


Independence, choice and risk: a guide to best practice in supported decision making



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Independence, choice and risk: a guide to best practice in supported decision making

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Contents

Foreword	1
Executive summary	3
About this guide: who it is for and how to use it	8
Section One: Independence, choice and risk: the principles and what they mean for people	9
What do we mean by risk in decision making?	10
What is reasonable risk?	11
The governing principle behind good approaches to independence, choice and risk	12
Section Two: Putting the principles into practice	14
Working across systems	15
Assessment	17
Personalisation and care planning	18
Recording discussions about choice and risk	19
A supported decision tool	20
Resources	21
Risk and the law	21
Duty of care	22
Human rights	22
Risk and the preservation of rights	24
Health and safety	26
Mental capacity	27
Mental health	28
Risk and dementia	29
Safeguarding	30
Carers	32
Transition from child to adult	33
Assistive technology	35
Section Three: Embedding a common approach into corporate activity	37
The role of the Director of Adult Social Services (DASS)	38
Developing a learning culture	38
Managing decisions on choice and the use of resources	39
The role of executive members	40
Overview and Scrutiny Committees	41

Shared approaches between agencies	41
Commissioning and the provision of services	42
System management and regulation	43
Regulation and inspection	43
Performance assessment	44
Managing the media	45
Insurance and compensation claims	46
Conclusion	48
Annex A: A supported decision tool	49
Annex B: Key links to wider initiatives	52
Annex C: Issues and solutions: some illustrative cases	54
Annex D: Glossary	61

Foreword

Our White Paper *Our health, our care, our say* and the Green Paper *Independence, Well-being and Choice* responded to what people told us they wanted from health and care services in the 21st century. They wanted to have more control over their lives and be able to make real choices about services and the opportunity to take control over the sorts of things that others might just take for granted.

We are introducing more and more opportunities for people to choose services and take control: direct payments have been available for a long time, but now there is a duty on councils to discuss direct payments with everyone as a first option. Currently there are 13 authorities testing out the use of individual budgets, designed to place the person at the centre of the process. If the pilots prove successful, we want everyone who wants one to have the opportunity of an individual budget.

Choice and control are what everyone wants for themselves and those they care for, but sometimes the decisions they make may seem to others as too risky. Risk is a concept that tends nowadays to have mainly negative connotations. We live in a world where, when things go wrong, the media and society in general are quick to look for someone to blame, and this is particularly the case when people using health and social care services are involved. But avoiding risk altogether would constrain the choices people can make.

To make good choices, people need to understand the consequences and take some responsibility for them. So we want to promote a culture of choice that entails responsible, supported decision-making.

This is timely: the Better Regulation Commission's report on risk¹ calls for a redefinition of society's approach to risk management, to recognise that, within the right circumstances, risk can be beneficial, balancing necessary levels of protection with preserving reasonable levels of choice and control. In response, the government is setting up a citizens' forum to debate what should be the right balance between rights and responsibilities. The Commission for Social Care Inspection highlights many of the same issues in its report on what older people say about choice and their responses to ageing.²

1. *Risk, responsibility and regulation – Whose risk is it anyway?*, Better Regulation Commission, October 2006

2. *Making choices: taking risks*, Commission for Social Care Inspection, December 2006

This guide forms a vital building block in constructing the vision for community services. It can be a complicated job for all involved to achieve this, especially if people have a different understanding or perception of risk. We want to encourage practitioners and their organisations to adopt the common approach set out in this guidance as the basis for working practice, through proper processes and agreements. That way we can all work together to help people achieve their potential without compromising their safety.



A handwritten signature in black ink that reads "Ivan Lewis". The signature is written in a cursive style.

Ivan Lewis
Minister for Care Services

Executive summary

Purpose of the guide

1. When the Green Paper *Independence, Well-being and Choice* consulted the public on a vision for the future of social care, people told us they wanted to have more control over their lives and be able to make real choices about services, taking their own decisions about things that others might take for granted. The White Paper *Our health, our care, our say* responded to that call, setting out plans for the future of health and social care in the 21st century in which choice and control are critical components. However, giving people more choice and control is not always as simple as it may seem. Everyday life involves us all in making choices and decisions. People using health and social care services are no different. Some choices might involve taking risks and while this can be a positive thing, it can also pose questions over people's safety, the safety of others and who is ultimately responsible if something goes wrong.
2. People perceive risk differently, including people using health and social care services, practitioners, family carers and others working in support of individuals. This can be difficult for practitioners and confusing for the individual and their carers. We have developed a common set of principles that we want to encourage people and their organisations to use as the basis for approaches to supporting people in making decisions about their own lives and managing any risk in relation to those choices.
3. The advice given in this document does not replace any existing risk guidance, including those risk management processes contained within the Care Programme Approach, Multi-Agency Public Protection Arrangements (MAPPA) or on safeguarding vulnerable adults.
4. The guide is for the use of everyone involved in supporting adults using social care within any setting, whether community or residential, in the public, independent or voluntary sectors. This includes all NHS staff working in multi-disciplinary or joint teams.

Good approaches to choice and risk

5. The governing principle behind good approaches to choice and risk is that people have the right to live their lives to the full as long as that does not stop others from doing the same. Fear of supporting people to take reasonable risks in their daily lives can

prevent them from doing the things that most people take for granted. What needs to be considered is the consequence of an action and the likelihood of any harm from it. By taking account of the benefits in terms of independence, well-being and choice, it should be possible for a person to have a support plan which enables them to manage identified risks and to live their lives in ways which best suit them.

The practicalities of managing risk in relation to choice

6. Multi-disciplinary working is very effective in ensuring that a person is supported in a seamless way, and it is satisfying to the practitioners involved. But dilemmas arise when practitioners of different disciplines cannot agree about what arrangements it would be best to support. Even in situations where choices may be very limited, people need to be supported and encouraged as far as possible to make choices about how to live their lives and manage any risks. When disagreements do occur, an agreed process for quick resolution needs to be in place involving appropriate senior management to avoid an unnecessary delay in service provision.
7. We propose that arrangements be put in place to manage more complex situations where there are different views held between the individual, the family carers or the professionals to seek agreed solutions. Ultimately, the local authority has a statutory duty of care and a responsibility not to agree to support a care plan if there are serious concerns that it will not meet an individual's needs or if it places an individual in a dangerous situation. Such arrangements will enable all those involved to explore the issues and set arrangements which go as far as possible in meeting the individual's aspirations, whilst balancing the needs and risks to themselves and others.
8. As part of any assessment process, it will be necessary to identify and assess any risks involved in supporting the person. Person-centred planning approaches identify what is important to a person from his or her own perspective and find appropriate solutions. We commend person-centred approaches for everyone.
9. Even when good approaches are used and the correct processes followed, the reality is that, if something goes wrong, sometimes people may not want to accept responsibility and will look for someone else to blame. It is therefore vital to keep accurate records of discussions that take place about areas of choice. Such documentation will be critical in order to protect the person in making their choices, as well as the position of the local authority, PCT or private provider of care in the event of any complaints or litigation. They are also valuable in giving a structure to the discussion about choices and their consequences.

10. We propose the use of a supported decision tool (at Annex A) to manage the process of choice, assess the potential impact of any risks, and provide documentation of the actions and decisions.
11. Uncertainty about rights and responsibilities in relation to the law can inhibit good approaches to supporting choice and managing risks. We provide clarification over the relevant legislation (duty of care, human rights, health and safety, mental capacity) with illustrative examples, to suggest in broad terms when it is appropriate for health and social care practitioners to support people in their choices and avoid litigation. However, we would stress the need to seek legal advice if there is any doubt in an individual case.
12. We discuss how good approaches to risk and choice fit in with other policies and practices. People with mental health problems or suffering from dementia also have the right to exercise choice, although this may sometimes be constrained in some areas by lack of capacity. Appropriate risk assessment and management contained within the Care Programme Approach may need to be in place. Safeguarding measures need to be put into place when the risks from supporting a person to do what they want suggest there is a danger of abuse, either of themselves or others.
13. The needs and wishes of carers should be acknowledged at all times, and any conflict of wishes should aim to support the rights of all involved. Transition planning for children who become adults needs to start in good time for them to manage well the choices that open up to them when they become adults. Assistive technology – telecare and telehealth – can provide flexible and personalised services responsive to individual need, and can reduce risks.

Corporate approaches to risk

14. A major inhibiting factor in achieving good outcomes for people in relation to choice and control is operating within a regime where there exists a fear of putting the organisation at risk, both financially, in terms of public relations, reputation or in breach of the law. The most effective organisations are those with good systems in place to support positive approaches rather than defensive ones. The corporate approach to risk that an organisation takes overwhelmingly influences the practices of its workforce.
15. The leadership role of the Director of Adult Social Services (DASS) in promoting health and well-being will be critical to focusing on positive outcomes for people who use social care services. Working with key partners, not least PCTs and the independent and voluntary sectors to effect change, we encourage the DASS to use this guidance as a means of raising the debate about risk and shifting the balance away from risk-aversion towards supported decision-making.

