleblowing', rather than sharing fears or concerns of inappropriate risk taking or potential abuse, may be viewed as the only option. However, as Manthorpe and Stanley (1999) highlight, this can have high personal costs for the 'whistleblower' and one needs to be sure of the evidence. Hence, the focus is frequently on 'overt' risk or abuse, such as physical abuse rather than less over forms of abuse, i.e. emotional or verbal.

Alaszewski and colleagues' study also demonstrated that not all staff in the same agency held similar views on risk and the documentation from agencies similarly differed with regard to how risk was approached and the management plans advocated. Difference emerged most clearly between the different groups of clients staff supported and worked with. For example, Alaszewski and Manthorpe (1998a) found that the child care agencies in their sample were generally more defensive in their approach compared to the agencies working with people with learning disabilities. In the latter, the importance of lay involvement in risk discussions and assessments was more likely to be recognised and the potential of 'risk' as a learning process acknowledged. Although this was a small scale study and reasons for the differences between agencies was not explored, the authors suggest the importance of Douglas' (1992) concept of 'security' as a potential starting point to understanding differences. Child care agencies may feel more vulnerable and less secure than other agencies. In such a context, it is easier to close ranks, become risk adverse and apportion blame rather than be open to learning. Hence, as Alaszewski and Manthorpe (1998a) suggest it is important to explore organisational procedures or structures when seeking to understand staff attitudes and approaches to risk taking and its management. Moreover, the wider current climate of litigation, media moral panics and professional scapegoating surrounding a number of high profile child and mental health incidents and its potential impact on professional behaviour (i.e. more risk averse and safety focused) has been noted by a number of authors (Alaszewski and Alaszewski, 2000b; Horlick-Jones, 2005; Manthorpe, 2004; Petts *et al.*, 2001; Sellars, 2002; Taylor, 2006).

The size of an organisation and its funding base has also been found to influence how risk is viewed and managed. Reviewing the literature surrounding risk management for people with mental health problems, Ryan (1996) suggests that large organisations tend to be more risk adverse compared to smaller organisations, the latter were found to be more supportive of their staff. Similarly, Thom and Blair (1998) concluded from their overview of the literature surrounding risk management for people with dementia in the field of occupational therapy that voluntary organisations frequently prioritised the importance of service users' perspectives, and therefore sought to include service users in assessments and discussions of risk. For Thom and Blair, this approach stood in contrast to current policies and approaches in the field of occupational therapy where the focus was felt to be largely on functional ability and safety, and on professional and carers' perspectives. Hence, the authors

advocate moving towards a more holistic approach to risk management based not only on functional assessments of safety but also service users' subjective ideas.

Research showed that some agencies clearly have formal policies and procedures, others were in the process of writing them and some did not have any formal guidance. This was most clearly demonstrated in Alaszewski and colleagues' studies. In Alaszewski and Manthorpe's (1998a) study of 42 agencies providing care for vulnerable children and adults, the majority did not have 'well developed strategies', indeed, many could not provide any risk related documentation, whereas, in their 1999 study of 31 agencies providing support for people with learning disabilities, most (24) had risk policies in one form or another (see also Alaszewski and Alaszewski, 2002). However, these were largely 'embedded' in the wider sphere of health and safety guidance rather than 'empowerment' policies for users (i.e. risk as a positive and potential learning experience). Only a very small minority of policies had what they term, 'bridging policies', i.e. policies that recognised the need to balance both protection and empowerment. The development of recognised and accepted policies and guidelines surrounding risk is, as the authors' highlight, important; a lack of policy can have important negative implications for practitioners, especially in terms of feeling supported. This research highlights the lack of uniformity amongst different agencies in both the types of policies that exist and the form they take, i.e. if they are formally written or informal. However, the results must be viewed in context, as the research was conducted over seven years ago.

The effect of a lack of formal policies was demonstrated for both practitioners and service users in Herring and Thom's (1997) study of three local authorities and their guidance towards home care workers purchasing alcohol for older clients living at home. Although all three authorities did not have a formal procedure, unwritten policies and accepted practices had emerged, which reflected each authority's approach to the risk associated with buying alcohol for clients. The first authority prioritised choice and the right to take risks and so workers were expected to buy alcohol for their clients if requested. The second authority focused on the potential danger that alcohol could bring (i.e. drinking and then falling) and so did not encourage staff to purchase alcohol. The third authority took the middle ground, recognising both risk and rights; in practice there was no clear or consistent policy, individual staff made their own judgements. Although this may look the most accommodating policy, as Herring and Thom suggest, this had two negative effects. For service users, the authors found there was the danger of inconsistency, with different practitioners adopting different approaches to risk assessment and management (i.e. some staff would buy alcohol and others would not) and for practitioners, a lack of guidance lead to confusion, uncertainty and increased personal anxiety.

Research has also demonstrated a lack of formal training and discussion of 'risk' on trainee practitioner curricula (Alaszewski et al., 1998a). Exploring a range of nursing

training courses, the authors found that discussions of 'risk' in nursing practice varied across different courses and institutions. Risk was frequently incorporated into wider discussions of health and safety issues or raised in relation to choice and empowerment rather than being a specific curriculum module in itself. The authors felt this could lead to inconsistency and potential confusion for students, indeed, many students participating in the study felt that 'risk' was addressed most clearly in their practical placements. However, this once again lacks uniformity, as students may or may not experience risk in their placements. For Alaszewski *et al.* development of 'risk' on the curriculum as a distinct topic area was advocated.

Different practitioner views and approaches – within and between agencies
One cannot presume that just because guidance and policies exist in agencies that they are always used or drawn on in everyday practice and decision making. Research shows that guidance may be used flexibly by different practitioners depending on a complex range of issues such as professional autonomy; perceptions of one's professional role and responsibilities, especially to the organisation and its users. Differences have been noted between managers and practitioners in the value and role attached to official agency guidance and its use in their everyday practice. For example, drawing on previous empirical research (see Alaszewski and Alaszewski, 1998; Alaszewski and Manthorpe, 1998a, 1998b; Alaszewski *et al.*, 1999; Harrison *et al.*, 1998) note that, although practitioners acknowledged the existence of formal guidance, it was only regarded as one potential source of information. Whether formal guidance was used or not depended on its perceived relevance and usefulness in the wider context of each practitioner's own professional judgement. In contrast, as Alaszewski and colleagues highlight, managers tended to adhere more strictly to agency policies and guidance. Professional judgment drew on wider factors, such as client circumstances and preferences and practitioners' own experience. Drawing on past knowledge and experiences when assessing and managing risk was valued by these practitioners (this will be further explored in Section 4.5). The different roles and experiences of practitioners and managers working within the same organisation can lead to conflict and differences of opinion in terms of 'when', 'how much' and 'which' risks should be taken by clients and the support practitioners should or can offer.

Differences of opinion were also noted between the same professionals working with different groups of clients. This was demonstrated in Alaszewski *et al.*'s (1998a) study exploring the views and experiences of nurses (see also Alaszewski, 2003; Alaszewski and Alaszewski, 2000b; Manthorpe and Alaszewski, 2000). Interviews with study participants revealed that although most nurses (59 out of 72) were very aware of risk and its associations with danger and professional accountability, a smaller number (22) took a more positive approach to risk, recognising its empowering potential as a positive learning experience for service users. Differences were also found between nurses in terms of the client group they worked with. Alaszewski *et al.* identified three models of risk from their research with nurses:

- Risk as a 'hazard' and the nurse as a 'hazard manager' – this was largely associated with nurses working in the field of mental health.
- Risk as potentially 'empowering' and the nurse as a 'risk facilitator' – this view was more likely to be held by nurses working in the sphere of learning disabilities.
- Risk as a 'dilemma' and the nurse as a 'dilemma negotiator' – this perspective was associated with nurses working with older people.

The authors acknowledge that not all the nurses interviewed fell neatly into these groups, however, they suggest that these three approaches to risk and risk management reflect the wider professional ethos and social contexts within which nurses are trained and practice.

The potential for differing opinions and actions was also noted by Alaszewski *et al.* (1998b) in their review of evidence on practitioners in different service settings, for example, doctors in the NHS and social workers from social services. A key factor is the degree of professional scrutiny experienced. Doctors have a relatively high degree of professional autonomy and face frequent peer review. In contrast, social workers have less autonomy from their employers and often face public and supervisory/employer review rather than peer review. For Alaszewski *et al.* (1998b) the different types and degrees of scrutiny experienced by doctors and social workers raises questions concerning the role and impact of scrutiny on professionals risk management practices.

The potential for different organisational approaches, different approaches between practitioners and managers and also different approaches amongst practitioners depending on the clients they work with has implications for multi-agency working and developing a shared understanding of 'risk' and accepted practices or management strategies. Three empirical studies focusing on substance misuse) (Didlock and Cheshire, 2005; Kearney *et al.*, 2003; Turning Point, 2006) demonstrated the problems of multi-agency working when different agencies have different priorities and timescales. For example, Didlock and Cheshire (2005) found that some young people were more 'at risk' of reduced services and support as adult services had higher eligibility thresholds compared to children's services. The studies draw on different samples and employed different research methods: Turning Point held focus group and individual interviews with children and parents affected by alcohol misuse using their services; Kearney *et al.*, conducted a survey involving 105 social service departments across England and Wales and interviewed a member of staff from most participating departments and Didlock and Cheshire sent a questionnaire to statutory national and regional drug teams working within young people's services and held interviews with key staff in these teams. However, all three detected a lack of understanding amongst practitioners working in both child and adult services with regard to the other's roles and responsibilities. For example, practioners from adult services were unclear 'when' or 'how' to draw on the support and/or expertise of practitioners from children's services if a mother's alcohol misuse

put her children 'at risk'. Indeed, the studies by Turning Point (2006) and Kearney *et al.* (2003) highlighted that an absence of shared procedures frequently led to a focus on risk assessment and support for the adult service user (here mothers who misuse alcohol) or her children rather than a more holistic picture of the family as a whole.

Training issues

As the literature in the above sections has demonstrated, the need to provide more training and support for practitioners in relation to identifying and/or defining risk and the different ways it can be managed is a shared theme. One model for staff training and guidance frequently noted is Titterton's (2005; 1999) 'Person Centred Risk Assessment and Management System' (PRAMS), which seeks to provide a standardised and comprehensive model of practitioner risk assessment that is also flexible and relevant in different organisational settings and types of agency. PRAMS has five stages:

- firstly, staff discuss and establish 'risk' principles
- secondly, creating risk policies
- thirdly, assessing risk with staff discussing the appropriateness of different models of risk assessment
- fourthly, devising risk plans for service users and their families
- finally, managing risk, developing practical risk management strategies.

In Titterton's model, defining, assessing and managing risk is viewed as a cumulative and fluid process; although practitioners take the lead, the views of others (service users and carers) are central. Following training conducted by Titterton, 40 Scottish practitioners (mostly social workers) undertaking the PRAMS course completed an evaluation questionnaire. Although only a small and specific sample, the practitioners' responses were positive. PRAMS was felt to increase both their confidence when approaching risk taking and their awareness of the complexity surrounding risk and lay perceptions. Similar benefits of increased confidence, recognition of the complexity of risk and importance of lay participation have also been noted with regard to 20 practitioners working with mental health service users (16 were employed by social services, three community based nurses and one voluntary sector worker) undertaking risk training by Stanley and Manthorpe (1997).

The organisational context and ethos within which practitioners work can provide differing degrees of support depending on whether a 'closed' or 'open' approach to risk is advocated. However, interpersonal support has also been found to be important for both social workers and their clients. This was demonstrated in Burke's (1997) study of a diverse range of risk cases (users defined as 'at risk' in a range of social care settings) referred and allocated to two teams of social workers over the period of a year. Burke found that the social workers who received the highest levels of personal supervision were the most likely to take action on risk referrals and achieve a definite outcome for clients. This suggests that regular personal

supervision can be positive for social workers and for clients (benefits for clients appear assumed rather than directly evidenced), as Burke notes, it helps social workers clarify the nature of risk and discuss appropriate action.

4.4.2 Risk and the domestic sphere – informal/formal ambiguities and tensions

The introduction of direct payments - and, more recently, individual budgets - as alternatives to directly provided services, raises a number of questions about risk for both service users and their paid carers. These developments shift responsibility for securing and coordinating appropriate support to the private sphere – to users and their families; but at the same time they may also introduce new risks for people who are employed as personal assistants.

Twelve studies (Clark, 2006; Clark and Spafford, 2001; Fleming and Taylor, in press; Flynn, 2005; Glendinning *et al.*, 2000a, 2000b; Healy *et al.*, 1999; Hendey and Pascall, 2001; Lornas, 2006; Ryan and Values into Action, 1999; Scourfield, 2005; Taylor and Donnelly, 2006; Ungerson, 1999) were identified that examined the risks experienced by users of direct payments and/or their paid personal assistants (PAs). Most focused on the experiences of direct payment users and/or their PAs; only two studies (Clark and Spafford, 2001; Lornas, 2001) included the perspectives of care managers. Studies included a wide range of different direct payment users, including older people, disabled adults and adults with learning disabilities. However the majority of studies were relatively small scale; for example, Flynn's (2005) study involved only 16 disabled people and 14 PAs; Ungerson's (1999) study included only nine PAs. Glendinning *et al.* (2000a, 200b) and Clark's (2006) studies involved slightly larger samples (42 and 41 direct payment users respectively).

The majority of studies that examined experiences of using direct payments emphasised the positive impact that direct payments have had on users' quality of life and overall well-being (Clark, 2006; Flynn, 2005; Glendinning *et al.*, 2000a, 2000b; Hendey and Pascall, 2001). Benefits commonly included retaining (or regaining) personal independence and living a 'normal' life through opportunities to tailor support to individual needs and exercise greater choice over who provided support and when. Other benefits included greater continuity in relationships with paid carers, maintaining valued social and work activities and reduced dependence on family and friends.

However, seven studies also identified potential risks for direct payment users; particularly risks of personal abuse and the recruitment of trustworthy and reliable PAs. Many direct payment users were aware of their potential vulnerability; recruiting a reliable and trustworthy PA was felt to be fraught with problems and dangers, especially, as this was often a totally new experience. Finding a 'good' PA was often

felt to be, as Clark (2006) notes, largely 'hit or miss' or 'pot luck' (Flynn, 2005). Evidence of abuse experienced by direct payment users is documented in Flynn's study (2005) of 16 direct payment recipients from Northern England. The recipients had a range of physical and learning impairments and two had mental heath problems. Although a small sample, Flynn's interviews found that almost half (seven) had experienced abuse in one way or another, whether physical, emotional, financial or sexual, from their PA. For example, some recipients had had money stolen from them, others felt their PA was 'bossy' or treated them with little respect and some, expressed concern that their PA generally 'took advantage' and was lazy. Although these are very specific experiences, as Flynn's herself notes, they raise an area of potential concern.