16. To change the culture around the provision of services and address the fear of blame among staff, we propose that organisations and their partners consider establishing a joint choice, empowerment and risk policy that promotes more open and transparent practices. It will need to be supported by senior leadership and shared across the organisation and their partners. There need to be clear lines of accountability and support within the professional team and the respective responsibilities of the council, PCT, independent and voluntary sector organisations, the member of staff and the individual using services. The policy would best be supported by appropriate working arrangements and systems.
17. Where there is a dispute over appropriate support for a person, including the use of resources, conflict resolution mechanisms will be necessary. Such mechanisms might include referral to senior management or a multi-disciplinary decision making panel; whatever the mechanism, the funding body, whether it is the local authority, responsible for meeting assessed needs under community care legislation, or the PCT with responsibility for continuing care, will have the final say. Where there are joint funding arrangements, agreed mechanisms need to be in place to ensure that there are no delays in people receiving services.
18. Various measures can be taken to influence performance in these areas and to promote a common approach. Executive members with responsibility for adult social services will have a role in ensuring that best practice approaches to choice and risk are embedded in local policies and practices. The Local Government and Public Involvement in Health Bill will place a statutory duty on PCTs and Local Authorities to undertake joint strategic needs assessments, whose findings will need to feed into the Sustainable Community Strategy and therefore the Local Area Agreement. Local authority Overview and Scrutiny Committees also have a vital role in ensuring that their local NHS partners do all that is necessary to support people in their chosen environment for the wider well-being of the local population.
19. Practitioners need support to work across systems, and multi-disciplinary arrangements need to ensure a common approach to risk through inter-agency agreements and through good commissioning practices.
20. Increasingly, improvement in the quality of service provision will be driven by the choices people make, combined with healthy competition between different service providers. *Our health, our care, our say* made a commitment to have an integrated health and social care regulator which will support an integrated approach to improving outcomes for people using health and social care services.

21. The Commission for Social Care Inspection's (CSCI) inspection processes are currently being refocused onto outcomes for users of services rather than minimum standards. CSCI stresses that registration of care services should not inhibit the services provided to individuals. Enabling people to exercise choice and control over their lives, and therefore the management of risk, is central to achieving better outcomes for people.
22. The media are highly influential in people's views of risk and how it should be managed. We suggest that good practice in media management is vital to the reputation of the organisation and its corporate approach to managing risk.
23. Fear of compensation claims inhibits good practice towards supporting choice but steps can be taken to mitigate complaints and avoid litigation.
24. Within a commonly agreed approach to choice and risk, there will always be scope for wide interpretation of the issues surrounding individual cases. Annex C provides some further illustrative case studies based on real life case stories to assist practitioners and their organisations to develop their thinking. We very much want to encourage organisations to embed this guidance into their policies, their agreements with other agencies, their own cultures and working practices. In this way, we can help people to achieve their potential without their safety being compromised.

About this guide: who it is for and how to use it

The possibility of risk is an inevitable consequence of empowered people taking decisions about their own lives. But the issues around choice and risk are complex, and when things go wrong people often look for someone to blame, not wanting to take responsibility themselves. This guidance therefore aims to support the principle of empowerment through managing choice and risk transparently in order to enable fair appraisal of the decision process, should it become necessary.

We recognise that sometimes people's decisions might be perceived by professionals or family members as carrying some degree of risk, and this guide is intended to help those involved in helping individuals to retain greater control of their lives.

We commend its use to promote choice, while managing risk proportionately and realistically. It should have a two-fold use – in multi-disciplinary teams to foster a common approach to risk and in organisations as the basis for corporate policies, as well as in contractual and other agreements. The aim should be to have a common approach to risk among all parties concerned in delivering health and social care, which will promote the sharing of responsibility for risk in a transparent and constructive way.

This best practice guide is for the use of everyone involved in supporting adults (18 and over) using health and social care within any setting, whether community or residential, in the public, independent or voluntary sectors. This includes all NHS staff working in multi-disciplinary or joint teams.

The proposals suggested in this document do not replace any existing risk guidance, including those risk management processes contained within the Care Programme Approach, Multi-Agency Public Protection Arrangements (MAPPA) or on safeguarding vulnerable adults. Nor do they conflict with professional codes or clinical practice guidelines; rather, they provide a common approach to risk for use across health and social care systems.

The guidance primarily relates to the need for and provision of social care services rather than medical care. In this document we are focusing on supporting people to make the everyday choices and decisions which are right for them, their families and the communities in which they live. However, in treating users of services³ in a holistic way, health or medical risks may well need to be taken into account, as well as risks to maintaining independence.

3. Users of services is the term used to describe people who use primarily social care services

Independence, choice and risk: the principles and what they mean for people

Section summary

This section on a common approach to decision-making and risk in social care includes:

- what people who use social care services think about choice and risk
- what we mean by the term 'risk' in the decision making process
 - everyone perceives it differently
 - it is often viewed negatively and can prevent people from doing things that most people take for granted
 - a perceived risk needs to be tested and assessed to see if it is real
- what is reasonable risk
 - it is about striking a balance between empowering people to make choices, while supporting them to take informed everyday risks
- the governing principle behind good approaches to choice and risk
 - people have the right to live their lives to the full as long as that doesn't stop others from doing the same
- to put this principle into practice, people supporting users of services have to:
 - Help people to have choice and control over their lives
 - Recognise that making a choice can sometimes involve an element of risk
 - Help people understand their responsibilities and the implications of their choices, including any risks
 - Acknowledge that there will often be some risk, and that trying to remove it altogether can outweigh the quality of life benefits for the person
 - Continue existing arrangements for safeguarding people

1.1 *Our health, our care, our say* sets out outcomes which everyone using health and social care services in the 21st century has a right to expect. Of these, two are particularly relevant to this guidance:

- choice and control and
- personal dignity

The principles for choice and risk described here relate directly to achieving these outcomes.

What people say about risk....

‘People spend most of their lives taking risks but not thinking much about it; then suddenly once they need care, risk is a big, negative thing’

‘The focus on keeping everything safe results in a huge waste of people’s potential’

‘Once people are with us in a care setting we do not just look at the big issues which brought them into contact with services – we scrutinise everything about them. It’s like being in a gold fish bowl – I have bad days, make bad decisions – the last thing I’d want is to be judged on them’

‘Life is about risk, we take risks every minute of the day. We must not let it inhibit us, we must use it to guide us and make us think, but it should not restrict our ability to lead lives to the full’

‘I don’t get up in the morning and think about a risk plan, I just think about what I want to do in my life’

What do we mean by risk in decision making?

1.2 Risk is the inevitable consequence of people taking decisions about their lives. But it means different things to different people.⁴ There is no one definition. In social care, as in the rest of life, risk can be viewed negatively. Because of perceptions of risk which may or may not be real, a person might be prevented from doing things which most people take for granted. So perceived risk must be tested and assessed against the likely benefits of taking an active part in the community, learning new skills and gaining confidence. What needs to be considered is the consequence of an action and the likelihood of any harm from it. By taking account of the benefits in terms of independence, well-being and choice, it should be possible for a person to have a support plan which enables them to manage identified risks.

4. For a review of literature about different perceptions of risk, see www.york.ac.uk/inst/spru/pubs/pdf/risk.pdf

- 1.3 A decision about the perceived or actual risk needs to be taken in conjunction with the person using services themselves, as well as the professionals involved. Just as taking a risk is a personal choice, levels of risk are perceptions, and a judgement about an acceptable level of risk should be a joint decision.

What is reasonable risk?

- 1.4 Balance and proportionality are vital considerations in encouraging responsible decision making. Reasonable risk is about striking a balance in empowering people who use services to make choices, ensuring that the person has all the information, tailored to their specific needs, in the appropriate form, to make their best decisions.
- 1.5 Risk needs to be explored in context for each individual. Risk is dynamic and may fluctuate – for example, a small task such as making a cup of tea may suddenly place an older person recovering from a broken hip at an increased risk of falling. A good approach to risk in social care bases itself on human rights, and it is important that the individual be given timely support to make decisions that best suit their needs.

Example of supporting choice and managing the risks

Emily, 97, lives in a care home. She walks with two walking sticks, which affects her ability to carry out some activities of daily living. Emily gets up very early; members of staff help her wash and dress, then offer her tea. When she lived with her family, she would get up herself and then sit in the kitchen drinking cups of tea until the rest of the family got up.

Soon after arriving in her new home, Emily insisted on going into the dining room in the mornings and making her own tea. Staff were concerned that Emily was at great risk of falling or of scalding herself. The dining room is unsupervised at this time as staff are busy in residents' room. They cannot lock the dining room, as other residents like to go in and out.

Emily could not understand why there was a risk, as she has always made her own tea. Making her own tea helped her feel at home in her new environment.

Care home staff reviewed Emily's care plan with her, explaining their concerns, and found a way for Emily to make her morning tea, minimising the risks. Emily accepted shared responsibility for any risks and, with her family, agreed that the home would leave out on a table in the dining room all that she needed to make her tea in the mornings.

Outcome: This small task meant a huge amount to Emily. This was recognised; consequently, her wishes were supported and staff did not need to worry about her walking round the dining room unaided.

- 1.6 Where a practitioner or support worker is asked to support a choice activity about which they have concerns or do not feel comfortable, they should use their own judgement, but also seek impartial advice from a person they trust, such as their manager. For example, a paid carer assisting a person with personal care is asked to open a can of beer which the person intends to use to take their medication. Individual practice is governed by professional codes of conduct and these will influence the way in which decisions are made in relation to risk.

The governing principle behind good approaches to independence, choice and risk

People have the right to live their lives to the full as long as that doesn't stop others from doing the same.

- 1.7 This principle underpins all activities surrounding a person's choices about their daily living. To put this principle into practice, people supporting users of services have to:

- **Help people to have choice and control over their lives**

Each of us is unique; support has to focus on the person, their wishes and aspirations. Some people may have very specific needs or difficulties in accessing appropriate support, such as some members of black and minority ethnic communities, people with mental health problems or people with a sensory or learning disability.

- **Recognise that making a choice can involve some risk**

Sometimes, making a decision that involves taking a small risk can make a big difference to someone's quality of life, particularly if they make that decision for themselves.

- **Respect people's rights and those of their family carers⁵**

People have the basic right to live as they choose. They should be supported to enjoy their basic rights, but understand too that with rights come responsibilities.

- **Help people understand their responsibilities and the implications of their choices, including any risks**

People need to be fully informed about the potential consequences of the choices open to them, so that they can take into account any risks involved and manage them. They may need help to do this, so practitioners need to ensure that people have accurate and appropriate information in a form that they genuinely understand, in order to make their best decisions. It is equally important that these decisions are documented.

5. The term family carers is used to mean all those who provide care and includes family or friends

- **Acknowledge that there will always be some risk, and that trying to remove it altogether can outweigh the quality of life benefits for the person**

Managed risk cannot and should not be eradicated just because individuals have come into contact with social care services. Some risks cannot be completely removed or managed, however much support the person may have.

- **Continue existing arrangements for safeguarding people**

This includes ensuring that the right balance is struck between enabling people to lead independent and dignified lives with the need to avoid and prevent unnecessary harm to themselves or others.

Example: assessing and managing risks to achieve a positive outcome

Andy, 42, has a learning disability, and lived, until recently, in a long stay hospital since the age of 5. He had never been on holiday, because he displays challenging behaviour. Staff supported Andy to find a suitable holiday location, by searching the web. This way Andy could look at pictures and discuss them with staff to help him make an informed choice. Staff contacted the owner of the cottage that Andy chose to discuss the environment and explain Andy's requirements. At a multi-disciplinary meeting, a risk assessment was undertaken, funding was agreed for staff to accompany Andy, and a support plan was developed to ensure that Andy still had a certain amount of structure whilst on holiday.

Outcome: The holiday was a great success with positive gains both for Andy and for the staff who support him. Andy developed confidence in his ability to manage a new environment with a change in structure more to his liking, and staff experienced him in a positive light, which helped them adopt more appropriate and positive responses towards him. There was considerable learning for all involved. Andy is now planning another holiday.

Putting the principles into practice

Section summary

This section on the practicalities of managing risk in relation to choice includes:

- how risk relates to:
 - working across health and social care
 - needs assessment and FACS
 - the move to personalisation of care
 - good practice in care planning
- the critical importance of recording discussions accurately
- using a supported decision tool to manage the process of choice, assess the potential impact of any risks, and provide documentation of the actions and decisions
- the funding body has the final sanction on what it is appropriate to resource
- clarification over relevant legislation
 - there is an important distinction to be made between putting people at risk and enabling them to choose to take reasonable risks
 - regard to a person's human rights must underpin the actions and decisions of all public authorities
 - health and safety legislation should not block reasonable activity
 - informed choice includes the option to choose 'unwisely'
 - decisions made on behalf of people who lack capacity must be made in their best interests and be the least restrictive option

- how this fits in with other policies and practices:
 - people with mental health problems or suffering from dementia need not be treated any differently from anyone else
 - safeguarding measures need to be put into place when the risks from supporting a person to do what they want suggest there is a danger of abuse
 - carers' needs and wishes (including young carers) are important too, and any conflict of wishes should aim to support the rights of all involved
 - planning for children who become adults needs to start in good time for them to manage decision making well as adults
 - assistive technology can provide flexible and personalised services responsive to individual need, and can reduce risks

Working across systems

2.1 Practitioners often work as part of multi-disciplinary teams across systems. This way of working enhances the possibility of holistic care and support being delivered without the person going through numerous assessment processes. It also means that the full ranges of skills from different professionals are available to support a person with complex needs.

2.2 The most effective arrangement is for care to be co-ordinated by one practitioner, acting as the point of contact for everyone concerned, drawing in specialist advice and help as and when required. This person, drawn from any discipline, keeps in close contact with the user of services and carer, ensures the support plan is meeting their needs and is responsible for arranging reviews. They also ensure that the individual receives timely support or care, including any agreed specialist equipment, without referral to someone else outside the team.

2.3 In this way, not only are the individual and their carer supported effectively, but the care co-ordinator also benefits from working closely with the other team members, resulting in creative solutions, managing complex care packages and sharing risk decisions. Under these arrangements, no one person, including the individual or their carer, is managing the risks alone.

2.4 Timely access to joint funding is essential where packages of health and social care are provided. Processes need to be clear and responsive. But there can be tensions and dilemmas when practitioners cannot agree about what arrangements it would be best to support. In complex situations where choices are very limited, people still need to

be supported to make choices about how to live their lives and manage risks. Trial periods in less than ideal situations might be considered, even when the risks may at first seem rather high. A common scenario would be a person wishing to return home from hospital when clinical opinion is that this would be too risky.

- 2.5 When disagreements do occur, an agreed process for quick resolution needs to be in place involving appropriate senior management to avoid an unnecessary delay in service provision. Where a local authority is paying for care and support, it remains accountable for ensuring that the individual's needs are appropriately met. If, however, following appropriate risk management procedures and full discussion with the individual and other members of a joint team, it believes that the care plan is inappropriate, the local authority has both the right and the responsibility not to sign off that care plan.
- 2.6 PCTs with responsibility for continuing care will have the final say on funding continuing care. Where there are joint funding arrangements, agreed mechanisms need to be in place to ensure that there are no delays in people receiving services.
- 2.7 For more on inter-agency working, see paras 3.8-3.10.

Example of managing conflicting professional views

Mr H, 60, was admitted to hospital after a major stroke following the death of his wife. He had two teenage daughters at home. Mr H's level of cognition did not appear to have been affected by the stroke, but this was difficult to gauge because he had also sustained moderate communication problems.

Mr H made a limited recovery and wanted to return home. But at a multi-disciplinary case conference the hospital team expressed concern that the risks of a home discharge were too great. They were particularly worried that he would refuse home care services and that his support needs would be placed on his daughters at an unacceptable level. The hospital social worker, who was Mr H's care co-ordinator, acknowledged these risks but had to weigh these against:

- Mr H's capacity to understand the risks, when these were clearly explained to him, and his wishes to return home.
- a need for the family to be reunited, to avoid further emotional trauma to the children, who had barely had time to grieve for the loss of their mother.

The social worker was prepared to support Mr H in his wishes, but fully acknowledged the very real concerns of his health colleagues. He negotiated with his health colleagues a temporary solution that everyone could agree – to test out the identified risks. This would enable Mr H to exercise his choice and rights, but monitor for any possible detrimental effects, so that no one else suffered unduly. Everyone in the team agreed to share the risks with Mr H, so that no one person made the decision on their own.

Outcome: Mr H did successfully return home with assistance from his extended family and a comprehensive care package. Many of the risks identified proved to be less problematic to manage than anticipated, and the type of care his daughters gave him was entirely appropriate.

Assessment

- 2.8** Local authorities are under a statutory duty within the NHS Community Care Act 1990 to carry out an assessment of need, to determine an individual's eligibility for services.⁶ People who are potentially ineligible for services but who would have to fund them themselves, are still entitled to an assessment of their needs.
- 2.9** Fair Access to Care Services (FACS) poses the question, 'What is the risk to loss of independence or greater loss of independence if nothing is done?' Three of the four assessment domains in FACS are particularly important in this context: health and safety, autonomy, and involvement in family and wider community life (including leisure, hobbies, unpaid and paid work, learning and volunteering). FACS also requires local authorities to assess risk to the carer.⁷ Whilst a person has the right to make choices and be supported to manage any risks, if they are asking their local authority to provide help to do this, this will in practice be done within the local threshold for eligibility and available resources.
- 2.10** For people who are eligible for services, a risk assessment will generally be necessary to establish relevant issues, which may range from risk of accidental harm to risk of self-harm or of abuse, or in a small number of cases risk to others. This could give rise to a conflict between the risks identified in the risk assessment and the steps the individual wants to take to ensure that his or her autonomy is not unnecessarily compromised and to enable active engagement in the wider life of the community. We encourage the use of the supported decision tool at Annex A to address such issues (see para 2.18).

6. Section 47 NHS and Community Care Act 1990 and Fair Access to Care Services

7. For advice, see SCIE's Practice guide 5: Implementing the Carers (Equal Opportunities) Act 2004 at www.scie.org.uk/publications/practiceguides/carersguidance/index.asp

It is important that good quality information is recorded which includes the type of risk, its specific nature and context and any actions to be taken to manage the risk.

- 2.11** Health professionals also have important assessment, care planning and management responsibilities. NHS services must carry out a continuing health care assessment to decide whether an individual's care needs are primarily health care needs and outside the legal scope of social services provision.⁸ Often health professionals' input will be needed to ensure that a community care assessment is comprehensive and its conclusions sustainable.⁹ They too have a responsibility to ensure that, wherever possible, the choices made by the individual are respected and supported.