In order to reduce the risks associated with recruiting PAs, research on direct payment users has found the following strategies are employed:
- recruitment through an agency or third party
- drawing on the personal recommendations of others (Clark, 2006; Ungerson 1999)
- using people already known and trusted, such as family and friends (Clark, 2006; Ungerson, 1999; see also Flynn, 2005)
- 'Topping up' a direct payment with additional payments from one's own pocket to offer higher levels of pay to PAs (Clark, 2006; Flynn, 2005; Hendey and Pascall, 2001)
- Employing PAs from the same minority ethnic community (Clark, 2006).

However, these strategies were not unproblematic. For example, recruiting a PA through an agency could introduce new risks for direct payment users, of reducing the level of control they were able to exercise over how and when their support needs were met, because of constraints imposed by the agency on what PAs are allowed to do (Scourfield, 2005; Ungerson, 1999).

For direct payment users, the responsibilities of being an employer can be a significant source of stress. Lornas (2006), in her study of 22 care managers from two areas of one local authority, and Clark and Spafford's (2001) evaluation of a pilot project (36 older people and their carers were interviewed along with a range of care managers and practitioners in one authority) found that care managers, who can play a crucial role in encouraging take-up of direct payments, frequently failed to do so because they considered (from their own observations and evaluations) the role of employer and its associated responsibilities to be excessively demanding and stressful for disabled or elderly people. Three studies (Hendey and Pascall, 2001; Lornas, 2006; Ryan and Values into Action, 2006) found the risk of this emotional stress was increased by the lack of training or support for direct payment users in their roles as employers. Indeed some care managers (Clark and Spafford, 2001; Lornas, 2006) simply withheld information about direct payments to potential recipients because they thought this to be in users' 'best interests'.

Risks and the role of personal assistant

The private employment situation of personal assistants can make them equally vulnerable (Flynn, 2005, Glendinning *et al.*, 2000a, 2000b; Scourfield, 2005). Personal assistants' working situations are often isolated, with little opportunity to derive support from colleagues; job descriptions may be ill defined or fluid; and opportunities to belong to trades unions or similar support organisations may be limited. Some PAs may be asked to perform tasks which they feel are at, or beyond, the boundaries of their expertise (Glendinning *et al.*, 2000b). Questions may also arise about who is responsible for the employee's health and safety and about who is liable in the event of accident or injury to the employer.

Given the constraints that currently exist on using direct payments to employ close relatives, no English research was found on the risks (for either direct payment users or relatives) of employing close relatives. Policy developments in this area mean that it is a priority for future research (see Chapter 5). However, research (Flynn, 2005; Ungerson, 1999) has found risks in employing close friends. These arise from the introduction of new obligations into an existing close relationship: direct payment user employers may thus find it hard to 'discipline' or 'sack' an unsatisfactory PA; conversely PAs may find it harder to resign from an exploitative work relationship. Indeed, as both service users and PAs in Flynn's study noted, it was not clear who to turn to for help and advice if conflicts arose.

4.5   Risk and the importance of personal knowledge and experience

This section explores the importance of personal knowledge and experience when assessing 'what is' risky behaviour and how it is subsequently managed. It focuses specifically on studies that explore in depth the different types of knowledge and experience prioritised by practitioners, informal carers and service users; and how these differences can lead to different approaches to learning about risk and its management. For practitioners, the length and type of their experience, in particular differences between official guidance and personal intuition will be examined. For informal carers, the role and importance of personal knowledge and/or experience of the person they care for and, for service users, personal knowledge of their own illness/condition, will be examined.

Table 4.5 References discussing the theme of risk and personal knowledge and experience by subject area* (n=22)

Subject area	Number of references discussing risk and 'knowledge/experience'
General**	9
Mental health	4
Older people	5
Disability	3
(specifically learning disability)	3
Substance misuse	1
Total	**22**

* It is important to note that a number of the references in the literature reviewed and identified as exploring the importance of personal knowledge and experience, either discussed the same study or the study's authors have written more than one article/chapter/book discussing aspects of the same study.
** 'General' refers to those references discussing more than one area, often older people, those with learning disabilities and mental health service users.

Amongst the 22 studies exploring the importance of personal knowledge and experience, 19 were empirical studies, the remaining three references were largely scholarly discussions, reviewing the literature and presenting the authors' own comments. As Table 4.5 highlights, nearly half (9) were studies exploring risk and personal knowledge/experience in more than one area (i.e. classified as general), and comparisons were often drawn between user groups such as, mental health, disability and older age.

4.5.1 Risk and the role of 'experience' amongst practitioners

Five references (Alaszewski, 2003; Alaszewski and Alaszewski, 1998, 2000a, 2000b; Alaszewski *et al.*, 1998) highlighted the importance of everyday experiences in the process of learning about 'risk', especially student nurses' 'risk learning'. All five of these references drew on the findings of Alaszewski *et al.*'s (1998a) empirical study. This qualitative study used a range of methods, including, a diary study of 20 nurses and six social workers; observations of a multidisciplinary team and interviews with nursing lecturers and students (73 nurses spread over the specialisms of mental health, older people and adults with learning disabilities). The study also interviewed users and carers (as discussed in subsequent sections). The study was a relatively large scale study and drew on a range of participants across different specialisms.

The study demonstrated that the majority of participants, lecturers, mentors and students felt that practice, especially student placements, provided an important

source of risk learning, frequently from 'trial and error'. Everyday experiences, both nursing and personal life experience were also recognised. Formal teaching was often more peripheral. When considering how this impacted on the teaching of risk within courses, Alaszewski *et al*. (1998a) noted that although everyday experiences may be valued, they are a very individualised and unstructured form of learning. Moreover, not all students face the same placement practice experience or indeed, life experiences. Alaszewski *et al*. (1998) suggest that in the future, practitioner training courses should acknowledge the importance of 'everyday experiences' and provide a range of learning environments for students to learn about and discuss risk, both in the formal context of the classroom and also more informally on placement. As previously noted, (see Section 4.4: Risk and difference organisational contexts), Alaszewski *et al*. (1998a) also demonstrated the lack of consistency across practitioner training courses with regard to formal 'risk' teaching and the prominence it is given. Hence they advocate the need for more comprehensive and focused risk training courses for practitioners, especially student nurses.

Furthermore, Alaszewski *et al*.'s study (see also Alaszewski and Alaszewski, 2000a) also demonstrates that how and when nurses draw on the experience of other practitioners depends on the perceived complexity of risk and its management. For example, in most day-to-day situations, nurses relied on their own judgements and experiences when assessing risk and planning management strategies. If a case was regarded as complicated or controversial and the nurse felt s/he lacked experience, other practitioners would be consulted. This could be either asking 'the team' for advice and guidance, or drawing on the experiences and knowledge of practitioners from other agencies. Alaszewski and Alaszewski (1998) noted that, as practitioners became more experienced (both nurses and social workers) they frequently faced more complex and potentially controversial situations of risk assessment. As professionals became more experienced the degree of support they receive can vary but, as the authors note, it is usually less support than students receive. Students had supervisors or mentors with whom to discuss risk issues or specific clients. Interviews and diary entries demonstrated that experienced nurses continued to find risk assessment stressful and thus, as Alaszewski and colleagues (1998) highlight, would have welcomed more support.

How practitioners approached and managed risk was also influenced by the length and type of their experience, both clinical and personal. This was demonstrated by Reich *et al*. (1998) in their study comparing 38 female student occupational therapists with 38 qualified and more experienced female occupational therapists. Drawing on four hypothetical vignettes of frail and disabled older hospital in-patients classified as 'high' risk discharges, the occupational therapists were asked to decide if the patients should be allowed to return home, as they all wished or, if they should be discharged to residential/nursing care. Results highlighted that student occupational therapists were more likely than experienced colleagues to challenge the older patients' wishes to return home and thus were more likely to recommend

discharging them to residential/nursing care. The authors suggest that this difference in approach between students and experienced occupational therapists is associated with the degree of experience of the qualified practitioners. Qualified occupational therapists drew on their own previous clinical experiences and practice. Experience gave these practitioners greater confidence to use their own judgement and move beyond the facts given within each vignette. For the students with less experience, a more safety focused and risk adverse approach emerged. Although differences between the two groups were found, the authors recognised that there were limitations to their research, as the sample was limited to one particular group of female practitioners and focused on four very specific vignettes with limited information for participants to draw on. Hence, the authors suggest the benefits of extending the study to other groups of practitioners; exploring both male and female views and a wider range of risk situations.

Godin's study of how community mental health nurses (CMHNs) used standardised practices and formal risk assessment tools similarly demonstrated the importance of practitioners' experience. Drawing on 20 CMHNs (purposively selected) from a range of specialisms (older people, forensic, adolescence and generic nursing), Godin showed that although all the CMHNs knew of formal risk assessment tools, how and when these were used varied. Some practitioners viewed the tools as useful, whereas others regarded them as too restrictive, prescriptive or 'mechanical'. For the majority, the best policy was a mix of formal assessment tools and intuitive practice based on past experience. In many assessments, the CMHNs interviewed reported that they drew on personal knowledge, intuition and 'gut feelings' in the process of risk assessment and planning; however, they also noted that they used formal assessment tools to record and legitimate their decisions as professionals. Forms were filled in according to official policy and guidance. Godin highlights that the CMHNs were very aware of the wider social context within which they worked, i.e. mental health users were viewed as 'dangerous' and the public fears that surround this. In such a context, the nurses recognised a need to follow 'correct' procedures in order to protect themselves and 'cover their backs'. With regard to personal safety, this was an area where intuition and personal experience were prioritised; knowing when to withdraw from a situation or protect oneself was based on personal encounters with clients. Although drawing on a relatively small and purposively selected sample of practitioners, Godin's study demonstrates how informal procedures grounded in personal and professional experience can co-exist with formal policies and procedures. Retaining a degree of professional autonomy was important to these CMHNs.

The results of Reich *et al.* and Godin's studies in many way mirror the much quoted study by Benner (1984) which documents how nurses, as they gained experience and became more confident in their ability, moved from being 'novices' to 'expert' risk assessors. Benner highlighted that experience was also linked to nurses becoming less dependent on official guidance and more willing to draw on their own personal

experiences and feelings. Benner's nurses share many similarities to Reich's occupational therapists and Godin's community mental health nurses.

Risk and the importance of experience for service users

Four studies examined the importance of service users' experience of risk: Alaszweski *et al.* (1998a, 1999); McConkey and Smyth (2003); Ryan (2000). The role of experience in terms of how risk is viewed and managed by users and how this can differ by gender and ethnicity experiences has also been noted in a small number of other studies, for example, Atkin and Ahmad, 2000. These will be discussed in Section 4.6: Risk and wider socio-economic factors. Although service users' views are represented here, the literature is relatively limited and focuses on a small number of key studies. Two of the studies Alaszewski *et al.* (1998, 1999) have been discussed in prior sections (especially Section 4.4: Risk and different organisational contexts).

The importance of personal experiences and knowledge of one's own illness/condition was demonstrated in Ryan's (2000) study of 22 mental health service users. The users interviewed had a range of mental health problems (schizophrenia, bipolar disorder and depression) and illness experiences, such as length of illness and experience of hospitalisation. Although a small sample from only two locations, the study's results clearly demonstrate how length and personal experience of their illness impacted on users' interpretation of 'risk' and the management strategies adopted.

Three risk management strategies adopted by respondents were noted: 'pro-active', 'passive' and 'no strategy'. Pro-active strategies usually involved direct action and often focused on actively managing the physical or social environment, such as removing oneself from potentially 'dangerous' situations. Strategies could, as Ryan notes, take many different forms amongst different users. For example, if there was a danger of harming others, some users described how they withdrew from social situations and spent time alone; other users noted how the company of others could help prevent self-harm. Ryan found that these pro-active strategies were frequently associated with length of illness (those with longer experiences were more likely to adopt active strategies) and users' own insights and knowledge of their illness and its effects on their behaviour or personality. Ryan thus demonstrates that taking an active strategy often rested on users learning from past experiences or thinking ahead about potentially risky situations and trying to avoid these.

The second strategy, passive, emphasised 'least resistance' and focused on what Ryan terms 'low consequence risks'; these were usually risks that did not involve immediate violence to the self or others. Here, length of illness and personal experience of one's illness were less prominent factors. When facing risky situations, these users decided in advance to 'submit' to or not actively challenge the ideas of other people, especially others' views of what was 'risky' behaviour. Avoiding

potentially risky situations was important, for example, avoiding ignoring name calling in the street. For some, these decisions were based on their knowledge and experience that giving in was often easier than challenging decisions which could lead to conflict with carers and affect the type and level of personal support received. In these instances, being assertive about risk and risk taking was not viewed as worth either the effort or potential negative effects.

The third 'no strategy' was usually employed by those with little insights or personal experiences of their illness, for example, those not receiving treatment. Here, users did not have planned strategies but rather reacted (or not) to events as they occurred. Ryan concludes that the study highlights the importance but diversity of users' personal experiences and the need for practitioners to be sensitive to these differences, creating opportunities for users to voice their experiences during the assessment process.

The importance of users' personal understanding of danger was also highlighted in Alaszewski *et al.*'s (1999) study of risk management in services for adults with learning disabilities. Drawing on two focus group discussions with adults with learning disabilities in residential and community settings (exact numbers are not given, participants in each group ranged from four to 12), users generally talked about risk in terms of 'danger'. Their personal experiences of risk focused on things being 'too hard' or 'difficult' for them to do or alternatively, situations that might 'hurt' them. For example, one service user highlighted the danger of fire if they lived alone; for another, their physical safety was felt to be at risk if they went out alone in the dark. As Alaszewski *et al.* note, this frequently reflected their parents' views of risk and danger.

However, different groups of service users can have very different experiences of risk. This was highlighted in Alaszewski *et al.*'s 1998a study exploring risk and nursing practice. In addition to exploring the ideas of practitioners and teaching about risk (see Section 4.4: Risk and different organisational contexts) the authors also explored the ideas of service users. Focus groups were conducted with adults with learning disabilities, mental health service users and older people (once again, exact numbers of participants are not given; participants were recruited from pre-existing groups in the voluntary sector). Although all service users associated risk with 'danger', discussions revealed that differences between the three groups existed:

- adults with learning disabilities were more likely to see positive aspects of risk taking, i.e. as an opportunity to learn and become more independent
- mental health service users were often aware of the link between mental health and public fears of danger but were also aware of personal risks and dangers, such as risks to their health from the side effects of medication
- older people were aware of personal risks such as falling in the home, but also the importance of managing these risks to maintain their independence.

Alaszewski *et al.* suggest that service users' personal ideas in many ways reflected their experiences of practitioners' ideas and management strategies (see Section 4.4: Risk and different organisational contexts for more details on practitioner views). Service users were aware of how professionals defined risk and this could colour their own definitions of risk.

The importance of listening to service users' personal experiences of risk was also demonstrated in McConkey and Smyth's study (2003) of young people with severe learning disabilities (and their parents) leaving two special schools in Belfast. The authors interviewed 34 young people and 38 parents. As noted in Section 4.2 (Risk and competence), the young people generally viewed themselves as more competent than their parents did, especially in their ability to do everyday tasks perceived as 'risky'. Here, the important point to note is the difference in opinion between young people and their parents with regard to sexual risks. Parents' fears of abuse for their son/daughter focused on sexual abuse from the public. However, drawing on their own experiences of actual abuse or fears of abuse, the young people highlighted very little sexual abuse and if they had been abused it was often from others with learning disabilities rather than 'the public'.

In contrast, young people feared and suffered more verbal or emotional abuse, such as teasing. McConkey and Smyth emphasise the importance of recognising these differences between parents and young people when assessing risk and planning risk management strategies. This is a relatively small and very specific study of one particular group of service users (i.e. young people with severe learning disabilities). However, the study does highlight the general importance of listening to service users' actual experiences; their own experiences of risk can be very different to their parents' fears.

4.5.2 Risk and the importance of experience for informal carers

Ten references were identified that examined risk and the experience of informal carers (Alaszewski, 2005; Alaszewski *et al.*, 1999; Clarke, 1999, 2000; Clarke and Heyman, 1998; Manthorpe and Alaszewski, 2000; McConkey and Smyth, 2003; Ryan, 2002; Smith, 2001; Turner and Street, 1999;).

Length of caring experience could influence how risk was viewed and managed by informal carers. This was most clearly demonstrated by Ryan's (2002) study of mental health service users. Here, 13 informal carers of the mental health users were interviewed. The carers supported a range of users (including those with schizophrenia, bipolar disorder and depression) and had cared for different lengths of time (from four to 20 years). Informal carer interviews also demonstrated that carers' approach to risk management differed and that strategies were often grounded in personal experience.

Ryan identified two key risk management strategies: active and passive. Active strategies were associated with longer experiences of caring, with more experienced carers drawing on their knowledge of the person they supported, their mental health illness and subsequent support needs. This knowledge and experience guided their actions. Active risk management strategies involved the carer taking direct action, for example, encouraging or preventing the person they supported from taking risks. Carers recognised the need to balance different types of risk and their consequences, such as risks of self-harm or self-neglect by the mentally ill person with their right to take risks and be independent. In contrast, passive risk management strategies focused on the 'least line of resistance' and did not involve direct action or intervention by carers. This strategy was more often adopted by less experienced and confident carers who were at an earlier stage of their caring career or who had less knowledge of the cared for person's mental illness and support needs.

In addition, although not as frequently discussed by carers as the previous two strategies, Ryan found that some, usually the more experienced carers, sometimes saw a need for covert risk management such as, administering medication without users' consent. Here, carers stressed the need to balance the costs and benefits of service user self-harm with the protection of others, either themselves or the wider community. For many, this was often a difficult decision, as carers were aware of power inequalities and conflicting rights and responsibilities, i.e. the rights of users but also their own responsibility to protect the user and other people. In conclusion, Ryan notes the importance of informal carers' knowledge of the person they supported, however, he feels that practitioners frequently ignore or dismiss this experience in their assessments and suggests that in the future, they should seek to address this.

Not all practitioners however, ignore carer experience, as Smith (2001) demonstrates. Drawing on one case study (Mr Davies), a man with schizophrenia and a history of violent behaviour and hospitalisation, Smith documents how, as a mental health social worker, he drew on and prioritised the experience of Mrs Davies and her knowledge of 'when' to take risk management action. Mrs Davies' experience was viewed as pivotal. Of course, one cannot generalise from such a specific case study, however, Smith highlights the importance of practitioners listening to carers and respecting their past experience.

This has similarly been illustrated by Clarke's research with informal carers of older people with dementia. Clarke (1999, 2000) and Clarke and Heyman (1998) examined the normalisation process informal carers employed in their assessments of what is 'risky' behaviour for the person they are caring for and how this risk should be managed. Clarke's work has been discussed in Section 4.1 with regard to risk and normalisation. Here, Clarke's study of 23 carers demonstrates the importance of everyday life experiences for carers, especially each carer's current and past experiences of their personal relationship with the older person. As the health and/or

ability of the older person altered, this similarly impacted on how the carers viewed what was risky and how it should be managed. Carers also prioritised personal knowledge and individual experience and practitioners prioritising medical knowledge and general experiences (see Section 4.1 for more details of these different knowledge bases). With two very different sets of knowledge based on different types of experience, Clarke suggests that the danger for misunderstandings and tensions is ever-present between carers and practitioners.

The final issue to be discussed is 'trust. The concept of 'trust' is much discussed by theorists in late modern society (see Beck, 1992; Giddens, 1991). 'Trust', especially 'trust' in professionals and expert knowledge can act as an important 'buffer' to the uncertainties of risk in society. However, how far professionals and experts can be trusted or relied upon is much debated, as professional knowledge is frequently challenged and proven incorrect. Such contradictions and challenges, it has been argued (see Taylor-Gooby, 2004), can lead to increased public uncertainty and greater emphasis on personal experiences and lay knowledge rather than 'expert' knowledge. The importance of personal ideas and experience guiding the 'trust' relationship with practioners/staff was clearly documented in Alaszewski *et al.*'s (1999) study of informal carers (often parents) of adults with learning disabilities (see also Manthorpe and Alaszewski, 2000). The study drew on two focus group interviews with carers, one group caring for adults with learning disabilities using residential services, the other for adults using community services (as noted previously, each group had between four and 12 participants). Alaszewski *et al.* found that carers were more willing to accept professionals' views of risk and risk management, even if they viewed risk more positively and advocated more risk taking opportunities than carers usually wanted, if carers 'trusted' practitioners. Alaszewski *et al.* found that trust was frequently based on carers' personal experience of practitioners, especially if a practitioner demonstrated an informed understanding of their son/daughter, communicated their ideas clearly to carers and parents could see that their son/daughter was happy with the risks being suggested. Practitioners thus had to earn the 'trust' of informal carers and continue demonstrating its value; it was, as Alaszewski *et al.* suggest, 'conditional'. If parents experienced situations that challenged their 'trust' in practitioners, this 'trust' could easily be withdrawn with parents reverting back to personal experiences and previous risk management preferences.

4.6 Risk in the context of wider socio-economic factors

This section will review the literature in relation to how wider socio-economic factors such as, financial and material resources, gender and ethnicity can influence how service users, informal carers and practitioners view and manage risk. Material resources, gender and ethnicity will each be discussed separately, however they are often interconnected. In addition, it is important to note that the number of studies

reviewed is relatively small compared to other sections, the ideas and issues raised are important but are also frequently tentative, as the majority of the studies identified are based on small samples and specific areas of social care. Indeed, many of the authors are themselves very aware that they are only beginning to explore these complex issues and thus suggest further research needs to be conducted.

4.6.1 Risk and the availability of financial and material resources

Literature exploring how the availability of financial and material resources can impact on concepts of risk and management planning will be reviewed in this section. Within the literature there is a general awareness that resources, their level and the type available can affect risk assessments and priorities, however, the 11 studies identified here seek to explore this in greater depth. Two key areas will be examined: firstly, risk and resource allocation in the context of organisations in which practitioners work and secondly, the effect of material resources on informal carers risk assessments and management strategies. The literature is not equitably distributed, only two references were identified exploring the impact of material resources on informal carers' risk management and these two references discussed the same empirical study. None of the studies reviewed appeared to focus on how 'risk', especially risk management was affected by service users' own personal financial and material resources.

Table 4.6 References discussing the theme of risk and material resources by subject area* (n=11)

Subject area	Number of references discussing risk and material resources
General**	6
Disability	3
(specifically learning disability)	3
Older people	2
Total	**11**

* It is important to note that four of the references in the literature reviewed and identified as exploring the importance of material resources, either discussed the same study or the study's authors have written more than one article/chapter/book discussing aspects of the same study.
** 'General' refers to those references discussing more than one user group, often older people, those with learning disabilities and mental health service users.

Amongst the 11 studies exploring the importance of personal knowledge and experience, eight were empirically based research, the remaining three references were largely scholarly discussions, reviewing the literature and presenting the

authors' own comments. Table 4.6 demonstrates that over half (six) of the identified references explored the effect of material resources on risk assessment and planning in a 'general' context, i.e. broader than one user group/type of service. The two areas of specialism that did arise in the literature reviewed were studies focusing on risk in learning disability and older age.

Risk, resource allocation and its effects

In nearly half (five) of the identified references (Davis *et al.*, 1998; Heyman *et al.*, 1998; Kemshall *et al.*, 1997; Postle, 2002; Waterson, 1999) the importance of risk as an eligibility criterion was noted. Indeed, both Kemshall *et al.* (1997) and Waterson (1999) in their review of the literature surrounding the personal social services and probation service suggest that, as risk assessment and monitoring have become key concepts and practices for practitioners, they have developed an increasingly important role as a means to allocate limited resources. Kemshall *et al.* and Waterson suggest that eligibility to resources and, once eligible, then the type and level of support received can rest on perceived level of risk rather than the concept of 'need'. Risk may have become a means to judge and evaluate perceived 'need'. As Waterson (1999) notes, risk and danger are often linked together, especially in the probation service when judging 'who' to prioritise with resources in order to prevent risk or ensure the safety of others. Waterson argues that those regarded as 'high risk' or the most 'dangerous' are often targeted before those viewed as 'less risky' and dangerous.

Risk as a resource allocator was clearly demonstrated in Postle's (2002) study of 20 care managers (some worked specifically with older people, others more generically) in two English social service offices. From interviews with and observations over four months of the care managers, Postle explored how risk assessments and decisions were influenced by resource availability. Postle highlights that social workers face a tension in their work, as community care policies advocate more support in the community for service users, especially in their own homes but practitioners have limited resources to meet this need. Stricter eligibility criteria are thus required and risk, as Postle argues, has become a mechanism for assessing eligibility and prioritising resources. The effect of this increased emphasis on risk and assessing degrees of risk leads, as Postle notes, to some service users receiving reduced support in the home, if they are not defined as 'high risk'. In addition, Postle also found that this emphasis on risk and eligibility had an important effect on the role of social workers and their own practice. For example, they have become, as Postle suggests, 'front line manager gatekeepers' with continuous risk assessment but actually very little time to sit down and work directly with clients, thinking and planning ways to address the risks users have identified in their own lives. Although a small and specific sample of only two social service offices, Postle's work raises wider questions about the future direction of social work and role of social workers, which were similarly shared by the authors of all five references noted above.

Practically, limited resources can act as barriers to pro-active risk management strategies. This was demonstrated in the work of Heyman (2005) and Healy and Yarrow (1998). Heyman's concept of a 'risk escalator' where service users either move up or down the escalator (upwards towards greater safety but reduced autonomy and risk taking opportunities or downwards towards greater personal autonomy and risk taking with a reduced focus on safety) has been previously noted in Section 4.3: Risk and control. Here, it is important to note the role of resource availability (or lack of availability) as a key factor in the direction of the escalator. Practitioners and service users' ideas and actions may, as previously noted, be important but if resources are unavailable, the escalator can either grind to a halt or be reversed. For example, Heyman found limited places in either residential settings or community rehabilitation programmes were a common problem preventing patients moving either up or down the escalator. As he argues, this can have very real consequences for both patients and practitioners. For patients, they may feel 'stuck' on one level or moved up or down more quickly than they feel comfortable with. For instance, if they are ready to move 'up' the escalator to a rehabilitation scheme but a place is not available or they may be feel pressured and rushed to the next phase, i.e. moving on too quickly from hospital if their place is required by another person. For practitioners, moving patients on to the next stage too quickly may be viewed as 'risky' but beyond their control. Although one must be wary of generalising from specific case studies, Heyman's work highlights how risk management is a complex relationship of subjective and objective factors. Ideas and values are important but practical barriers can often dictate the direction of risk management.

Healy and Yarrow's (1998) study explored the views of 71 health and social care practitioners (including GPs, nurses, social service staff, health promotion managers, housing staff) working with older people from a range of statutory and voluntary sector settings on how to prevent accidents in the home and promote the general health of older people. Drawing on data from interviews (telephone and group), practitioners highlighted four key areas they felt should be prioritised in order to prevent accidents and enable older people to live more safely in their own homes. These were:

- home safety checks
- regular health checks for those over 75 years
- clear and accessible information on risk prevention in areas such as, personal health promotion and safety in the home
- community exercise programmes, a means for older people to keep fit and mobile (it was felt this might help to prevent falls).

However, the nurses interviewed felt they frequently could not develop these risk management strategies. In addition to professional and inter-agency barriers, they were very aware of inadequate resources impeding their work. In particular, as Healy and Yarrow note, they felt their work was frequently focused on health and safety

issues after an accident had occurred, it was reactive rather than proactive. It thus focused on individual clients rather than positive strategies to prevent risk occurring amongst older people as a whole in the community. For Healy and Yarrow, this raised further issues of prioritisation and prejudice, as practitioners felt resources were not targeted to older people, they were a low priority reflecting, as previously discussed in Section 4.2: Risk and competence, re ageism in wider society. Healy and Yarrow's relatively comprehensive study demonstrates the frustration that practitioners can feel, as they try to juggle pro-active risk prevention strategies with wider material barriers.

Two studies (Alaszewski and Alaszewski, 1998; Clark *et al.*, 1996a) demonstrated that limited resources and subsequent targeting of resources could also lead to differences of opinion and thus potential tensions between professionals working in the same agency and across agencies. In Alaszewski and Alaszewski's review of the literature, including data from their own previous study focusing on nurses and social workers (see Alaszewski *et al.*, 1998a), they noted that conflict between practitioners and managers could occur around the idea of 'cost effective' packages of care and support. Providing the example of a social worker working closely with a family to assess risk and meet a client's complex needs at home, they contrast the package of care suggested by the social worker, here, the social worker's recommendation for a paid carer to go into the client's home to cook a meal each day with the preferences of the case manager for meals on wheels. Providing meals on wheels was regarded by the case manager as a similar but more 'cost effective' service, however, it was, as the social worker noted, not what the client wanted. As Alaszewski and Alaszewski note, the availability of resources can thus lead to two different approaches to risk management and preferred options. However, as the authors suggest, this difference in perspective can raise a number of complex issues, especially for social workers working more closely with families compared to the more detached position of managers. There are tensions, as the authors highlight, for social workers trying to meet client needs/preferences and the demands of managers whilst also fulfilling their professional obligation of a 'duty of care' and protecting clients.

Different priorities were also noted between practitioners working in different agencies. In Clark *et al.*'s (1996a) relatively large scale study exploring the process of hospital discharge for older people within two hospital trusts, health and social care practitioners associated with the discharge of older people (in total 50 older people over two cohorts) were interviewed. The interviews demonstrated that how client 'need' was defined (i.e. 'when' to return home and on return 'how best' to provide support in order to ensure a 'safe' discharge) differed between different types of professionals and could reflect the diverse priorities of different agencies. For example, the authors found that a 'safe' discharge for hospital occupational therapists was frequently linked to wider resource issues such as, a desire to prevent delayed discharge, patient throughput was thus important. In contrast, social workers

tended to focus on their own budgetary restrictions, in relation to what services they could realistically assess clients for and subsequently provide in the community. As Clark *et al.* note, practitioners were aware of resource implications for their own profession, issues of health and safety were often felt to be put first at the potential expense of client preferences and independence. Clarke *et al.*'s study provides a comprehensive overview of different practitioner perspectives (and also of service users' ideas (as discussed in Section 4.1: Risk and normalisation) and demonstrates the potential for continuing inter-agency tensions, frequently related to resource limitations and the need for prioritisations in order to protect one's agency resources.