Personalisation and care planning

- 2.12** Personalisation means that systems and those working within them treat each person as an individual; choice and control are critical elements in moving towards more personalisation in health and social care. For some time now, direct payments have been one way of people exercising more choice and control, and individual budgets will go further in encouraging people to find solutions that best support their assessed needs, rather than fitting them into existing models of service. In Control¹⁰ has piloted self-directed support, supporting people to design the support they need themselves, with help and advice. But choice and control should also be available to people receiving directly managed services and one way we can achieve this is by supporting individuals to make their own choices about how they wish to get on with their lives.
- 2.13** When a local authority is assessing a person's needs, it must consult them and, if appropriate, their carer. It must also take all reasonable steps to reach agreement with them in relation to the services it is considering providing to them to meet their needs.¹¹ In working out what support or services are needed, the individual's wishes and needs are central to the planning process. Person-centred planning is an approach which helps identify what is important to a person from his or her own perspective, and identifies personalised solutions. We commend person-centred planning approaches for everyone.

8. Delayed Discharges (Continuing Care) Directions 2004 and Continuing Care (NHS Responsibilities) Directions 2004

9. Section 82 NHS Act 2006 imposes a general duty of co-operation between NHS bodies and local authorities 'in order to secure and advance the health and welfare of the people of England and Wales'

10. For more information, see the In Control website at <http://www.in-control.org.uk/how/index.php>

11. Community Care Assessment Directions 2004

2.14 Some features of person centred planning:

- it enables social inclusion
- it is a process owned and controlled by the person (and sometimes their closest family and friends)
- through flexible plans it builds on the strengths of the person and supports them in finding their own solutions

2.15 This approach, however, needs to be realistic and proportionate:

- work alongside the person to encourage them to use their strengths and resources
- consider with them how their outcomes can be achieved and what risks may be involved
- small things can make a huge difference to people's well-being
- a person's wishes should not necessarily be over-ruled by someone who thinks they are making an unwise decision
- risks need to be shared – no one person should take full responsibility
- the local authority is ultimately accountable for public funds and is entitled to set limits. Social care will play a part in meeting people's needs, but it is not designed to meet all their aspirations

2.16 During 2007, the Department of Health will be publishing guidance on person centred and integrated care planning for health and social care, which will provide more detail on how to put into practice the person-centred approach.

Recording discussions about choice and risk

2.17 We have said that people should as far as possible be able to choose the support they receive and be helped to manage any risks involved in promoting their best outcomes. But the reality is that, if something goes wrong, some of them will not want to accept responsibility. In addressing issues of risk, therefore, it is impossible to over-emphasise the importance of keeping accurate records of discussions that take place about areas of choice. Such documentation will be critical in order to protect the person in making their choices, as well as the position of the local authority or private provider of care in the event of any complaints or litigation, and will encourage an open discussion with the individual about the consequences of particular choices.

Example of the importance of keeping good documentation

Mr T, 78, lives alone in his own home. He has prostate cancer, is mobile, alert and fully orientated, but is not motivated to get up and remains in bed most days. He is determined to remain at home and has refused offers of support from the Macmillan nursing team. He has missed several urology outpatient appointments, and has been refusing the district nurses access to give medication. His telephone has been disconnected because he has not paid the bill, and his doorbell does not work.

He will not accept help from his niece, his only relative, who is very concerned about him and has contacted social services for help.

Mr T has every right to remain at home. Attempts need to be made to develop a rapport with him using his niece, GP and any friends as intermediaries. Income maximisation and assistive technology could support him to remain at home if he would agree to them. Support for his niece and, if appropriate, a carer's assessment, would also be advisable. Sharing the risk decision making with him and all concerned will ensure that no one person is managing it alone.

Outcome: Mr T's wishes are respected, but there is clear documentation of his assessment, including a risk assessment, and a record of all attempts to engage Mr T to ensure that he fully understands the risks he runs in refusing assistance; these will provide evidence that the right procedures have been followed, should anything go wrong.

A supported decision tool

- 2.18 Some choices may be crucial to the person's quality of life, well-being and sense of 'being in control' – for example an older person entering a care home might want to continue doing what they have always done, such as going for a walk every day; or a person with a learning disability might want to go to college or to find a job.
- 2.19 A practical tool (at Annex A) has been developed to help focus on the outcomes the person wishes to achieve. It is designed to guide and record the 'conversation' about choice and risk. There may be areas of disagreement between people, their family carers and practitioners, needing negotiation and support. We commend the use of this tool as a means of providing documentary evidence for everyone concerned.
- 2.20 The tool is for use in conjunction with existing needs assessment and care planning processes – it will be particularly helpful to a person with complex needs or if someone wants to undertake activities that appear particularly risky. The person can be properly supported to complete it for themselves, as far as possible. Attention needs to be given to the support needs of those with special language and sensory

needs. It can be used equally in health and social care contexts, and it has potential application for any organisation or individual providing advice and support services to people who are self-funders and ineligible for support from their local councils.

Resources

- 2.21** Questions of resources will inevitably raise significant issues in supporting choice. This is not only about financial resources; the workforce and how stable it is, available housing stock, access to transport, employment, education and training opportunities and leisure facilities will all have an impact. The challenge for services is to find creative solutions, making the best use of all the available resources.
- 2.22** Professionals need to ensure that resource pressures do not lead to placing individuals at risk. In practice there may be a thin line between enabling someone to live their chosen lifestyle that involves a degree of managed risk taking, and placing them at risk through the under-provision of services. Careful care planning and allocation of appropriate resources to meet assessed needs is an essential part of risk management. Ultimately, the funding body has the final sanction on what it is appropriate to resource, and this is for local decision. Some of the decisions may be tough ones – for example, it may become unsustainable to support a person at home; a move into residential care may be necessary.
- 2.23** The most important resource is time spent with the person to develop a good support plan. Good, clear information to help people make informed choices, with the use of appropriate interpretation and advocacy services for those with language or sensory needs, will ensure the best possible outcomes.

Risk and the law

- 2.24** Fear of breaching the law can understandably influence how far it seems reasonable to support a person in managing risk. However, there are some basic principles to bear in mind, which we go on to discuss:
- Our legal system is concerned with concepts of negligence, abuse and foreseeability of harm
 - Informed choice includes the option to choose ‘unwisely’
 - Decisions made on behalf of people who lack capacity must be made in their best interests and with the least restriction
 - The human rights of people must underpin the actions and decisions of all public authorities

Duty of care

- 2.25** There is a fear that supporting people to take risks will expose health and social care providers and commissioners to compensation claims if things go wrong. Local authorities, health bodies, private care providers and individual care staff do all owe a duty of care to individuals for whom they provide services. A duty of care is an obligation placed on an individual requiring that they exercise a reasonable standard of care while doing something (or possibly omitting to do something) that could foreseeably harm others. For an action to succeed in negligence, there must be an identified duty of care. That means that organisations and individuals must maintain an appropriate standard of care in all the circumstances of their work and not be negligent. The likelihood of any proceedings being successful will only arise where a duty of care is breached through negligent acts or omissions and an individual suffers injury as a result. There is, of course, nothing to stop an individual bringing an action whether it is well founded or not.
- 2.26** An individual who has the mental capacity to make a decision, and chooses voluntarily to live with a level of risk, is entitled to do so. The law will treat that person as having consented to the risk and so there will be no breach of the duty of care by professionals or public authorities. However, the local authority remains accountable for the proper use of its public funds, and whilst the individual is entitled to live with a degree of risk, the local authority is not obliged to fund it. In very difficult cases, there will need to be a robust process whereby conflict about the acceptability of risk or otherwise can be properly debated and resolved (see para 3.5).
- 2.27** Providers and/or commissioners could, however, be exposed to litigation if they place people in a position of risk. There is an important distinction between putting people at risk and enabling them to choose to take reasonable risks.

Human rights

- 2.28** There is a duty¹² on all public authorities, and bodies carrying out functions of a public nature, not to act incompatibly with rights protected under the European Convention of Human Rights.¹³ This can extend to a positive duty to protect rights. This duty does not apply, however, to private bodies, such as private care homes, when they are not exercising functions of a public nature. When considering human rights, therefore, it is

12. Section 6 of the Human Rights Act 1998

13. The European Court of Human Rights (ECHR) also considers international human rights instruments apart from the ECHR, such as those of the United Nations. For example, in certain cases, the Court has attached considerable weight to the United Nations Convention on the Rights of the Child

important to establish that the organisation or establishment concerned is a public authority, or is exercising functions of a public nature. If in doubt, seek legal advice.

- 2.29** Article 8 concerns the right to respect for private and family life, home and correspondence. In the first example below, the High Court said that Article 8 was engaged to protect the sisters' right to participate in the life of the community and to have access to an appropriate range of recreational and cultural activities. However, just because Article 8 is engaged does not mean that a person has a right to a particular service or accommodation. The rights of the person is balanced against the rights of others (for example, in the case below of the sisters with their carers to be protected from physical injury) or the limited availability of public resources.

Example 1: balancing the rights of one group against another

The case of R (A&B and X&Y) v East Sussex County Council (2003):

The assessment of A&B, two young disabled people, identified that they liked and responded positively to swimming and to horse riding, but the application of manual handling regulations meant that they were unable to do either. The court decided that the rights of care staff to a safe working environment had to be balanced against the rights of A & B to undertake activities they enjoyed. This meant that the risks to the health and safety of the staff must be kept to a minimum that was consistent with A & B being enabled to exercise their human rights. Article 8 is not an absolute right, but any interference with it must be justified and proportionate. In the first place it was for the local authority to formulate its manual handling policy and to make the appropriate assessments. The Court therefore asked the local authority to complete this task – this was not something for the court to do.

Outcome: A & B exercised their human rights to undertake activities that support staff had felt were too risky to staff.