Risk, resources and informal carers
Heyman and Huckle's (1993a, 1993b) study of 20 adults with learning disabilities attending two adult training centres suggested that 'how' informal carers (largely parents of the adults) approach and manage risk may reflect their wider socio-economic circumstances and the resources available to them. As noted previously in Section 4.2: Risk and competence, Heyman and Huckle found that carers viewed everyday risks, such as going out with friends and developing relationships with others, especially with the opposite sex, as 'hazards' and thus potentially dangerous. Parents generally adopted one of two approaches to risk management: treating 'hazards' as a danger to be avoided at all costs or as a 'risk' that should be carefully negotiated but not necessarily always avoided. Amongst the carers interviewed, Heyman and Huckle noted differences which appeared to be based on socio-economic circumstances. For example, professional and skilled manual parents and two parent families tended to be more likely to view 'hazards' as 'dangers to be avoided' compared to parents in unskilled occupations or unemployed families. Amongst the latter, 'hazards' were more likely to be viewed as risks to be managed. Heyman and Huckle stress that they did not explore the socio-economic circumstances of carers in-depth, their study was relatively small and focused on a specific group of people, however, the very existence of these observations raised some important questions and issues for them, as they noted:

- The importance of material factors – does the level and type of resources parents have at their disposal influence how they view 'hazards' and feel able to manage them? Less affluent families may have fewer resources, such as the use of a car. This may mean that an adult with learning disabilities is forced to become more independently mobile (e.g. using public transport) compared to an adult who is always driven by their parents.
- Single or two parents – if there is only one carer, it may be harder to always accompany the adult with learning disabilities, especially if there are other siblings.
- Cultural differences – middle class values are often associated with protectiveness.

Heyman and Huckle suggest that material resources and social ideas and support networks may potentially have an important impact on how families view 'hazards' and seek to manage them in their everyday lives. The authors thus identify these

issues as an area meriting further investigation in terms of both the economic circumstances and situations faced by different types of families and also, other characteristics such as, gender and cultural values.

4.6.2 Risk and gender

Very few studies (five) specifically highlighted gender as a key factor in how risk was either viewed or actively managed by practitioners, informal carers or service users. Amongst the references identified (as Table 4.7 demonstrates), the studies spanned different groups of adults/service users. Four references reported empirically based studies and one provided a scholarly discussion. In terms of perspective, three focused on the experiences of practitioners, the remaining two, the ideas of service users and informal carers.

Table 4.7 References exploring issues of risk and gender by subject area (n=5)

Subject area	Number of references discussing risk and gender
General*	1
Disability	2
(specifically learning disability)	2
Older people	1
Young people	1
Total	**5**

* 'General' refers to those references discussing more than one area, often older people, those with learning disabilities and mental health service users.

Two key areas will be discussed in this section: firstly, the risk of sexual abuse, especially the different experiences of and views held between male and female practitioners working with adults with learning disabilities and secondly, the importance of gender in the caring relationship; how risk for older people is viewed differently by male and female informal carers and the effects that this can have on both the older person's personal view of and response to risk.

Risk, gender and the danger of sexual abuse
Gender differences emerged as an important theme in Brown *et al.*'s (1994) study of practitioners working with adults with learning disabilities in two health service districts and their knowledge of the risk of sexual abuse faced by their clients. Drawing on data collected from 'work sessions' involving group discussions and a

self-completion questionnaire[12] the authors found differences between males and females in relation to the context and location of risk. Both male and female practitioners felt that adults with learning disabilities were often 'at risk' of abuse in their own home, with family members or people known to the adult with learning disabilities viewed as the most usual abusers. However, female staff were found to be more 'alert' to the risk of abuse in the wider community and the issue of 'stranger danger'. In addition, Brown *et al.* suggest that female staff were also more aware of the risk of abuse from other service users than male staff. However, male staff appeared to be more concerned about staff abuse or allegations of staff abuse from clients.

The authors link this recognition of and concern for wider community risks amongst female members of staff to general fears that pervade society and to which, women may be more sensitive and alert compared to their male counterparts. With regard to male concern of staff abuse, the authors highlight the need for clearer practitioner guidance and guidelines, especially for staff performing intimate care. 'Same sex' care policies, i.e. female staff providing intimate care for female service users and male staff for male service users, are frequently recommended as a means to ensure personal dignity or prevent potential embarrassment for both parties. In addition, Cambridge and Carnaby (2000) in their study of practitioners' experiences of providing intimate care, argue that same sex care policies can also help to protect female service users, who are frequently more 'at risk' of abuse from male carers than female carers. However, both Brown *et al.* and Cambridge and Carnaby recognise the limitations of same sex care policies, as they do not necessarily protect all service users from abuse, heterosexual and homosexual abuse can occur amongst both genders. Furthermore, as Cambridge and Carnaby have highlighted, there are practical difficulties to implementing same sex care policies, due to unequal numbers of male and female staff in social care settings. Male service users cannot always be guaranteed a male carer.

The final area of gender difference to emerge in the literature is the idea that female staff working with adults with learning disabilities are more 'at risk' of abuse than their male counterparts. Reviewing the literature (as it stood in 1999), Manthorpe and Stanley (1999) suggest that past research has indicated female carers have found it more difficult to report abuse to their managers or heads of care. In particular, reporting sexualised behaviour, such as, inappropriate actions or suggestions from service users whilst carers are performing intimate care tasks. Reporting potential abuse was felt to be particularly difficult if their manager was male. Manthorpe and Stanley argue that the difficulties experienced by female staff in terms of reporting abuse and managers' lack of understanding and/or prioritisation of such potential abuse must be viewed in the wider context of a gendered society, underpinned by

---

[12] A clear picture of the number of staff involved in the different parts of the research was difficult to ascertain, however, the authors note the staff consulted worked with a range of clients in different settings.

patriarchal ideas and presumptions. The authors suggest that amongst managers, especially male managers, there was often a general paternalism, in the sense that a manager was looking after his 'family' of carers, a situation which, it was felt could inhibit professional respect and regard. Indeed, as Manthorpe and Stanley note, female carers can feel patronised with their concerns dismissed or not taken seriously.

Despite the small number of studies documenting gender differences between male and female practitioners, it appears that this is an important area, especially the potential barriers and frustrations faced by female staff, as they clearly predominate in adult social care as key providers.

Risk, gender and informal carers
As noted above, the reviewers only found one study (Horton and Arber, 2004) that raised the issue of gender differences between informal carers and compared their approaches to risk and risk taking for the person they cared for. Interviews were conducted with the carers of 35 older people (65 years plus) all of whom had had two or more falls in the previous 12 months. Although Horton and Arber's study of informal carers drew on a relatively small and specific sample of participants; the gender differences that emerged were marked and from this data Horton and Arber developed a typology of five different risk management approaches adopted by carers, these were:
- 'protective' – the onus is on protecting the older person from harm and danger
- 'coercive' – an element of 'force' is present, with little room for negotiation between the carer and the older person
- 'negotiating' – the carer and the older person negotiate to reach a 'common ground' or understanding of risk taking and what is acceptable
- 'engaging' – negotiations are conducted and the older person is offered choices and opportunities for independence
- 'mutual respect' – both parties have mutual respect for one another and their ideas/concerns re risk but little action is taken.

The authors noted that male and female carers, especially sons and daughters, frequently adopted different strategies. For example, sons were more likely to adopt a protective or coercive approach to risk management, especially with regard to their mothers; risk taking was often 'non-negotiable'. In contrast, the authors found that sons were less risk adverse, especially in terms of protective or coercive strategies with regard to their fathers. There was, as Horton and Arber suggest a degree of recognition and respect for risk taking opportunities and independence. Amongst daughters caring for their parents, the approach taken was generally more respectful of the older person's wishes, desire for independence and thus opportunities to take risks and make choices. Risk management was based on negotiation and

engagement, indeed, as Horton and Arber note, mothers and daughters often had a 'peer like' relationship.

For Horton and Arber these differences raise a number of important issues. Firstly, they demonstrate that male and female carers approach and manage risk differently. Secondly, male and female carers treat their mothers and fathers differently; risk taking appeared to be more acceptable for fathers compared to mothers in the eyes of their sons. Thirdly, results highlighted the importance of power and the existence of different power relationships. For example, as the authors note, sons expected mothers to take a more passive and submissive role to risk taking and its management compared to fathers, whereas, daughters tended to treat their parents more equitably, respecting the ideas and preferences of both. Indeed, mothers often accepted their sons' dominance, submitting to their wishes. The authors suggest that these differences reflect wider gender inequalities and presumptions within society. For Horton and Arber, these gender differences are important as they impact on the risk taking opportunities available to older men and women in different ways, with mothers having fewer opportunities to take risks in their everyday lives.

Looking to the future, the authors argue that practitioners need to be aware of these gender differences and the danger that a son's risk management strategies may be disempowering, especially for mothers. Hence, they suggest there is a need for practitioners to work with both sons and mothers towards a shared and more empowering approach to risk taking, encouraging sons to be less coercive and mothers to be less passive. Horton and Arber acknowledge the preliminary nature of their findings and thus suggest this is an area for further research.

4.6.3 Risk and ethnicity

Only nine references specifically explored the importance of ethnicity in how risk is viewed and managed by service users, informal carers or practitioners. As Table 4.8 documents, the small number of studies identified was spread over a range of subject areas, however, two-thirds (six) focused on older people and mental health issues. Amongst these nine references, five were empirical (four articles and one end of project report) and four were discussion pieces. Out of the five empirical studies, only one focused specifically on ethnicity, the remaining four studies had small sub-samples of black and minority ethnic participants in their wider sample. This limited evidence base must be borne in mind, one must be wary of making generalisations, especially when one considers the heterogeneity between different ethnicities. The literature will be discussed in two broad sections: firstly, ethnicity and practitioners, exploring the role and impact of ideas and prejudices and secondly, ethnicity and service users and informal carers. Here, the importance of ethnicity in risk management will be considered.

Table 4.8   References discussing the theme of risk and ethnicity by subject area* (n=9)

Subject area	Number of references discussing risk and ethnicity
Mental health	3
Older people	3
General**	1
Disability	1
(specifically learning disability)	1
Young people	1
Total	**9**

* It is important to note that three of the references in the literature reviewed and identified as exploring the importance of ethnicity discussed the same study.
** 'General' refers to those references discussing more than one area, often older people, those with learning disabilities and mental health service users.

Ethnicity and practitioners

Four studies highlighted the role of ethnicity in relation to practitioners (Browne, 1995; Langan and Lindow, 2000; Manthorpe and Stanley, 1999; Warner and Gabe, 2004). The area where potential racial and ethnic prejudice in relation to risk was most frequently noted was in mental health. Indeed, both Langan and Lindow and Manthorpe and Stanley's literature reviews highlighted Browne's (1995) study exploring issues of race in two psychiatric hospitals with a range of practitioners (the actual number of staff in Browne's study was hard to ascertain). Risk and danger in mental health are frequently linked to colour of skin. Indeed, as highlighted previously in Warner and Gabe's (2004) study of 39 mental health social workers, 'dangerousness' for these social workers was often associated with black mental health service users, especially young black males (see Section 4.2: Risk and competence for a more in-depth discussion of Warner and Gabe's study). Indeed, Browne's study provides empirical evidence documenting racial ideas and prejudice and how these can impact on practitioners' perceptions of risk amongst black mental health service users and the management techniques they adopt. For example, Browne notes that 75 per cent of practitioners felt that black clients were more likely to be viewed as 'dangerous' than their white counterparts. This was found to influence practitioners' risk management practices in two ways. Firstly, black patients were more frequently physically restrained than white service users and secondly, black patients were more likely to be prescribed sedatives. Browne highlights that the risks black mental health service users personally face, for example, from this increased medication are frequently ignored, the focus, as previously noted in Section 4.2: Risk and competence is clearly on danger and protecting others.

In addition, Browne also suggests that these harsh risk management practices were often legitimised and rationalised by reference to biological and cultural ideas of 'difference', such as, certain races being psychologically more prone to schizophrenia and mental illness than others. Langan and Lindow (2000) and Manthorpe and Stanley's (1999) scholarly discussions both recognise the existence of racism in mental health services and advocate the need for practitioners to become more aware of this racism in order to evaluate and monitor their own practice when conducting risk assessments and developing management plans.

Ethnicity, service users and informal carers
Two studies (Help the Aged, National Care Forum and National Care Homes Research and Development Forum, 2006; Shah, 2005) highlighted the importance of being sensitive to the needs of different cultural and ethnic groups when conducting individual care assessments. Although both are discussion pieces rather than empirical studies, and focus more generally on care assessments as opposed to specific procedures/practices for risk assessment, they advocate the need for practitioners to consider the individual ethnic and cultural preferences of clients. The importance of cultural understanding and sensitivity within service users' risk management strategies were also reiterated and briefly discussed in two studies (Clark, 2006; Daker-White *et al.*, 2002).

In Daker-White's *et al.*'s study exploring both service users with dementia (largely younger adults) and their informal carers' perceptions of everyday risk, a sub-sample of a person with dementia and four carers (three Asian and one African Caribbean) were interviewed. Amongst the ethnic minority carers, Daker-White *et al.* did not find any real differences in how risk was viewed and managed compared to white carers. Risk was viewed as a balancing act between ensuring safety for the person with dementia and respecting their independence. However, amongst the ethnic minority carers, issues of ethnicity emerged in relation to, as the authors note, the problems language and communication barriers can bring and, in contrast, the value of culturally sensitive services, especially specialist services that understand and respect cultural practices.

Although this is a very small and specific sub-sample of ethnic minority carers, the research does highlight the value of shared language and cultural understanding. This has also been demonstrated in Clark's (2006) study of the experiences of older people and direct payments, as discussed in Section 4.4: Risk and different organisational contexts. Clark interviewed a small sub sample of six Somali older women (out of a wider sample of 41 older people) and found that these women valued the opportunity direct payments gave them to employ a personal assistant from their own community. As Clark emphasises, having a shared language was very important to these Somali women and was also felt to be a means to reduce the potential risk of abuse. For these women, being able to communicate their ideas and personal care preferences was valued, if they could not explain how they wished

care to be provided, this was felt to increase the risk of misunderstandings and culturally inappropriate or unacceptable care practices. Clark suggests a shared language helped to foster empathy and was felt to improve the quality of the Somali women's lives.

The final article reviewed in this section is Atkin and Ahmad's (2000) study of 25 young people with thalassaemia major. This has been discussed previously in Section 4.1: Risk and normalisation and in Section 4.2: Risk and competence, in this section, the important point to highlight with reference to ethnicity, culture and religion is that although ethnic, cultural and religious ideas were noted amongst the young people, ethnic and cultural differences were not definite and did always direct risky behaviour, i.e. the young people's medical non-compliance.