- 2.30** There is no human right to suitable accommodation outright, but in the example below the High Court found that, on the basis of the facts of this particular case, Article 8 was breached by a local authority.

Example 2: human rights

The case of R (Bernard) v Enfield LBC (2002):

Following a stroke, a severely disabled woman was restricted to an electric wheelchair. Her husband cared for her and they had six children. They applied to the local housing authority for a suitable property. The property which the claimants were occupying was unmodified for disabled use. The toilet was not accessible to the disabled woman, which led to frequent instances of incontinence. The couple were forced to live in the living room which was also occupied by two of the children. The High Court found that the local authority had acted unlawfully and incompatibly with Article 8 in failing for over 2 years to provide suitable accommodation. There was a breach of Article 8, since the local authorities' conduct condemned the Claimant to living conditions which made it virtually impossible to have any meaningful private or family life in the sense of Article 8.

Outcome: In this case, the local authority was obliged to provide the claimant with suitable accommodation.

Risk and the preservation of rights

2.31 A balance needs to be struck between risk and the preservation of rights, especially where the person has capacity, has weighed up the information and is aware of the consequences – it may be a risk they are willing to take for the sake of independence. There is an understandable desire from practitioners and carers for the person to be safe, but this may be at a cost to them in the only situation where they have any control. People of course do not lack capacity in the round, it is situation specific. And as with all citizens, their rights should only be compromised in those very rare cases where the law explicitly deems those ordinary rights to have been suspended (eg compulsory detention under Mental Health Act 1983).

Example: respecting a person's wishes

Pria is an Asian woman in her 50s, living with Huntingdon's disease and motor neurone disease. She is currently supported at home with her family by a package of health and social care.

Pria is finding it difficult to take adequate nutrition orally. Her doctor wants to insert a stomach tube to increase her nutritional intake and her family agrees. Pria is adamant that she does not want this fitted; it has been determined that she does not lack mental capacity, and that she fully understands the consequences of not having the treatment.

Outcome: Although Pria's family and doctor are concerned about Pria's choice, they respect her wishes even though they think she is making an unwise decision, and all agree to revisit the question on a regular basis.

2.32 However, there will be times when services need to intervene:

- When support is needed to maximise independence and to help to minimise risk
- To raise awareness of the risks to ensure everybody understands what the risks are and ensure they are making informed decisions
- When one person's choice places an unmanageable responsibility on another, to ensure others are protected, including children

2.33 Care homes are required¹⁴ to ensure that all parts of the home to which individuals have access are free from hazards to their safety so far as reasonably practicable. They must also ensure that they have identified and eliminated all unnecessary risks to the health or safety of individuals as far as possible. In care homes or group homes the rights of one individual may conflict with another. For example where bathrooms are shared the ability of a person to judge the temperature of bath water for themselves is key. The Health and Safety Executive (HSE) reports that, for a variety of reasons, bath water temperatures are not always checked and as a result numerous incidents of scalding, some fatal, have occurred over the past few years. This means that in accommodation where at least one individual is assessed as not able to judge a significant risk, such as hot water, then health and safety legislation requires a mixer valve to be fitted to the bath to 44°C. In these circumstances the risk is reduced for everyone, not just those who cannot judge the temperature for themselves. This is one example where the risk is too high and the benefit too low to reduce the precautions to suit individual needs.

14. Pursuant to the Care Homes Regulations 2001 which are made under the Care Standards Act 2000. There are also National Minimum Standards in place relating to care homes. The Regulations (S.I. 2001/3965) contain provisions relating to the health and welfare of service users

Health and safety

- 2.34** There is a legal duty placed on all employers to ensure, so far as is reasonably practicable, the health, safety, and welfare at work of all their employees. In addition, there is a duty¹⁵ to protect the health and safety of other people who might be affected by their undertaking,¹⁶ such as people who use services. The case of R (A&B and X&Y) quoted on page 23 illustrates well how fears of breaching health and safety legislation can prevent people from being supported to do certain activities. This may be due to concerns about the individual's health and safety, or be related to fears that the support worker or another third party will be harmed, with the threat of claims of negligence, or prosecution, over the horizon.
- 2.35** HSE endorses a sensible approach to risk,¹⁷ which seeks to address these concerns. Health and safety legislation should not block reasonable activity. Through the care planning process risk assessments are undertaken which should also fulfil the requirement under health and safety legislation, providing the risk to both the person using the service and their family carer are considered as described below.
- 2.36** HSE believes risk management is about taking practical steps to protect people from real harm and suffering, not about bureaucratic back covering or hiding behind the legislation when a difficult decision has to be made. HSE recommends five simple steps to risk assessment:
1. Identify the hazards
 2. Decide who might be harmed and how
 3. Evaluate the risks and decide on precautions
 4. Record your findings and act upon them
 5. Review your assessment and update if necessary
- 2.37** These provide a framework to achieving the delicate balance between managing risks posed to the carer's own well-being against the pressures of their caring role and the needs and rights of the person using care services.
- 2.38** The simpler the process and practice of risk assessment, the more effective it can be. However, the greater the risk, the higher level of authority should be required to sanction the activity. This approach should support front line workers through

15. Health and Safety at Work etc Act 1974, Section 2

16. Health and Safety at work etc Act 1974, Section 3

17. For the HSE's principles of sensible risk management, see <http://www.hse.gov.uk/risk/principles.htm>

sharing responsibility and not leaving them exposed to managing high levels of risk without the authority to manage those risks effectively. Staff at all levels should be engaged in this process.

Mental capacity

2.39 The Mental Capacity Act 2005 sets out, among other things, what must be done when someone is not considered able to make a particular decision or decisions for themselves. Enshrined in the Mental Capacity Act is the principle that people must be assumed to have capacity unless it is established that they do not. Capacity in this sense means that they are able to make decisions for themselves. Even if they only have capacity to make some decisions but not others, or if their lack of capacity is temporary, they may still be able to make some clear choices and decisions. The Act explicitly acknowledges that people with capacity may make what some people would consider to be ‘unwise decisions’, but that does not mean that they do not have the capacity to make those decisions, even if practitioners and carers’ views are at odds with them. Among other things, the Act gives a new role to advocacy with the setting up of a statutory Independent Mental Capacity Advocate (IMCA) service which, in specified circumstances, will support and represent people who have nobody else to speak for them when certain types of decisions are being made.

2.40 The following are derived from the Act:

- Always assume a person has capacity unless established otherwise
- Do not treat people as incapable of making a decision unless you have tried all you can to help them
- Do not treat someone as incapable of making a decision because their decision may seem unwise
- Do things or take decisions for people without capacity in their best interests
- Before doing something to someone or making a decision on their behalf, consider whether you could achieve the outcome in a less restrictive way

2.41 For the purposes of the Act, a person lacks capacity in relation to a particular matter if he or she is unable to make a decision for him or herself in relation to the matter. This would be because of an impairment of, or a disturbance in the functioning of, the mind or brain. This means that he or she is unable to understand or retain the information relevant to the specific decision, or use it to weigh the information or communicate their decision.

- 2.42** People with capacity to make their own decisions may make unwise decisions. In assessing capacity under the Act, services must ensure that the person has all the appropriate information in a suitable form and as much support as possible to help him or her make the decision themselves. The Act sets out clearly what must be done if someone considers that a person is unable to make a decision for themselves and must be followed by professionals and carers. Anyone who is paid to provide care to someone who may lack capacity, must also have regard to the Code of Practice. If the local authority is providing the service it can, however, refuse to fund something that it deems to be inappropriate in terms of meeting the person's needs.
- 2.43** Where someone lacks the mental capacity to make a decision about a course of action, including one involving any level of risk, they will not be able to give consent. In these circumstances, any decision or action must be made on the basis of what is in the person's best interests, following the requirements in the Act. In some circumstances, the Court of Protection may need to be involved in certain decisions and as a last resort where agreements cannot be reached through other dispute resolution or mediation processes.
- 2.44** Further advice on implementing the Mental Capacity Act is available in *Making Decisions*,¹⁸ the guidance booklet for people who work in health and social care, and in the Code of Practice itself.¹⁹ Certain people²⁰ are under a duty to 'have regard' to the Code, and the possible consequences of not doing so.²¹
- 2.45** The Act received Royal Assent in April 2005 and is due to be fully implemented by October 2007. Some parts of the Act were implemented in April 2007 and others later in the year.

Mental health

- 2.46** Just as for everyone else, it is important to take a positive approach to risk with people who have mental health problems. The same good principles apply, yet the impact of mental illness can add complexity to the risk management process. For example, it is important to recognise that people's needs may fluctuate and therefore it is important

18. *Making Decisions: A guide for people who work in health and social care*, Mental Capacity Implementation Programme, 2006. Available online at: www.dca.gov.uk/legal-policy/mental-capacity

19. See http://www.opsi.gov.uk/acts/en2005/ukpgaen_20050009_en_cop.pdf

20. See s.42(4) of the Act

21. See s.42(5) of the Act

to review and monitor risk agreements regularly. The engagement of the individual and their family carer in this is crucial.

2.47 The Department of Health has commissioned a programme of work to help improve the assessment and management of clinical risk in secondary mental health services. The National Risk Management Programme²² sets out to find a balance between positive approaches to risk-taking among users of services, and safety to self and others. A review of the Care Programme Approach is also considering how positive risk assessment and management can be better integrated into care assessment, planning and review processes.