For Atkin and Ahmad, interviews with young people with thalasseamia demonstrated that on one hand, ethnicity may appear to play a role in how they viewed the effects of medical non-compliance and its future impact on their ability to fulfil family obligations. For example, the South Asian young people in the authors' sample were more aware of fulfilling family obligations and their ability to do so compared to other young people with chronic illnesses in the wider population (here the authors drew on past research with other groups of chronically ill young people). The concerns of the thalassaemic young people were also gendered, as the boys focused on looking after their parents in old age and the girls on their domestic responsibilities. As previously noted by the authors, medical non-compliance brings the risk of poor personal health, such as increased tiredness and the danger of diabetes and heart problems, all of which can impede undertaking and fulfilling family obligations. However, Atkin and Ahmad found many similarities between the South Asian young people in their study and white peers in the general population. Independence was the key factor in many of these young people's assessment of risk and decisions as to whether to continue pursuing a strategy of medical non-compliance. As Atkin and Ahmad conclude, asserting independence and seeking greater autonomy was the key theme that cut across all ethnicities.

Religion and its role as a means to make sense of and/or cope with the risks of one's illness brings was also discussed, albeit briefly, by Atkin and Ahmad. Amongst some of the South Asian young people a belief in Allah could provide a source of strength for them and helped to make sense of the pain and suffering they faced. In addition, a belief in the sanctity of life could also, for some young people, prevent pursuing medical non-compliance due to its associated health risks. However, Atkin and Ahmad conclude that issues of religion, ethnicity and culture were in many ways peripheral to the young people in their study in terms of rationalising the risky act of medical non-compliance.

4.7 Risk and the role of technology

In this final section, four references are reviewed surrounding the theme of risk and the role of technology, how it impacts on risk and raises potentially new ways of risk management for service users, informal carers and practitioners. Although a very small number of studies are reviewed, three out of four discuss technology in relation to risk and older people and the fourth focuses on young people. Three references report empirically based research and one provides a scholarly discussion.

4.7.1 Risk and the role of 'smart' technology

The potential benefits of introducing 'smart' or 'telecare' technology into residential settings are explored by two of the studies (Kelly, 2005; Vallelly *et al.*, 2006). Kelly reports the results of a pilot project introducing 'telecare' technology into the homes of older people in one Scottish authority (West Lothian). 'Telecare' technology includes devices such as emergency pendants for older people, lifeline units, smoke detectors and flood detectors. The technology is linked to a care centre staffed by a range of practitioners, with support provided as and when needed (i.e. 24 x 7). Drawing on personal experiences, reported staff observations and monitoring authority data, Kelly suggests that the introduction of 'telecare' technology has brought a number of benefits for service users, their carers and also the authority. For service users, Kelly argues technology has enabled many older people to return home or remain in their own homes for longer and has also provided a greater sense of security, as older people know that their call will be answered day or night. Similarly, Kelly suggests that informal carers and family members have reported reduced levels of anxiety, as technology is viewed as more reliable than an older person calling for help. Finally, Kelly notes cost savings in terms of reduced levels of delayed discharge from hospital or residential settings.

'Telecare' technology is thus presented by Kelly as an important means to manage a fear of risk in the home for elderly people and if it does occur, prompt support and risk management can in turn be taken. Reporting the response received from practitioners, Kelly notes that problems can occur as staff need to accept and develop new ways of working, both on a personal level and with other practitioners from different agencies. For Kelly, the introduction of 'telecare' technology has generally been a positive experience; however, this evaluation must be viewed in context. It is a personal evaluation and think-piece with a lack of systematically collected data and only focuses on one group of users in one specific authority.

The views and experiences of service users and practitioners are discussed in more depth in Vallelly *et al.*'s (2006) recently completed longitudinal study of 'extra care' housing for older people. Drawing on data (questionnaire based) which tracks the care and support needs of 60 residents living in extra care housing over three years

and interviews with 30 residents from six case study housing courts, Vallelly *et al.* explore the use of 'electronic assistive technology', in particular, personal alarms installed in residents' rooms. Vallelly *et al.* highlight the potential benefits of alarms for residents with many similarities to Kelly noted, for example, opportunities to promote increased independence for older people and a sense of security. In addition, Vallelly *et al.* note the potential of increased privacy for older people, if they are not being constantly checked. However, the authors found only three examples of alarms actually being used; many had been planned but not actually implemented or activated. In addition, the authors also found that staff viewed alarms as potentially problematic and a nuisance, especially if residents used them 'inappropriately', i.e. staff faced many false alarms. With this negative attitude, the authors found that staff may view the alarms as potentially 'risky', as they do not know if a resident really needs help or not. Inappropriate use could also lead to a resident being moved to a different setting. Appreciating that alarms may have potential benefits for older people, the authors suggest that more training on how to use and respond to alarms is required for both residents and staff. In addition, the authors also recognise the potential benefit of other forms of assistive technology and thus suggest this merits further research.

4.7.2 Risk and the role of information technology

Using information technology to develop a more accurate data base of information in order to highlight those felt to be 'at risk' in the community is discussed by Iliffe *et al.* (2005). A Health Risk Assessment for Older People (HRAO) has recently been developed and Iliffe et al's study explores if this assessment can be extended to include social care and thus provide a process of single risk assessment for health and social care practitioners. The HRAO is based on a 'computer expert system' with patients completing a personal health questionnaire to identify 'risk' factors. The information is then entered into a computer package and each person receives a personalised risk assessment and associated behaviour management advice to address potential risks. However, as the social care part of the research is currently still under study, there is no evidence as yet available on the effectiveness of this information technology based technique for identifying people potentially 'at risk'.

The potential benefits of information technology as a means of providing support for specific groups of service users are highlighted by Morris's (1999) review of the literature surrounding the transition experiences of disabled young people and/or young people with complex health needs. The importance of peer support and feeling the 'same' rather than 'different' to other young people was discussed in Section 4.1: Risk and normalisation. In the literature reviewed by Morris, sharing experiences, ideas and coping strategies was valued by many young people as a means to learn how to manage one's disability/illness and also help to reduce the risk of social isolation. However, as Morris notes, poor health, current treatment and risk of cross

infection or merely living a long way from friends (especially if one has left school/a placement in the transition from child to adult services) may mean that some young people cannot actually meet their peers face-to-face. Drawing on the experiences of a small number of initiatives amongst support groups, Morris highlights how information technology, such as video conferencing, internet chat rooms and videos, have been used to link young people together and keep in-touch. Although Morris focuses on a small number of specific charities, such as the association of youth with 'ME', she recognises the potential of this information technology for future development, especially creating a virtual community for other groups of disabled and/or chronically ill young people.

Chapter 5   Overview

5.1   The Scoping study

5.1.1   Aims and objectives

The aim of this scoping study was to identify and review research evidence on perceptions of risk and risk-related practice in the field of adult social care. It focused on identifying different perceptions of risk within and between different groups of adult social care service users and service providers; and how any such differences were negotiated and managed in practice.

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, including the impact of corporate approaches on the behaviour of front line staff.
- To identify significant gaps in evidence on the perceptions and management of risk within and between different groups of adult social care service users and professional staff.

5.1.2   Scope of the review

The review covered recent data from 1990 onwards and concentrated on empirically based research conducted in the UK, particularly research carried out in England. Due to time and resource limitations grey literature was not included within the review. The review focused on perceptions of risk and their negotiation and management in front-line practice with regard to social care services and other support arrangements, including services provided by the public, private, formal/voluntary and informal sectors and different forms of user-directed support. The review included a range of service users such as, older people, disabled people, young people moving to adult services, men and women, members of black and ethnic minority communities, drug and alcohol service users and carers. The review excluded acutely mentally ill people and services for them. As risk is an extremely diverse concept and broad area of study, research evidence from a range of disciplines, including social policy, sociology, psychology and media studies was thus searched and included.

5.1.3 Methods

Seven relevant electronic databases and four social care related websites were searched, 31 academics and researchers of risk were consulted; and recent copies of a small number of key journals were also hand searched. Initial database searches generated a large number of potential references (1,430), 151 references were finally identified as relevant to and included in the study. All 151 references were read by the lead researcher and relevant information from each reference was entered onto an access database (see Chapter 2 for more details).

Establishing clear parameters enabled the researchers to provide a more focused and in-depth review of the evidence base. However, setting parameters invariably leads to the exclusion of some empirical research which may be relevant but does not match the project's agreed search terms. For example, some articles may not use the term 'risk' as a concept or key word although the research may address issues of risk and its management. Hand searching key journals enabled the researchers to identify some of this literature but some may nevertheless have been missed. Additional and/or more peripheral databases or websites could have been searched and grey literature included. Despite these limitations, a thorough search of the evidence base was conducted from a range of relevant sources with the researchers striving to ensure, as far as possible, consistency in the search terms used and inclusion/exclusion criteria applied.

5.2   Overview of the evidence base

It is important to note that although 151 references were identified and reviewed, only 94 of these were actually empirically based studies and within this, some of these references discussed the same study. In addition, many of the 57 literature reviews and scholarly discussions also reviewed the same empirical studies. Hence, the actual evidence base that currently exists is smaller and more limited than the number of identified references would suggest. The following overview seeks to summarise the scope of the evidence base and so only focuses on the references identified as primarily empirical research.

The evidence surrounding risk and adult social care is not evenly balanced in terms of either the type of social care services or the participants involved. The voice of service users may frequently be advocated in current government policy and good practice guidance but it was not always present in the research reviewed. Out of the 94 empirical studies reviewed, very few focused solely on the views/experiences of service users (5) or informal carers (2) compared to those that examined only on the views of practitioners (32). The views of service users and informal carers were much more likely to be considered alongside the views of practitioners. Indeed, the vast majority of studies identified (76 studies overall) included the ideas and experiences

of practitioners in one way or another. Twenty studies explored service users' and practitioners' ideas and experiences, 16 studies, service users, informal carers and practitioners' experiences and eight studies, informal carers and practitioners' views. In general, the perspectives of informal carers have received less attention compared to both practitioners and service users.

Amongst the studies that examined the ideas and experiences of either service users or informal carers, research was not evenly spread across different types of services. The five studies reporting the views of service users did not include users from mental health services or older people and only one of the studies focused on the views of disabled people. These were disabled young people in the transition from child to adult services rather than disabled adults. Service user only perspectives were largely from the field of substance misuse. The two studies focusing solely on the views and experiences of informal carers discussed risk in relation to the care of mental health service users and older people.

As noted in Chapter 1, an in-depth evaluation of the quality of studies identified was beyond the scope of this study; however, as demonstrated in Table 3.2, 80 out of the 94 empirical studies drew on qualitative research methods. Within this, many of these were essentially either small scale quantitative or case studies drawing on relatively small samples from specific geographical locations. In addition, a number also drew on qualitative data from case studies; indeed, some practitioners discussed their own practice based cases. In contrast, very few studies (12) drew on both qualitative and quantitative research methods and only two studies employed solely quantitative methods.

The following section summarises the evidence base identified surrounding the main types of services included in the review and the research conducted on different types of service users and practiconers. It highlights key themes that have emerged and then identifies important gaps, the chapter concludes by suggesting a number of areas for future research.

5.2.1 Mental health

The majority of studies exploring risk and mental health focused on 'risk and danger', especially, the idea that mental health service users are a danger to others. Amongst these studies, the ideas, experiences and practices of mental health service staff and practitioners were frequently explored, in particular, practitioners' perspectives of mental health users as 'dangerous'. Studies examined how practitioners assess degree or degrees of 'danger'; the presumptions that their views and assessments are based on; and the resulting risk management strategies that they employ.

The research identified was frequently grounded or explored in relation to the wider socio-economic context within which practitioners work and also live. Researchers thus contextualised their research against the background of previous official inquiries and media scares and/or scandals involving mental health service users and the dangers they have posed to society, in particular, physical 'harm' to 'innocent' members of the public. Much of the research considered how this wider social context of fear and blame, especially the concern surrounding litigation (whether real or apocryphal), is 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.*, 1998a, 1999; Alaszewski and Manthorpe, 1998), have demonstrated that although practitioners from different areas of social care (mental health, older people and learning disabilities) can view risk differently, mental health service practitioners are more likely to focus on risk as 'danger' compared to colleagues in other areas of social care.

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

Although one of the two studies focusing only on the voice of informal carers was in the field of mental health, there were generally view few studies exploring the ideas and experiences of risk and its management from the perspective of informal carers of mental health service users. This seemed to stand in contrast to research in other areas, especially older people and adults with learning disabilities, where the views of informal carers were more frequently examined, usually alongside practitioners'.

5.2.2 Older people

The majority of studies of risk and older people focused on the everyday risks older people may encounter when they return to or seek to remain living in their own home (as opposed to a residential care setting). In general, the main area of concern focused on the physical risks older people could face; for example, falling or physically harming themselves as a result of doing 'risky' actions in areas such as housework, cooking, bathing or showering. There appeared to be less research 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 to another care setting; this usually involved assessment of risk in relation to older people returning home. This research explored how risk was assessed by different parties (especially service users and practitioners) and the level of participation in these assessments by different stakeholders, especially the older person being assessed. The research (particularly 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 which excluded older people's inclusion were discussed, both in terms of practitioner ideas/presumptions and also organisational practices and/or structures.

The evidence base relating to risk in relation to older people includes a range of perspectives and experiences. The views of staff and practitioners from both social care and health care are explored in a number of studies; indeed, research has compared the views and experiences of different practitioners across social care and health care settings and agencies, for example, the views of hospital occupational therapists and community based social workers. How risk was viewed and the management strategies adopted frequently reflected their wider professional ethos and priorities, and the organisational context. In addition, the views of practitioners and managers within the same area of social care were also compared and areas of potential conflict noted.

Research exploring informal carers' perceptions and management of risk highlighted the importance of placing their perceptions of what is risky behaviour in the context of the subjective meanings each carer personally attaches to their caring role and their past relationship with the older person. Research (especially Clarke, 2000; Clarke and Heyman, 1998) has shown this to be an active process that informal carers engage in, with 'risky' behaviour and 'how' or even 'whether' to manage potential risk 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.

Research has examined how older people viewed and personally assessed the risks they faced in their everyday lives. Again this is often a complex and lengthy process for older people involving issues of personal choice and the maintenance of independence and control. Studies indicated that for many older people definitions of 'risk' and deciding whether to take a risk are complex processes, frequently involving 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 can be viewed very differently by service users, their carers and practitioners. Research has 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's personal and family life.

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 1996a, 1996b, 1998, and Wilson's, 1994 research). However, as noted above, the importance of risk and damage to psychological well-being appears to be less well-researched.

5.2.3 Disabled adults

The research relating to disabled people focused predominately on people with learning disabilities. Out of the 22 references reviewed discussing risk and disability, 20 focused on adults with learning disabilities. The remaining two studies included people with physical impairments. Research with mixed samples also tended to include learning disabled rather than physically disabled people. A slightly broader focus was found in studies exploring young people and the transition from child to adult services. Here, nine studies drew on samples of disabled young people but only two focused specifically on learning disability; the remaining seven studies included young people with physical or multiple impairments.