2.48 *Our Choices in Mental Health*²³ provides a best practice framework for providers to extend choices and practical support for people who use mental health services and their carers. The values underpinning the framework are:

- living a normal life as far as possible
- being included in local communities and activities
- not being stigmatised or discriminated against on any grounds
- easy access to up-to-date and accurate information
- genuine options and/or choices of care available locally
- personalised care plans that are built around the wishes of each individual and their carer
- services and staff that promote and enable recovery and well-being

These values are entirely consistent with the principles we have set out for all adults in Section One of this document.

Risk and dementia

2.49 Many people with dementia are supported to live at home by family, friends and paid carers. Like everyone else, their choices and wishes must be respected, whilst appropriate safeguards are put in place to ensure risks are minimised as far as possible. The complexity of supporting someone with dementia cannot be underestimated. Practitioners and family members may have considerable concerns about their safety, but people with dementia may not need 24-hour support immediately. Options need

22. For further information see <http://www.nimhe.csip.org.uk/our-work/national-risk-management-programme.html>

23. The document is available at <http://www.mhchoice.csip.org.uk/>

to be explored with family carers, and practitioners need to ensure that appropriate support is available. The use of assistive technology can greatly reduce risks.

Safeguarding

- 2.50** There is a delicate balance between empowerment and safeguarding, choice and risk. It is important for practitioners to consider when the need for protection would override the decision to promote choice and empowerment. People are not necessarily vulnerable per se – it is the barriers to putting into place proper procedures that cause vulnerability. Care planning therefore needs to ensure that an individual's safety is not put at risk through delays in providing services, and that a clear distinction is drawn between putting a person at risk and enabling them to manage risks appropriately.
- 2.51** The General Social Care Council's code of practice for social care workers²⁴ says that social workers must 'promote the independence of individuals while protecting them as far as possible from danger or harm'. Similarly, the Nursing and Midwifery Council code of professional conduct²⁵ says that, in caring for patients and clients, they must 'respect the patient or client as an individual' and 'act to identify and minimise risk to patients and clients'. The Health Professions Council expects the allied health professionals it regulates to be 'personally responsible for making sure that you promote and protect the best interests of the people you care for'.²⁶ While supporting choice, however, it can be difficult for practitioners to stand back and watch someone take a risky path. That is why it is important to engage in proper discussion with the individual, be sure they understand the consequences of the action, and document it.
- 2.52** Registration of groups in the workforce and employers' use of CRB checks go some considerable way to ensure that appropriate staff are employed within social care. A further move²⁷ will be that from 2008, direct payment recipients and others buying their own support will be able to check those who will be working with them. Individuals will retain the choice about whether or not to make a check, but a new duty will be placed on local councils to inform direct payments recipients of their right to engage with the new scheme. This will allow direct payment recipients the opportunity to decide how they vet the people that they employ, but ensure they are making an informed choice.

24. *Code of Practice for Social Care Workers*, General Social Care Council, 2002

25. *The NMC code of professional conduct: standards for conduct, performance and ethics*, Nursing and Midwifery Council, 2004

26. *Standards of conduct performance & ethics*, Health Professions Council, 2003

27. Under the Safeguarding Vulnerable Groups Act 2006

2.53 However, much abuse that occurs is opportunist, and can be avoided by users of direct payments by following basic, common-sense practices such as checking a person's references or a gap in their employment.

2.54 Good practice:

- considers the consequences of an action
- considers the likelihood of harm occurring
- supports the person to look at all options, even if they would differ from one's own choices
- supports the person to take any action to protect themselves (for example, employing someone who is subject to a code of practice)
- ensures that any other people involved are protected
- ensures procedures for safeguarding are implemented if there is a need for protection
- ensures that the person knows how to report incidents promptly
- liaises regularly with safeguarding bodies and has a good knowledge of their policies
- ensures clear accountability for actions
- clearly documents all options that have been considered

Example of achieving a balance between supporting choice and safeguarding

Maria, 32, has a well-paid job, and lives on and off with her mother. She has a mental health problem, with a history of male partners who exploit her financially when she is unwell. When well, she maintains her job and ceases contact with such partners. In the past, she has given them significant amounts of money, and she is currently involved with a man who has exploited her financially and holds some of her possessions.

At a Safeguarding Adults case conference Maria is supported to look at all the options and agree a protection plan which does not compromise her choices to live independently. Maria chooses to discontinue the relationship and asks for help from the police to regain her possessions. Had she continued her relationship with her boyfriend, good practice would be to continue to offer her support even though her decision might seem unwise. The emphasis would be on how she could be safeguarded from further exploitation and practical support such as financial safeguards, if she agrees.

Maria's protection plan supports her to live alone, provides financial safeguards during periods when she will be unwell, and assists her to return to work.

Outcome: Maria has agreed a protection plan and her choices have not been compromised.

Carers

- 2.55** Carers are vital to people living successfully in the community, though there may sometimes be understandable tensions for the carer in relation to their own needs and the interests of the person they care for. One person's needs, however, ought not be given greater priority over another's, and the choices that each wish to make need to be considered and acknowledged.
- 2.56** Services must offer support to carers (including a carer's assessment), if they agree to it,²⁸ and look for creative solutions with them. Carers concerns and their experiences of services will influence their perspective. When there is a child in the household consideration needs to be given to whether the child is a young carer and appropriate referrals made for support. Where the individual is a disabled parent, services provided need to support them in their parenting role, so that the risk of undermining them as parents can be avoided.²⁹
- 2.57** Where people's choices conflict with those that carers or family members might have made on their behalf, it is important to balance both sets of needs and ideally find a resolution acceptable to all parties. It may be helpful for someone (perhaps someone from an appropriate voluntary association or another practitioner) to act as an independent mediator. Another option is for the carers assessment and support to be offered by a different practitioner in order to avoid a conflict of interest. This

28. The Carers (recognition and services) Act 1995 placed an obligation on the local authority to assess the needs of the carer

29. See SCIE's knowledge review, *Supporting Disabled Parents and Parents with Additional Support Needs* at <http://www.scie.org.uk/publications/details.asp?pubID=107>

may be particularly advisable when one person is better than another at articulating their views.

- 2.58** The challenge for services is how to support the interests of the individual and ensure that family carers are involved in decision making, are supported and valued, and that their issues and concerns are heard. This involves a complex set of negotiations on the individual's behalf – the family carer needs to feel confident that the service being suggested or provided is consistent and of sufficient quality to minimise risks and keep their family member as safe as possible, and not result in carers having to provide a greater level of care than they are willing or able to do.

Summary of good practice in relation to carers and the decision-making process

Carers need good information on the services available, help from voluntary agencies, and peer support for both themselves and the individual.

All family members should make their own decisions. But since all decisions will impact on the family as a whole, it may help to have a facilitated discussion.

In complex cases, support may be needed from many different quarters through multi-agency working. One person may not be able to deal with this alone. Achieving a positive outcome for one individual should not be at the expense of another.

There should be shared decision-making processes.

A good carer's assessment and support plan will benefit everyone.

Ensure consideration is given to children who may be young carers.

If a conflict arises between family members, independent mediation may help.

Transition from child to adult

- 2.59** Transition is the process which addresses medical, psychosocial and vocational needs of young people as they move to adult centred services. Many disabled children will need varying levels of support to manage a successful transition to adult life. Children with a wide range of impairments and needs will need good joint working practices between children's and adult services to ensure that their needs are fully met and that those who need community care assessments and care planning are not lost to the system or put at unnecessary and avoidable risk.

2.60 Good practice in transition planning³⁰ begins at least by the age of 14 and in some situations there may be very good reasons for adult services to start working with the young person and their family well before the age of 18 to ensure there is consistency and trust built into the relationships. The approach will need to be based on choice and available resources, and ensure the needs of the young person are at the forefront of any support planning. In some cases it will be vital that the children's worker is also involved after the person reaches 18. It may also be necessary for the court of protection to be involved from age 16, to ensure that protection extends beyond the age of 18.

2.61 Good practice includes:

- having policies and procedures which support effective transition processes
- shifting the general view of risk as a potential danger for a child, to one of potential opportunity for an adult
- managing risks as a phased process with awareness of psychological and emotional issues
- managing family expectations (being clear about the level of support and resource available)
- being particularly flexible about needs up to the age of 25
- taking time to get to know the young person and their family, especially if they have communication difficulties
- acknowledging the rights of adults to take more responsibility for their decisions

Example of risk issues in transition

Joanna, 17 years 10 months, has been living for 2 years in a specialist eating disorder unit 200 miles from home, where her condition has steadily improved. Her clinical team considers she is not yet ready to move into a more independent unit, but think she should be able to within a year. Joanna's family are very anxious that her placement continues, with a phased process into the more independent provision when the team thinks she is ready.

30. For guidance, see *Transition: getting it right for young people*, Department of Health 2006 and *National Service Framework for Children, Young People and Maternity Services Core Standard 4*, Department of Health 2004

Joanna herself, however, wants to discontinue all treatment and move in with her boyfriend who lives nearby. She has found a job in a local supermarket and intends to continue her A levels at night school. Her key worker is concerned that Joanna will leave without an appropriate support plan in place and without her parent's support for the choices she is making. The centre have no powers to keep Joanna against her wishes.

Joanna should have been referred to adult services well before her 18th birthday so that appropriate plans could be made to ensure her views about her future and those of her family carers were considered.

The adult worker meets Joanna, together with her care team and family and they discuss her choices as a young adult, and explore options for her future, including risk issues associated with her decisions. Joanna agrees to ongoing therapeutic support from the unit and weekly contact with her key worker. A crisis bed is available if she needs it, and Joanna receives a direct payment to cover the therapeutic support and accommodation costs. Although Joanna's family carers are still concerned about her, they feel reassured by the plan, and by the fact that she is making her own decisions and is taking control.

Outcome: Joanna has been supported in her wishes, and because she understands the concerns of others and the risks involved, she has agreed to a contingency plan which helps to mitigate the risks.

Assistive technology

2.62 Assistive technology (telecare and telehealth) brings new opportunities for people to receive practical support to remain independent, manage risks in their chosen environment, and give reassurance and support to family carers. Thus, it can have a significant impact on maintaining physical and mental health and emotional well-being. It does not replace human contact, but supports people outside the time that they have personal support.

2.63 Assistive technology can provide flexible and personalised services responsive to individual need, importantly preserving dignity. It is not only for use in a person's own home – it can also be used in care provided facilities.

2.64 Devices to support independent living and reduce the risks involved include:

- gas detectors with automatic shut off valve
- flood detectors
- temperature extremes detectors

- fall detectors
- bed leaving/chair leaving pressure mats
- bed leaving pressure mats linked to lighting
- door exit sensor devices
- epilepsy sensors

- 2.65** Telecare links devices to community alarm systems that send an alert to a control centre, with staff available 24/7 to determine the appropriate response.
- 2.66** Telehealth provides the means of monitoring a person's physical signs from their own home, such as blood pressure, temperature, pulse and rate of respiration, oxygen saturation and glucose monitoring. Data is transmitted to a response centre where a clinician will interpret the information and make the appropriate response. This means a timely contact with a nurse or a GP and treatment, which could prevent a situation deteriorating and avoid a hospital admission, without the person having to leave their home.
- 2.67** *Building Telecare in England*³¹ sets out a vision for the development of telecare services. An accompanying guide, the *Telecare Implementation Guide*,³² provides a resource for commissioners, managers and practitioners in a wide range of statutory and voluntary sector organisations to implement telecare for the benefit of people living in their local communities.
- 2.68** Extra Care Housing can provide a good alternative to residential or nursing care, and help people maintain a higher level of independence and well-being. People can live independently within their own home but with 24 hour support on site which might include the use of assistive technology. Evidence suggests that with higher expectations of this type of resource come more choices about taking everyday risks, resulting in increased activity, as any risks are managed within the home environment.

31. *Building Telecare in England*, Department of Health, July 2005

32. *Telecare Implementation Guide*, Care Services Improvement Partnership, July 2005

Embedding a common approach into corporate activity

Section summary

This section on developing a corporate approach to risk and decision making includes:

- how the corporate approach to risk that an organisation takes overwhelmingly influences the practices of the workforce
- how certain key people are critical to cultural change:
 - the DASS and executive members
 - members of Local authority Overview and Scrutiny Committees
- corporate culture can be changed by establishing a choice, empowerment and risk policy
- managing decisions on funding for care where more than one agency is involved or there is disagreement
- practitioners need support to work across systems, and multi-disciplinary arrangements need to ensure a common approach to risk:
 - through inter-agency agreements
 - through commissioning
- CSCI's inspection processes are being refocused onto outcomes for users of services rather than minimum standards
- registration of care services need not inhibit the services provided to individuals
- enabling people to exercise choice and control over their lives, and therefore the management of risk, is central to achieving better outcomes for people
- the role of the media and how to manage it
- fear of compensation claims can inhibit good practice towards supporting choice but steps can be taken to mitigate complaints avoid litigation

- 3.1** Front-line members of staff do not operate in isolation: whatever good practices they might wish to follow, they must still work according to corporate guidelines and systems, and we are told that in some cases the corporate approach works against

supporting people to assess fully the choices open to them and make informed decisions about their lifestyle. Section 2 has explored the issues for front-line staff and their managers, and has emphasised a focus on achieving positive outcomes for individuals according to any personal risks they are supported to take. A major inhibiting factor in achieving these good outcomes can be operating within a regime where there exists a fear of putting the organisation at risk, both financially, in terms of public relations, reputation or in breach of the law. The most effective organisations are those with good systems in place to support positive approaches rather than defensive ones.

The role of the Director of Adult Social Services (DASS)

- 3.2** The leadership role of the Director of Adult Social Services (DASS) in promoting health and well-being will be critical to focusing on positive outcomes for users of services. In working closely with the full range of providers of community services, including PCTs and other NHS organisations, the DASS could use this guidance as a means of raising the debate about risk and shifting the balance away from risk-aversion towards supported decision-making. They or their senior managers could also consider briefing key corporate leadership colleagues on this guidance, in areas to include legal services, health and safety and complaints.³³

The DASS has a role in promoting social inclusion and well-being with a view to developing sustainable services that promote independence and minimise the need for intensive homecare and residential care. They also have to ensure that services have arrangements in place, which include consideration of the needs of families.

Developing a learning culture

- 3.3** Practitioners tell us that too often they are blamed when things go wrong. There are many examples where the perceived risk of doing something and the fact that ‘it has never been tried before’ become barriers to people having opportunities to grow and develop. Coupled with this is the fear amongst practitioners that they will be blamed if things go wrong, as well as the fear of litigation. Many practitioners also fear bringing negative media attention to themselves and their organisations. Addressing the blame culture is crucial if attitudes to risk are to change.
- 3.4** There are several steps that organisations can take to change the culture surrounding the provision of services. Organisations could consider establishing a choice, empowerment and risk policy that promotes more open and transparent practices.

33. Guidance on the Statutory Chief Officer Post can be found at <http://www.dh.gov.uk/assetRoot/04/13/55/78/04135578.pdf>

It would need to be supported by senior leadership and shared across the organisation and their partners; with clear lines of accountability and support within the professional team, and the respective responsibilities of the council, the member of staff and the individual using services. This needs to be supported by appropriate working arrangements and systems.

Example of developing a learning culture

In Gateshead the council has a positive risk-taking policy for social care, which also applies to the its sports, leisure, libraries and arts services when they work with disabled adults and older people. By taking a person-centred approach to risk, the policy emphasises the full involvement of disabled and older people in decision-making and the need to support them to pursue their aspirations. The policy also sets out the council's expectations of staff. It recognises that any positive risk-taking approach must be balanced with the council's responsibilities to implement the Multi-agency Public Protection Arrangements or policy and practice arising from requirements in relation to safeguarding, care standards and health and safety. Leaders are committed to a positive risk-taking approach, a factor critical to its success. The council has also organised training for practitioners in the approach, using a specialist trainer, and believes this is important to the policy's implementation. Through its commissioning arrangements and Service Level Agreements the council aims to encourage agencies and services it contracts with to adopt a positive risk-taking approach, to ensure consistency.

For further information contact: StuartBracking@Gateshead.gov.uk.

Managing decisions on choice and the use of resources

- 3.5** The use of the supported decision tool at Annex A is encouraged as a means of guiding and documenting choices, decisions and risks. Each care plan needs to identify clear lines of accountability. Where there is a dispute between the individual and practitioner, or a question over the appropriate use of resources, conflict resolution mechanisms will be necessary, though the local authority, responsible for meeting assessed needs under community care legislation, will have the final say. Mechanisms could include referral to senior management or a decision making panel.

Example of managing risk and resources

In Oldham a risk enablement panel has been set up as part of the individual budget pilot to manage complex cases where risks are perceived as barriers to enabling the person to achieve their outcomes. It ensures that the proposed use of the individual budget plan will meet the identified needs of the person concerned.

The panel's membership consists of senior social care managers, (including Adult Protection) and health staff, who also hold budgetary responsibility and who are in a position to make timely decisions about resources to support people, as well as give advice on managing the complex issues.

The strength of this approach is that it is multi-disciplinary, enabling a holistic approach, which ensures that all possible options are explored and plans put in place with the appropriate resources – along with the individual budget – to reduce risks.

Anyone can attend the panel, and people using services are supported to meet two panel members if there are areas of disagreement to discuss further.

For further information contact:
beverley.maybury@oldham.gov.uk
karen.saville@oldham.gov.uk

The role of executive members

3.6 The Local Government White Paper *Strong and Prosperous Communities* placed a commitment on the Department of Health to legislate for Health and Wellbeing partnerships under the Local Strategic Partnership. To meet that commitment, the Local Government and Public Involvement in Health Bill will place a statutory duty on PCTs and Local Authorities to undertake joint strategic needs assessments. Statutory guidance will make clear that the findings of this joint needs assessment should feed into the Sustainable Community Strategy and therefore the Local Area Agreement. Undertaking a joint analysis of the population's needs, and how they can affect these, will enable them jointly to agree more effective long-term health and well-being priorities. This will be instrumental in implementing policies on the extension of choice in local services, including social care and supported housing. Executive members with responsibility for adult social services will play an important role in ensuring that best practice approaches to choice and risk are embedded in local policies and practices.

Overview and Scrutiny Committees

3.7 Local authority Overview and Scrutiny Committees also have a vital role in ensuring that their local NHS partners do all that is necessary to support people in their chosen environment for the wider well-being of the local population. *Strong and Prosperous Communities* announced that the scope of Overview and Scrutiny will be extended to include scrutiny of the response from both local authorities and PCTs to the reports of Directors of Public Health on improving the health of the local population. So local authorities will also be scrutinising the actions and decisions of their own or other local authorities' executive. Agreeing to adopt the principles for choice and risk set out in this guidance will ensure a consistent approach to supporting people to maintain their independence, and thereby promote health and well-being in the population.