Much of the evidence base in this area was grounded in the theoretical framework of normalisation (see O'Brien, 1992; Wolfensberger, 1972). Inherent within this, there is recognition that taking risks is part and parcel of everyday life and that risk taking can be a positive learning and personal developmental experience for people with learning disabilities. A number of studies highlight the importance of normalisation, in particular they explore how normalisation theory is both recognised by practitioners working with people with learning disabilities and can guide the degree of risk taking they advocate. Indeed, evidence comparing practitioners in different areas of social care found that 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.*, 1998a, 1999).

Research on risk and disabled adults has examined the ideas of all parties; service users, informal carers (usually parents) and staff/practitioners. However, the views of informal carers/parents are 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, a number of studies demonstrated that adults with learning disabilities' perception of risk, what is risky behaviour and thus dangerous for them,

frequently mirrored their parents/carers views on risk and danger (see in particular the work of Alaszewski *et al.*, 1998a, 1999; Heyman and Huckle, 1993a, 1993b, 1995). Only a small number of studies have explored and found differences of opinion between people with learning disabilities and their parents (McConkey and Smyth, 2003). 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.

The majority of research discussing risk for people with learning disabilities focuses 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 research interest. Research explored both the fear that people with learning disabilities were vulnerable to sexual abuse, i.e. they were often 'victims', and, also the issue of people with learning disabilities 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 (Brown *et al.*, 1994; Thomson, 2000) have explored practitioners' views of, and concerns surrounding, service users as potential abusers.

A number of studies have focused on informal carers/parents' fears of risk and their 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 clearly try to manage risk (recognising that some degree of risk taking is necessary) whereas, other parents seek to avoid risk taking 'at all cost' (see Heyman and Huckle, 1993a, 1993b, 1995). 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.

5.2.4 People who misuse substances, black and ethnic service users and their families and young people in transition from child to adult services

Database searches identified very little research in the area of risk with regard to people who misuse substances; service users and their families from black and ethnic minority populations; and young people in transition from child to adult services. This stands in contrast to other areas of adult social care included in this review, such as mental health service users, older people and people with learning disabilities.

People who misuse substances

The small (three studies) body of literature identified in this review focused on service users' perspectives of risk and how it was managed in everyday life. The importance of seeking to maintain normal life, its usual patterns/routines, and presentation of 'the self', especially, the idea that one was 'in-control' and coping was noted. The authors of the studies exploring risk and alcohol misuse amongst parents noted the important wider effects this could have on the family as a whole, especially children. Indeed, parents, especially mothers were aware of the risks and dangers alcohol misuse could bring for their child(ren) and its effect on their lives, 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 noted and more co-ordinated working was advocated. The views of practitioners were largely absent from these studies.

5.2.5 Transition from child to adult services

In the small number of studies (12) exploring the transition from child to adult services (these studies were largely of the transition for 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 issues of independence. Research has examined the risks (either health related, 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.

People from black and minority ethnic cultures

Database searches identified only a small number of studies involving black and minority ethnic participants and within these studies quite specific and disparate groups of participants from black and ethnic minority groups were included. Furthermore, in some of these studies, people from black and ethnic minority communities formed only a small sub-sample of the total study sample.

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. However, the importance of ethnicity and cultural ideas within perceptions of risk and risky behaviour was not always found to be of primary importance; similarities with white service users and their families were often noted. In Atkin and Ahmad's (2000) study of young people with thalassaemia, although ethnically and culturally specific experiences/attitudes were found amongst these young people, they were not a key

factor in their 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 assessments of risk. Indeed, issues surrounding professional ethnicity and the ethnicity of service users and informal carers, and how these might interact and impact on definitions of risk have received little research attention.

5.3   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:

5.3.1 The voices of mental health service users and their informal carers

The voices of mental health service users and their informal carers were largely absent within the literature reviewed. In particular, there is a dearth of research exploring how risk is experienced by service users in their own personal lives; the focus is generally on the risks and dangers that mental health service users pose to others. However, mental ill-health can raise specific personal risks for service users, for example, as noted above: the risk of self-harm or injury; the risk of stigma and social isolation in the community within which service users live; increased surveillance from others (especially practitioners and carers); and the potential negative effects of medication.

- More research is needed to explore service users' experiences of these risks and how they are managed in their everyday lives.

The perspective of informal carers of mental health service users also appears to be an area receiving less consideration. The review identified only a very small number of studies exploring how informal carers viewed and managed the risks associated with supporting a mentally ill person, both in terms of the personal risks and consequences faced as a carer, and the risks experienced by the person they supported.

- More research is required on how risk is viewed by informal carers and also managed in both their own lives and the lives of users of mental health services.

5.3.2 Risk and gender

The role of gender in shaping the attitudes and behaviours of informal carers has received very little research attention. Apart from Horton and Arber (2004), the vast majority of studies reviewed either do not explore gender differences between carers or drew on gendered samples; for example, samples of informal carers were predominately female.

- More research is required exploring the role and impact of gender on informal carers' views of risk and how it is managed in different areas of social care.

- Research could also explore the interactions between male and female informal carers and male and female service users' attitudes towards and management of risk.

- Research is also needed on whether formal services respond differently to risk, relative to male and female service users.

Gender differences between staff were noted, especially with regard to adults with learning disabilities and sexual abuse. For example, there were differences between male and female care staff in relation to feeling personally threatened or 'at risk' and male and female staff took different views on 'when', 'where' or from 'whom' service users were 'at risk' of sexual abuse.

- More research is needed examining gender differences between staff in other areas of social care, such as mental health, older people, and substance misuse. Do male and female practitioners view risk differently and/or adopt different risk management strategies?

5.3.3 Ethnicity, culture and risk

As noted above, there is very little specific research exploring perceptions of risk or how risk is managed 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 is based on very small samples.

A number of areas require further research and consideration:

- Research with larger samples of service users, informal carers and staff/practitioners from different ethnic and cultural backgrounds in order to explore differences within and between different ethnic communities.

- Possible differences between different groups of black and ethnic minority service users, carers and practitioners and their white counterparts also require examination.

- There is a need for research specifically on the experiences of black mental health service users. Examination of possible differences between black mental health service users and their white counterparts is also required.

5.3.4 Socio-economic circumstance and material resources

The importance of limited material resources in shaping perceptions of risk and how this is managed is discussed in the literature. Studies have explored how risk has become a criterion for allocating resources, especially to those defined as 'at risk' or 'high risk'. These studies have focused largely on the perspectives and practice of practitioners. In contrast, there is less research on risk and the socio-economic circumstances and material resources that informal carers and service users have to draw on. The limited research appears to focus on two specific groups; parents of adults with learning disabilities and direct payment recipients. In the former, only one study (Heyman and Huckle, 1993a, 1993b) suggests the differences in the socio-economic circumstances and personal resources amongst parents of adults with learning disabilities may impact on how risk for their son/daughter was viewed and managed. However, as the authors themselves note, their work was tentative and no clear conclusions were drawn. In the latter, direct payment recipients paying personal assistants extra above the allocated rate was noted as a strategy for managing risks associated with poor quality care.

Three potential areas for further research are:

- How do socio-economic circumstances of informal carers of older people and of mental health service users' impact on their view of risk and how it is managed?

- How do the socio-economic backgrounds and access to material resources of service users impact on how they can or do manage risk?

- Do direct payment recipients from higher socio-economic backgrounds experience or feel that they experience fewer risks?

5.3.5 Disability

As noted previously, the focus in the studies identified was predominately on exploring risk perceptions and management in relation to adults with learning

disabilities. There appears to be a dearth of literature exploring risk in adult social care for people with other impairments such as physical disabilities, visual or hearing impairments.

Potential research areas therefore include:

- What risks do social care service users with physical disabilities, sensory impairments or multiple disabilities face in their everyday lives? Are these different to those encountered by adults with learning disabilities?

- How is risk viewed and managed by informal carers and practitioners supporting disabled service users with physical, sensory or multiple impairments?

Although research has explored how older people learn to adapt to changed life circumstances and physical functioning in relation to perceptions of risks and how risk is viewed and managed, this has received little, if any research attention amongst younger disabled people, especially those who experience progressive or fluctuating levels of impairment.

- More research is needed exploring the role and impact of disabled people's life histories and experiences of impairment on their perceptions of risk and how risk is managed

Although research on risk and adults with learning disabilities is grounded within the theoretical framework of normalisation there appears to be little research exploring risk from a broader social model perspective, particularly, the risks created by a disabling society.

- More research is required exploring the views and experiences of disabled people – does society create risks or additional risks, and how can these be managed?

One further area to consider is disabled parents. There is considerable debate about the appropriate policy and practice responses to disabled parents and their children, particularly the role of children ('young carers') in supporting parents with physical or learning disabilities or mental health problems (see the work of Becker, such as Bibby and Becker, 2000; Dearden and Becker, 2004). Alternative arguments draw attention to the risks to parents, children and families as a whole that arise because of the lack of support that parents receive from social care services with their parenting roles. The search terms employed in this review did not identify any research that addressed these issues specifically from the perspective of risks for parents. This may be because potentially relevant research (for example, Olsen and Tyers, 2004) has revealed that practitioners' concerns lie primarily with the risks that are presumed to face the children, rather than the parents, in such families. Any such research would have been outside the scope of this review, which focused on users

of adult social care services. Similarly Morris and Wates' (2006) review of research on disabled parents and parents with additional support needs does not specifically examine risk, although this review does show that disabled parents are more 'at risk' of experiencing material deprivation and social isolation. Morris and Wates also identify gaps in research evidence about disabled parents' own experiences of parenting and subjective evaluations of their support needs. How disabled parents define risk, the potential and actual responses of practitioners, and the extent to which parent-defined risks could be reduced are therefore additional areas where further research is needed.

5.3.6 Refining research methods

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

- More research is required drawing on: larger, more diverse samples with a range of health and socio-economic characteristics, from different geographical locations or social care settings

One specific area to develop is longitudinal research. Some studies have noted how views of what is risky behaviour and how it should be managed can alter over time, as situations and circumstances change or illness fluctuates. For example, research has illustrated how older people adapt to changed circumstances, redefine independence and what they are able to do/cannot do and 'how' carers' redefine 'normal' life and risk for themselves and the person they support. In a context of changing circumstances, longitudinal research would provide an opportunity to track these changes and explore how they impact on perceptions of risk and its management. However, only a small number of the studies reviewed provided a longitudinal perspective, collecting data at different stages of risk planning and management or from participants on more than occasion.

More longitudinal research is required, particularly:

- Between different groups (service users, informal carers and practitioners).

- Between different groups of social care service users, such as older people, mental health, learning disabilities, substance misuse.

- Tracking specific risk management strategies over time, especially, the different effects these might have on service users and their carers or family members.

5.3.7 Risk and psychological well-being

The relationship between risk taking and psychological well-being was noted in the research on older people; a number of studies have demonstrated that older people engage in complex processes weighing up the potential costs of risky actions with the psychological benefits that can result. However, the risk of damage to psychological well-being and how it is experienced and managed has received little consideration.

Areas to explore include:

- How are risks of damage to psychological well-being experienced by different groups of service users?

- How are risks of damage to psychological well-being experienced and managed by informal carers of groups of service users and by practitioners working with them?

5.3.8 Technology and IT

The evidence base exploring the role and impact of 'smart' technology in managing risk in the lives of service users, informal carers and practitioners was very small (Vallelly *et al.*, 2006; Kelly, 2005); indeed, the latter study was a pilot evaluation with older people in only one area. Despite this, a number of interesting consequences were noted concerning:
- Greater independence for service users
- Increased security and 'peace of mind' for users and carers
- Financial implications for service providers.

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 with other groups of social care users in addition to older people.

Future areas of research could include:

- New ways of working with 'smart' technology – how is 'smart' technology viewed by staff and practitioners within and across different agencies?

- How does the introduction of 'smart' technology impact on practitioners' practice, especially their opportunities to use professional knowledge, experience or personal intuition?

- Resource issues – does 'smart' technology raise further questions concerning risk, need and resource allocation?

- Does 'smart' technology influence the level of security and protection against risk service users feel in their everyday lives?
  How do other groups of people (staff and practitioners, informal carers) view the level of security or protection against risk that 'smart' technology brings?

- Issues of surveillance – do service users feel that 'smart' technology changes the level and type of risk surveillance experienced in their everyday lives?
  Do other people (practitioners, informal carers) feel that 'smart' technology changes levels of risk surveillance?
  Are differences between direct and indirect surveillance noted?

5.3.9 Risk in the context of self-directed support arrangements

Direct payments, In Control and individual budgets all represent different approaches to increasing the choice and control that users can exercise over their social care and other forms of support. This review has identified some research evidence on the identification and management of risk by users of direct payments. However this research is much less extensive than evidence on the benefits of self-directed support arrangements; it is restricted to the experiences of direct payment users; 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.

Some research evidence may become available through the evaluations of In Control and individual budgets that are currently under way, but neither evaluation has a primary focus on risk.

Areas for research include:
- Risk and its management in the context of changing relationships between disabled/older people, their newly paid helpers and other unpaid, informal carers.

- What risks– for example, financial and other abuse - arise for disabled/older people in the course of employing helpers and/or paying carers; how can choice and control be sustained at the same time as safeguarding against risk?

- What new risks – for example, health, safety, financial and other exploitation - arise for carers (whether longstanding family carers or not) in the course of being paid by an individual budget holder and how can these be minimised?

- How do different types of relationships between disabled/older people and paid helpers (for example formal employment relationships, casual payments to a longstanding family carer) affect the incidence and management of risk?

Bibliography

Adams, T. (2001) The social construction of risk by community psychiatric nurses and family carers for people with dementia, *Health, Risk & Society*, 3, 307-19.

Alaszewski, A. (2000a) Risk in nursing practice: developing and sustaining trust, in Alaszewski, A., Alaszewski, H., Ayer, S. and Manthorpe, J. (eds), *Managing Risk in Community Practice: Nursing, risk and decision making*, Balliere Tindall, London, 1-22.

Alaszewski, A. (2000b) Risk, trust and nursing: towards and ethical basis for risk assessment and management in practice, in Alaszewski, A., Alaszewski, H., Ayer, S. and Manthorpe, J. (eds), *Managing Risk in Community Practice: Nursing, risk and decision making*, Balliere Tindall, London, 157-76.

Alaszewski, A. (2002) Risk and dangerousness, in Bytheway, B., Bacigalupo, V., Bornat, J., Johnson, J. and Spurr, S. (eds), *Understanding Care, Welfare and Community: A reader*, Routledge, London, 183-91.

Alaszewski, A. (2003) Risk, decision-making and mental health, in Hannigan, B. and Coffey, M. (eds), *The Handbook of Community Mental Health Nursing*, Routledge, London, 187-96.

Alaszewski, A. (2005a) Risk communication: identifying the importance of social context, *Health, Risk & Society*, 7, 101-5.

Alaszewski, A. (2005b) Risk, safety and organisational change in health care?, *Health, Risk & Society*, 7, 315-18.

Alaszewski, A. and Alaszewski, H. (2000a) Improving the quality of risk management and decision making in practice, in Alaszewski, A., Alaszewski, H., Ayer, S. and Manthorpe, J. (eds), *Managing Risk in Community Practice: Nursing, risk and decision making*, Balliere Tindall, London, 131-56.

Alaszewski, A. and Alaszewski, H. (2000b) Risk: empowerment or control?, in Alaszewski, A., Alaszewski, H., Ayer, S. and Manthorpe, J. (eds), *Managing Risk in Community Practice: Nursing, risk and decision making*, Balliere Tindall, London, 23-46.

Alaszewski, A. and Alaszewski, H. (2002) Towards the creative management of risk: perceptions, practices and policies, *British Journal of Learning Disabilities*, 30, 56-62.

Alaszewski, A., Alaszewski, H., Manthorpe, J. and Ayer, S. (1998a) *Assessing and Managing Risk in Nursing Education and Practice: Supporting vulnerable people in the community*, English National Board for Nursing, Midwifery and Health Visiting, London.

Alaszewski, A., Alaszewski, H. and Harrison, L. (1998b) Professionals, accountability and risk, in Alaszewski, A., Harrison, L. and Manthorpe, J. (eds.), *Risk, Health and Welfare Strategies: Policies, strategies and practice*, Open University Press, Buckingham, 89-103.

Alaszewski, A. and Horlick-Jones, T. (2003) How can doctors communicate information about risk more effectively? *British Medical Journal*, 327, 728-31.

Alaszewski, A., Manthorpe, J. and Walsh, M. (1995) Risk: the sociological view of perception and management, *Nursing Times*, 22 November, 34-5.

Alaszewski, A. and Manthorpe, J. (1998a) Welfare agencies and risk: formal structures and strategies, in Alaszewski, A., Harrison, L. and Manthorpe, J. (eds), *Risk, Health and Welfare: Policies, strategies and practice*, Open University Press, Buckingham, 45-63.

Alaszewski, A. and Manthorpe, J. (1998b) Welfare agencies and risk: the missing link?, *Health and Social Care in the Community*, 6, 4-15.

Alaszewski, H. and Alaszewski, A. (1998) Professionals and practice: decision making and risk, in Alaszewski, A., Harrison, L. and Manthorpe, J. (eds.), *Risk, Health and Welfare: Policies, strategies and practice*, Open University Press, Buckingham, 104-26.

Alaszewski, H. and Alaszewski, A. (2000a) Decision making and risk in individual practice, in Alaszewski, A., Alaszewski, H., Ayer, S. and Manthorpe, J. (eds), *Managing Risk in Community Practice: Nursing, risk and decision making*, Balliere Tindall, London, 71-108.

Alaszewski, H. and Alaszewski, A. (2000b) Risk, decisions and teamwork, in Alaszewski, A., Alaszewski, H., Ayer, S. and Manthorpe, J. (eds), *Managing Risk in Community Practice: Nursing, risk and decision making*, Balliere Tindall, London, 109-30.

Alaszewski, H. and Alaszewski, A. (2005) Person centred planning and risk: challenging the boundaries, in Cambridge, P. and Carnaby, S. (eds), *Person Centred Planning and Care Management with People with Learning Disabilities*, Jessica Kingsley, London, 183-97.

Alaszewski, H. and Manthorpe, J. (2000) Finding the balance: older people, nurses and risk, *Education and Ageing*, 15, 195-209.

Alaszewski, H., Parker, A. and Alaszewski, A. (1999) *Empowerment and Protection: The development of policies and practices in risk assessment and risk management in services for adults with learning disabilities*, Mental Health Foundation, London.

Arksey, H. and Glendinning, C. (in press) Choice in the context of informal care-giving, *Health and Social Care in the Community*.

Arksey, H. and O'Malley, L. (2005) Scoping studies: towards a methodological framework, *International Journal of Social Research Methodology*, 8, 1, 19-32.

Arksey, H., Jackson, K., Croucher, K., Weatherly, H., Golder, S., Hare, P., Newbronner, E. and Baldwin, S. (2003) *Review of Respite Services and Short-Term Breaks for Carers for People with Dementia*, Final Report, Social Policy Research Unit, University of York, York.

Arksey, H., Kemp, P., Glendinning, C., Kotchetkova, I. and Tozer, R. (2005) *Carers' Aspirations and Decisions around Work and Retirement*, Research Report No 290, Department for Work and Pensions, Crown Copyright, Leeds.

Atkin, K. and Ahmad, W. (2000) Pumping iron: compliance with chelation therapy among young people who have thalassaemia major, *Sociology of Health and Illness*, 22, 500-24.

Ballinger, C. and Payne, S. (2002) The construction of the risk of falling among older people, *Ageing and Society*, 22, 305-24.

Banim, M., Guy, A. and Tasker, P. (1999) Trapped in risky behaviour: empowerment, disabled people and sexual health, *Health, Risk & Society*, 1, 209-21.

Beattie, A., Daker-White, G., Gilliard, J. and Means, R. (2004) 'How can they tell?' A qualitative study of the views of younger people about their dementia and dementia care services, *Health and Social Care in the Community*, 12, 359-68.

Beresford, B. (2004) On the road to nowhere? Young disabled people and transition, *Child: Care, Health and Development*, 30, 581-87.

Bhaumik, S. (2005) Service innovations: risk assessment in learning disability, *Psychiatric Bulletin*, 29, 1, January, 28-31.

Bibby, A. and Becker, S. (eds) (2000) *Young Carers in their Own Words*, (UK branch), Calouste Gulbenkian Foundation, London.

Bridge, C. (1997) Adolescents and mental disorder: who consents to treatment?, *Medical Law International*, 3, 51-74.

Brown, H., Hunt, N. and Stein, J. (1994) 'Alarming but very necessary': working with staff groups around the sexual abuse of adults with learning disabilities, *Journal of Intellectual Disability Research*, 38, 393-412.

Brown, H. and Thompson, D. (1997) Working with men with learning disabilities who sexually abuse others, *Mental Health Foundation Briefing No.12*, Mental Health Foundation, London.

Browne, D. (1995) Sectioning: the black experience, in Suman, F. (ed.), *Mental Health in a Multi-ethnic Society: A multi-disciplinary handbook*, Routledge, London and New York, 62-72.

Buchanan-Barker, P. and Barker, P. (2005) Observation: the original sin of mental health nursing?, *Journal of Psychiatric and Mental Health Nursing*, 12, 541-49.

Buri, H. and Dawson, P. (2000) Caring for a relative with dementia: a theoretical model of coping with fall risk, *Health, Risk & Society*, 2, 283-93.

Burke, P. (1997) Risk and supervision: social work responses to referred user problems, *British Journal of Social Work*, 27, 115.

Cambridge, P. and Carnaby, S. (2000) A personal touch: managing the risks of abuse during intimate and personal care, *Journal of Adult Protection*, 2, 4-16.

Carnaby, S. and Lewis, P. (2005) Involving young people with learning disabilities leaving school in planning for the future, in Cambridge, P. and Carnaby, S. (eds), *Person Centred Planning and Care Management with People with Learning Disabilities*, Jessica Kingsley, London, 84-99.

Clark, H. (2006) 'It's meant that, well, I'm living a life now': older people's experiences of direct payments, in Leece, J. and Barnat, J. (eds), *Developments in Direct Payments*, Policy Press, Bristol.

Clark, H., Dyer, S. and Hartman, L. (1996a) *Going Home: Older people leaving hospital*, The Policy Press, Bristol, (Joseph Rowntree Foundation Findings).

Clark, H., Dyer, S. and Hartman, L. (1996b) *Going Home: Older people leaving hospital*, The Policy Press in association with the Joseph Rowntree Foundation and Community Care Magazine, Bristol.

Clark, H., Dyer, S. and Horwood, J. (1998) *'That Bit of Help': The high value of low level preventitive services for older people*, The Policy Press in association with Community Care Magazine and the Joseph Rowntree Foundation, Bristol.

Clark, H. and Spafford, J. (2001) *Piloting Choice and Control for Older People: An evaluation*, The Policy Press, Bristol, (Joseph Rowntree Foundation Findings).

Clarke, C. (1999) Professional practice with people with dementia and their family carers: help or hindrance?, in Adams, T. and Clarke, C. (eds), *Dementia Care: Developing Partnerships in Practice*, Bailliere Tindall, London, 281-304.

Clarke, C. (2000) Risk: constructing care and care environments in dementia, *Health, Risk & Society*, 2, 83-93.

Clarke, C. and Heyman, B. (1998) Risk management for people with dementia, in Heyman, B. (ed.), *Risk, Health and Healthcare: A Qualitative Approach*, Chapman and Hall, London, 228-40.

Clarke, C., Luce, A., Gibb, C., Williams, L., Keady, J., Cook, A. and Wilkinson, H. (2004) Contemporary risk management in dementia: an organisational survey of practices and inclusion of people with dementia, *Signpost*, 9, 27-31.

Clarke, C.L., Lhussier, M., Minto, C., Gibb, C. and Perini, T. (2005) Paradoxes, locations and the need for social coherence: a qualitative study of living with a learning difficulty, *Disability & Society*, 20, 405-19.

Croucher, K., Quilgars, D., Wallace, A., Baldwin, S. and Mather, L. (2003) *Paying the Mortgage? A Systematic Review of Safety Nets for Homeowners*, Final Report, Department of Social Policy and Social Work, University of York, York.

Cunliffe, A., Gladman, J., Husbands, S., Miller, P. and Dewey, M. (2004) Sooner and healthier: a randomised controlled trial and interview study of an early discharge rehabilitation service for older people, *Age & Ageing*, 33, 246-52.

Daker-White, G., Beattie, A., Means, R. and Gilliard, J. (2002) *Serving the Needs of Marginalised Groups in Dementia Care: Younger people and minority ethnic groups*, University of the West of England and Dementia Voice, Bristol.

Davis, A., Ellis, K. and Rummery, K. (1998) *Access to Assessment: The perspectives of practitioners, disabled people and carers*, The Policy Press in association with The Joseph Rowntree Foundation and Community Care Magazine, Bristol.

Dawson, C. (2000) *Independent Success: Implementing direct payments*, York Publishing Services and The Joseph Rowntree Foundation, York.

Dearden, C. and Becker, S. (2004) *Young Carers in the UK: The 2004 Report*, Carers UK, London.

Didlock, N., Cheshire, R. in association with Turning Point and Addaction (2005) *Developing the Evidence Base: Young people with substance misuse problems*, Turning Point and Addaction, London.

Douglas, M. (1966) *Purity and Danger: An Analysis of Concepts of Pollution and Taboo*, Routledge and Kegan Paul, London.

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*, 13, 136-44.

Edwards, A. (2003) Communication risks, *British Medical Journal*, 327, 691-92.

Edwards, A., Elwyn, G. and Mulley, A. (2002) Explaining risks: turning numerical data into meaningful pictures, *British Medical Journal*, 324, 827-30.

Fiorentino, L., Phillips, D., Walker, A. and Hall, D. (1998) Leaving paediatrics: the experience of service transition for young disabled people and their family carers, *Health and Social Care in the Community*, 6, 260-70.

Fisher, M. and Social Care Institute for Excellence (SCIE) (2006) *Using Qualitative Research in Systematic Reviews: Older people's views of hospital discharge*, Social Care Institute for Excellence, London.

Fleming, G. and Taylor, B.J. (in press) Battle on the home care front: perceptions of home care workers on factors influencing staff retention in Northern Ireland, *Health and Social Care in the Community*.

Flynn, M. (2005) *Developing the Role of Personal Assistants, New Types of Worker Project*, Skills for Care - part of the Sector Skills Council, Leeds.

Gilmour, H., Gibson, F. and Campbell, J. (2003) Living alone with dementia: a case study approach to understanding risk, *Dementia*, 2, 403-20.

Glendinning, C., Halliwell, S., Jacobs, S., Rummery, K. and Tyrer, J. (2000a) New kinds of care, new kinds of relationships: how purchasing services affects relationships in giving and receiving personal assistance, *Health and Social Care in the Community*, 8, 201-11.

Glendinning, C., Halliwell, S., Jacobs, S., Rummery, K. and Tyrer, J. (2000b) Providing seamless personal support: the experiences of personal assistants, in Glendinning, C., Halliwell, S., Jacobs, S., Rummery, K. and Tyrer, J. (eds), *Buying Independence: Using Direct Payments to Integrate Health and Social Services*, Policy Press, Bristol, 22-53.

Godin, P. (2004) 'You don't tick boxes on a form': a study of how community mental health nurses assess and manage risk, *Health, Risk & Society*, 6, 347-60.

Harrison, L., Alaszewski, A. and Walsh, M. (1998) The influence of informal relations on the management of risk, in Alaszewski, A., Harrison, L. and Manthorpe, J. (eds), *Risk, Welfare and Society: Policies, strategies and practice*, Open University Press, Buckingham, 64-88.

Healy, J. (1999) *Coming Up For Care: Assessing the post-hospital needs of older patients*, Policy Studies Institute, London.

Healy, J. and Yarrow, S. (1998) *Safe at Home? Views of professionals on preventing accidents in the home among older people*, Health Education Authority, London.

Help the Aged, National Care Forum and the National Care Homes Research and Development Forum (2006) *My Home Life: Quality of life in care homes*, Help The Aged, London.

Hendey, N. and Pascall, G. (2001) *Disability and Transition to Adulthood: Achieving independent living*, Pavilion Publishing in association with The Joseph Rowntree Foundation, Brighton.

Herring, R. and Thom, B. (1997) The right to take risks: alcohol and older people, *Social Policy and Administration*, 31, 213-32.

Heyman, B. (2005) Health care risk escalators, in Bibace, R., Laird, J. and Valsiner, J. (eds), *Science and Medicine in Dialogue: Thinking through particulars and universals*, Greenwood Publishing Group, Westport, 43-61.

Heyman, B., Griffiths, C.B. and Taylor, J. (2002) Health risk escalators and the rehabilitation of offenders with learning disabilities, *Social Science and Medicine*, 54, 1429-40.

Heyman, B. and Huckle, S. (1993a) 'Normal' life in a hazardous world: how adults with moderate learning difficulties and their carers cope with risks and dangers, *Disability Handicap and Society*, 8, 143-60.

Heyman, B. and Huckle, S. (1993b) Not worth the risk? Attitudes of adults with learning difficulties, and their informal and formal carers to the hazards of everyday life, *Social Science and Medicine*, 37, 1557-64.

Heyman, B. and Huckle, S. (1995) Sexuality as a perceived hazard in the lives of adults with learning difficulties, *Disability & Society*, 10, 139-55.

Heyman, B., Swain, J. and Gillman, M. (1998) A risk management dilemma: how day centre staff understand challenging behaviour, *Disability and Society*, 13, 163-82.

Hird, M. and Cash, K. (2000) Power play, *Openmind*, 101, January/February, 12-13.

Hood, C., Jones, D., Pidgeon, N., Turner, B. and Gibson, R. (1992) Risk management, in The Royal Society (ed.), *Risk, Analysis, Perception and Management: Report of a Royal Society Study Group*, The Royal Society, London.

Horlick-Jones, T. (2005) On 'risk work': professional discourse, accountability, and everyday action, *Health, Risk & Society*, 7, 293-307.

Horton, K. and Arber, S. (2004) Gender and the negotiation between older people and their carers in the prevention of falls, *Ageing and Society*, 24, 75-94.

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*, 6, 115-32.

Hughes, B. (1993) A model for the comprehensive assessment of older people and their carers, *The British Journal of Social Work*, 23, 345-64.

Iliffe, S., Kharicha, K., Goodman, C., Swift, C., Harari, D. and Manthorpe, J. (2005) Smarter working in social and health care (SWISH): enhancing the quality of life of older people using an 'expert system', *Quality in Ageing: Policy Practice and Research*, 6, 4-11.

Iliffe, S. and Manthorpe, J. (2004) The hazards of early recognition of dementia: a risk assessment, *Aging and Mental Health*, 8, 2, March, 99-105.

Kearney, P., Levin, E. and Rosen, G. (2003 reprint) *Alcohol, Drug and Mental Health Problems: Working with families*, Social Care Institute for Excellence, London.

Kelly, D. (2005) Smart support at home: the integration of telecare technology with primary and community care systems, *British Journal of Healthcare Computing and Information Management*, 22, 19-21.

Kelly, S. and McKenna, H. (2004) Risks to mental health patients discharged into the community, *Health, Risk & Society*, 6, 377-85.

Kemshall, H., Parton, N., Walsh, M. and Waterson, J. (1997) Concepts of risk in relation to organizational structure and functioning within the personal social services and probation, *Social Policy and Administration*, 31, 213-32.

King, R., Raynes, N. and Tizard, J. (1971) *Patterns of Residential Care: Sociological studies in institutions for handicapped children*, Routledge and Kegan Paul, London.

Ko, B. and Mcenery, G. (2004) The needs of physically disabled people during transition to adult services, *Child: Care, Health and Development*, 30, 317-23.

Langan, J. (1999) Assessing risk in mental health, in Parsloe, P. (ed.) *Assessing Risk in Social Care and Social Work*, Jessica Kingsley, London, 153-78.

Langan, J. and Lindow, V. (2000) Risk and listening, *Openmind*, 101, January/February, 14-15.

Langan, J. and Lindow, V. (2004) *Mental Health Service Users and their Involvement in Risk Assessment and Management*, Joseph Rowntree Foundation and The Policy Press, Bristol.

Littlechild, R. and Blakeney, J. (1996) Risk and older people, in Kemshall, H. and Pritchard, J. (eds), *Good Practice in Risk Assessment and Risk Management*, Jessica Kingsley, London, 68-79.

Lomas, A. (2006) Care managers and direct payments, in Leece, J. and Barnat, J. (eds), *Developments in Direct Payments*, Policy Press, Bristol, 237-49.

Lupton, D. (1999) *Risk*, Routledge, London.

Manthorpe, J. (1997) Elderly abuse and key areas in social work, in Decalmer, P. and Glendinning, F. (eds), *The Mistreatment of Elderly People*, 2nd edition, Sage, London, 88-101.

Manthorpe, J. (2003) Risk and dementia: models for community mental health nursing practice, in Keady, J., Clarke, C.L. and Adams, T. (eds), *Community Mental Health Nursing and Dementia Care: Practice perspectives*, Open University Press/McGraw-Hill Education, Buckingham, 63-73.

Manthorpe, J. (2004) Risk taking, in Innes, A., Archibald, C. and Murphy, C. (eds), *Dementia and Social Inclusion: Marginalised groups and marginalised areas of dementia research, care and practice*, Jessica Kingsley, London and Philadelphia, 137-49.

Manthorpe, J. and Alaszewski, A. (2000) Service users, informal carers and risk, in Alaszewski, A., Alaszewski, H., Manthorpe, J. and Ayer, S. (eds), *Managing Risk in Community Practice: Nursing, risk and decision making*, Balliere Tindall, London, 47-70.

Manthorpe, J. and Stanley, N. (1999) Conclusion: Shifting the focus, from 'bad apples' to users' rights, in Stanley, N., Manthorpe, J. and Penhale, B (eds), *Institutional Abuse: Perspectives across the life course*, Routledge, London, 223-40.

Manthorpe, J., Walsh, M., Alasweski, A. with Harrison, L. (1997) Issues of risk practice and welfare in learning disability services, *Disability & Society*, 12, 69-82.

McConkey, R. and Smyth, M. (2003) Parental perceptions of risks with older teenagers who have severe learning difficulties contrasted with the young people's views and experiences, *Children and Society*, 17, 18-31.

Misselbrook, D. and Armstrong, D. (2002) Thinking about risk. Can doctors and patients talk the same language?, *Family Practice*, 19, 1-2.

Morris, J. (1999) *Hurtling into a Void*, Pavilion Publishing/Joseph Rowntree Foundation, Bristol.

Morris, J. and Wates, (2006) *Supporting Disabled Parents and Parents with Additional Support Needs*, Adults' Services Knowledge Review No.11, Social Care Institute for Excellence, London.

Murphy, L. (2005) Users' views of a dynamic risk assessment system, *Nursing Times*, 16 August, 35-37.

Neil, S., Nicole, P. and Raghu, R. (2003) Choice biography and the importance of the social, *British Journal of Learning Disabilities*, 31, 4, December, 159-65.

Newbigging, K. and Lowe, J. (2005) *Direct Payments and Mental Health: New directions*, Joseph Rowntree Foundation, York.

O'Brien, J. (1992) *Learning Together*, Central Council for Education and Training in Social Work, London.

Olsen, R. and Tyers, H. (2004) *Think Parent: Supporting disabled adults as parents*, National Family and Parenting Institute, London.

Paling, J. (2003) Strategies to help patients understand risks, *British Medical Journal*, 327, 745-48.

Papadopoulos, A. (2000) Towards the prevention of violence in domestic settings: a systems perspective, in Manthorpe, J. (ed.), *Without Due Care and Attention – The Abuse of Older People by Neglect (including self-neglect)*, Action on Elder Abuse, London, 25-9.

Parker, C., Barnes, S., McKee, K., Morgan, K., Torrington, J. and Tregenza, P. (2004) Quality of life and building design in residential and nursing homes for older people, *Ageing & Society*, 24, 941-62.

Parsloe, P. (1999) Introduction, in Parsloe, P. (ed.), *Risk Assessment in Social Care and Social Work*, Jessica Kingsley, London, 7-16.

Petts, J., Horlick-Jones, T. and Murdock, G. (2001) *Social Amplification of Risk: The media and the public*, Health and Safety Executive, Crown Copyright, Norwich.

Postle, K. (2002) Working 'between the idea and the reality' - ambiguities and tensions in care managers' work, *British Journal of Social Work*, 32, 335-51.

Pritchard, J. (1997) Vulnerable people taking risks: older people and residential care, in Kemshall, H. and Pritchard, J. (eds), *Good Practice in Risk Assessment and Risk Management 2: Protection, rights and responsibilities*, Jessica Kingsley, London, 80-102.

Pritchard, J. (2001) The myth of confidentiality: a social work view, in Cordess, C. (ed.), *Confidentiality and Mental Health*, Jessica Kingsley, London, 119-26.

Pugh, M. and Keady, J. (2003) Assessing and responding to challenging behaviour in dementia: a focus for community mental health nursing practice, in Keady, J., Clarke, C. and Adams, T. (eds), *Community Mental Health Nursing and Dementia Care: Practice perspectives*, Open University Press, Buckingham, 199-211.

Redfern, J., Mckevitt, C. and Wolfe, C. (2006) Risk management after stroke: the limits of a patient-centred approach, *Health, Risk & Society*, 8, 123-41.

Reed, J., Stanley, D. and Clarke, C. (2004) *Health, Well-Being and Older People*, The Policy Press, Bristol.

Reich, S., Eastwood, C., Tilling, K. and Hopper, A. (1998) Clinical decision making, risk and occupational therapy, *Health and Social Care in the Community*, 6, 47-54.

Ross, L. and Waterson, J. (1996) Risk for whom? Social work and people with physical disabilities, in Kemshall, H. and Pritchard, J. (eds), *Good Practice in Risk Assessment and Risk Management*, Jessica Kingsley, London, 80-92.

Ryan, T. (1996) Risk management and people with mental health problems, in Kemshall, H. and Pritchard, J. (eds), *Good Practice in Risk Assessment and Risk Management*, Jessica Kingsley, London, 93-108.

Ryan, T. (2000) Exploring the risk management strategies of mental health service users, *Health, Risk & Society*, 2, 267-81.

Ryan, T. (2002) Exploring the risk management strategies of informal carers of mental health service users, *Journal of Mental Health*, 11, 17-25.

Ryan, T. and Values into Action (1999) *Able and Willing? (Implementing direct payments for people with learning difficulties)*, Values into Action, Oxford.

Shakespeare, T., Gillespie-Self, K. and Davies, D. (1997) *The Sexual Politics of Disability*, Cassell, London.

Schur, H., Gamsu, D. and Barley, V. (1999) The young person's perspective on living and coping with diabetes, *Journal of Health Psychology*, 4, 223-36.

Scourfield, P. (2005) Implementing the Community Care (Direct Payments) Act: will the supply of personal assistants meet the demand and at what price?, *Journal of Social Policy*, 34, 469-88.

Sellars, C. (2002) *Risk Assessment in People with Learning Disabilities*, British Psychological Society/Blackwell, Oxford.

Shah, R. (2005) Addressing ethnicity and the multicultural context, in Cambridge, P. and Carnaby, S. (eds), *Person Centred Planning and Care Management with People with Learning Disabilities*, Jessica Kingsley, London, 135-46.

Shaw, A. and Shaw, I. (2001) Risk research in a risk society, *Research, Policy and Planning: The Journal of the Social Services Research Group*, 19, 1-16.

Smith, M. (2001) Risk assessment in mental health work, *Practice (UK)*, 13, 21-30.

Stalker, K. (2003) Managing risk and uncertainty in social work: a literature review, *Journal of Social Work*, 3, 211-33.

Stanley, N. and Manthorpe, J. (1997) Risk assessment: developing training for professionals in mental health work, *Social Work and Social Sciences Review*, 7, 26-38.

Stanley, N., Manthorpe, J. and Gillespie, L. (2004) *Concern and Confidentiality: GP's responses to young people in distress and their families*, Social Work Department, University of Hull, Hull.

Stevenson, D. (2004) Home trial, *Nursing Standard*, 19, 20-21.

Stevenson, O. (1999) Old people at risk, in Parsloe, P. (ed.), *Risk Assessment in Social Care and Social Work*, Jessica Kingsley, London, 201-16.

Tan, M. and Kimach, V. (2004) Portfolio of health advice for young people with disabilities transferring to adult care, *Child: Care, Health and Development*, 30, 291-96.

Taylor, B.J. (2006) Risk management paradigms in health and social services: professional decision making on the long term care of older people, *British Journal of Social Work*, 36, 807-76.

Taylor, B.J. and Donnelly, M. (2006a) Professional perspectives on decision making about the long term care of older people, *British Journal of Social Work*, 36, 1411-29.

Taylor, B.J. and Donnelly, M. (2006b) Risks to home care workers: professional perspectives, *Health, Risk & Society*, 8, 239-56.

Taylor-Gooby, P. (2004) (ed.) *New Risks, New Welfare: The transformation of the European welfare state*, Oxford University Press, Oxford.

Thom, K.M. and Blair, S.E. (1998) Risk in dementia - assessment and management: a literature review, *British Journal of Occupational Therapy*, 61, 441-47.

Thompson, D. (2000) Vulnerability, dangerousness and risk: the case of men with learning disabilities who sexually abuse, *Health, Risk & Society*, 2, 33-45.

Tindall, B. (1997) People with learning difficulties: citizenship, personal development and the management of risk, in Kemshall, H. and Pritchard, J. (eds), *Good Practice in Risk Assessment and Risk Management 2: Protection, rights and responsibilities*, Jessica Kingsley, London, 103-17.

Titterton, M. (1999) Training professionals in risk assessment and risk management: what does the research tell us?, in Parsloe, P. (ed.), *Risk Assessment in Social Care and Social Work*, Jessica Kingsley, London, 217-47.

Titterton, M. (2005) *Risk and Risk Taking in Health and Social Welfare*, Jessica Kingsley, London.

Turner, S. and Street, H. (1999) Assessing carers' training needs: a pilot inquiry, *Aging & Mental Health*, 3, 173-78.

Turning Point (2006) *Bottling It Up: The effects of alcohol misuse on children, parents and families*, Turning Point, London.

Ungerson, C. (1999) Personal assistants and disabled people: an examination of a hybrid form of work and care, *Work, Employment and Society*, 13, 583-600.

Vallelly, S., Evans, S., Fear, T. and Means, R. (2006) *Opening Doors to Independence - A longitudinal study exploring the contribution of extra care housing to the care and support of older people with dementia*, University of the West of England, Housing Corporation and Housing 21, Bristol.

Warburton, H., Turnbull, P. and Hough, M. (2005) *Occasional and Controlled Heroin Use: Not a problem?*, Joseph Rowntree Foundation, York.

Warner, J. (2006) Inquiry reports as active texts and the function in relation to professional practice in mental health, *Health, Risk & Society*, 8, 223-38.

Warner, J. and Gabe, J. (2004) Risk and liminality in mental health social work, *Health, Risk & Society*, 6, 387-99.

Waterson, J. (1999) Redefining community care social work: needs or risks led?, *Health & Social Care in the Community*, 7, 276-79.

While, A., Forbes, A., Ullman, R., Lewis, S., Mathes, L. and Griffiths, P. (2004) Good practices that address continuity during transition from child to adult care: synthesis of the evidence, *Child: Care, Health and Development*, 30, 439-52.

Wilson, G. (1994) Co-production and self-care: new approaches to managing community care services for older people, *Social Policy and Administration*, 28, 236-50.

Wolfensberger, W. (1972) *The Principle of Normalisation in Human Services*, National Institute of Mental Retardation, Toronto.

Appendix 1

Access Template

Endnote reference

☐

Bibliographic detail

☐

☐ original empirical   ☐ literature review   ☐ scholarly/discussion article   ☐ unpublished reports

RESEARCH

Research Focus/Questions

☐

Research Methods (approach, to do + analysis)

☐

Research Sample

☐

Research Adequacy/ appropriateness comments

☐

☐ normalisation   ☐ competence/social status   ☐ control (Info/knowledge/environment)

☐ wider socio economic factors

☐ age   ☐ different social settings/context   ☐ experience

☐ gender   ☐ technology   ☐ transition to adult services

☐ culture/religion   ☐ resources/finances   ☐ training

APPROACH/PERCEPTION OF RISK

Users/carers/profs perspectives

Comments Issues arising

RISK MANAGEMENT

Strategy/ies adapted or used

Effect/impact

Comments/issues arising

OTHER ISSUES

Other

PERSONAL COMMENTS

Personal comments/issues