Shared approaches between agencies

3.8 As part of their remit, the DASS will seek to ensure that decision making within multi-disciplinary arrangements are consistent, and that practitioners are supported to work across systems.

3.9 Agreements between agencies need to cover the following key areas:

- Clear procedures and protocols for joint working
- Clear roles and responsibilities
- A clear management structure for accountability
- A commitment to good quality supervision which includes professional development
- Agreed policies and procedures for delivering the service which everyone uses, including responses in crisis
- Agreed documentation for the needs assessment process, care planning, risk assessment/monitoring and review/recording
- Information sharing policies with partner agencies
- Timely process for resolving complex funding issues – panel with senior decision making/budget holder
- Processes for managing complex cases
- Processes for conflict resolution

Example of good joint working arrangements

In Warrington, the council with partners have developed joint policies for staff who work across health and social care systems in mental health in consultation with service users, carers and voluntary organisations, staff from Social Services and the 5 Boroughs Partnership Trust across the 5 boroughs.

It encourages staff to identify people's strengths and to take measured risks within a defensible risk assessment/care planning process to promote independence.

For more information contact:

r_millns@warrington.gov.uk or see www.5boroughspartnership.nhs.uk

- 3.10** Good communications and teamwork are important factors in effective inter-agency working. There can be differences of terminology between agencies, which hinder a common approach. Where possible, inter-agency agreements should include agreed definitions.

The West London Mental Health NHS Trust identified that differences in terminology between agencies were significant obstacles to finding a common way forward in inter-agency working. As part of the Mental Health National Risk Management Programme, pilots have been set up to develop an inter-agency framework, using the NHS's *Seven Steps to Patient Safety* as a basis, thereby to develop a shared learning culture. The aim is to agree a shared language and an inter-organisational safety framework for both health and social care that can be adopted nationally. The first pilot in Hounslow is led by PCT and social care director level managers, with a view to gaining sign up from police and the local prison. A draft inter-agency framework has been produced.

For further information contact:

Liz Fellow-Smith at elizabeth.fellowsmith@wlmht.nhs.uk

Commissioning and the provision of services

- 3.11** There are an increasing number of incentives now for commissioners and care providers to work together to create outcome based commissioning. If commissioners and providers have an explicit rather than an implicit approach to risk, together they can really empower people who use support services to have control over their daily lives. No one document can change the approach to risk, but we propose that the principles and values set out in Section One could act as a reference point for commissioners and providers to build a common approach to risk at a local level.

3.12 Where care providers experience difficulties in delivering outcome-focused care support, this guidance could play a vital role as part of any service specification where services are commissioned, by ensuring that monitoring processes are in place to measure how choice is being supported for each service, acting as a reference point to promote a common approach among all those involved. In order to do this successfully, commissioners and providers could together:

- agree the principles and values in Section One of this document, to avoid erroneous assumptions and differences of emphasis
- build local agreements around the approach to risk
- make the local agreements explicit for users of services

3.13 The *Commissioning Framework for Health and Well-being*³⁴ sets out a vision and practical proposals for the commissioning of health, care and well-being from 2008/09 that looks to strengthen local skills, capability and partnerships in 2007/08, to address local priorities. A large part of how this will be done is by offering people more choice over the services they want to access. This Framework and consultation process will support commissioners and providers to find the right balance between choice, risk and responsibilities for each person.

System management and regulation

3.14 The consultation document *The future regulation of health and adult social care in England*³⁵ set out the roles and functions for a new health and adult social care regulator announced in *Our health, our care, our say*. Increasingly, improvement will be driven by the choices made by service users and healthy competition between different service providers. The document describes how independent regulation will support these changes in future, within the context of cross-Government objectives to reduce the burden of regulation.

Regulation and inspection

3.15 From our consultation, we found a perception amongst some care providers that the Commission for Social Care Inspection's (CSCI) regulation sometimes inhibits a positive approach to choice and risk. These care providers said their discussions with CSCI inspectors tend to focus on health and safety, rather than the outcomes people want to achieve, and appropriate management of the risks.

34. Published for consultation on 6 March; see http://www.dh.gov.uk/en/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/DH_072604

35. *The future regulation of health and adult social care in England*, Department of Health, 2006

- 3.16 However, as part of the *Inspecting for Better Lives* programme, CSCI is now focusing regulation much more on the experiences of people using a service and are placing issues of risk firmly in the context of people being independent, having choices and exercising control. In future, evidence about how risk is managed by a care provider will be specifically related to the way they support people to achieve their desired outcomes and how appropriate health and safety management decisions contribute to this. CSCI addresses these issues in its report *Making Choices: taking risks*.³⁶
- 3.17 When a person's circumstances change or if they choose to change their support arrangements and need more specialised support, they may find that they are unable to remain with the care service they have chosen. It is sometimes said that the requirement to move is linked to the category of their service's registration with CSCI. But CSCI is flexible in its approach to registration categories and does not want them to be seen as a barrier to care providers developing innovative services to best meet people's changing needs. For example, there is nothing in CSCI's registration process to stop a person with dementia remaining in, and being cared for, in a non-specialist care home as long as that home can clearly demonstrate their ability to meet that person's developing dementia care needs. They might do this by training their own staff or by bringing in specialist support from outside the home. There is a tip-over point where the home might be delivering dementia specific care to such an extent that it has become regarded as specialist provision. At this point, it might be appropriate for them to apply for the dementia category to be added to their registration.
- 3.18 It is important that we do not try to make people fit registration categories in order for them to be accepted by or remain in services. People's needs are complex and varied and do not fit neatly into particular categories. Each registration category is not exclusive of others. A care service can be registered to provide care within a variety of categories. And categories can be varied as residents' needs change. It is up to services to demonstrate which care needs it can meet and how it will meet them.

Performance assessment

- 3.19 Outcomes for adult social care services were initially consulted on as part of *Independence, Well-being and Choice* and were a central component in *Our health, our care, our say*. This endorsed them as outcomes that social care services should be working on with their partners and confirmed that these would be built on to develop outcomes that apply both to the NHS and social care. *Strong and Prosperous Communities* also refers to future performance assessment for adult social care being mapped to the same seven outcomes.

36. *Making choices: taking risks*, Commission for Social Care Inspection, December 2006

3.20 CSCI consulted widely on the detailed development of an outcomes driven framework for performance assessment. It proposed using the seven health outcomes plus two additional performance measures, 'Leadership' and 'Commissioning and use of resources' as the basis for councils' performance assessment. There was broad agreement to this approach, which provides the opportunity to develop a range of new performance measures, which are outcome focused. Enabling people to exercise choice and control over their lives, and therefore the management of risk, is central to this approach. CSCI is working with the Healthcare Commission to develop further the framework to capture the appropriate, joint health and social care outcomes for performance assessment purposes from 2009 onwards.

Managing the media

3.21 The media are extremely influential in people's lives. However, it is important not to see the 'media' as a single entity, with a single purpose. The media are widely diverse, with thousands of varying elements with different functions and audiences. Each sees risk in a different way. For example, a national newspaper with a political or campaigning agenda covers risk in a different way to a local radio station. So, while it may be difficult to get straight reporting of a story in a national tabloid, it may be perfectly possible to do so through a television discussion programme. Overall, the media offer huge communication opportunities.

3.22 Every organisation will have a clearly defined procedure for media contact, and every member of staff needs to adhere to that process, to protect both themselves and their organisation. If there is a risk of negative coverage or a story appearing, the media contact needs to be briefed as early as possible so they can be prepared. All this argues strongly for a policy of working with the media, understanding its different parts, what its approach to risk is, and then developing good relationships, being as open and frank as possible.

The Institute of Public Relations Local Government Group runs a free crisis communications network for councils who need extra support during a media crisis.

For further information contact:
Theresa Knight at: Theresa.knight@derby.gov.uk.

IDeA provides a full list of tools and advice on managing the media. See its website at <http://www.idea-knowledge.gov.uk/idk/core/page.do?pageId=81771>

Insurance and compensation claims

- 3.23** In consulting on this guidance, we have been told that there is a genuine fear of the adverse consequences of empowering people to take risks; if things go wrong, not only will blame be directed at organisations or individuals, but this may lead to claims for compensation, resulting in higher insurance premiums. People talk about a ‘compensation culture’ in Britain today, whereby large numbers of people attempt to sue public and private bodies for damages after the American model. In its response to the Better Regulation Task Force’s report *Better Routes to Redress*,³⁷ the Government agreed that this compensation culture is in fact a myth – the number of small claims is actually decreasing. We know that between 2000 and 2005, the overall number of accident claims fell by over 5%.
- 3.24** There are mechanisms in local authorities and other organisations for people to make complaints about the care and services they receive. In most situations, sensitivity and an apology is what is required with reassurance that the occurrence will not be repeated. The system also provides opportunities for service improvement through investigative processes.
- 3.25** Large organisations such as local authorities generally have good, dynamic relations with their insurers and are well able to negotiate satisfactory insurance premiums. But smaller organisations such as small independent care providers or charities, can be less successful in this and can be extremely concerned about rising costs. A knock-on effect is that they can restrict staff and the people they support from undertaking certain activities for fear of incurring higher premiums. These smaller organisations in particular say that it is hard to find affordable insurance for some of their activities. And in their turn insurers cannot always offer low-cost insurance because administrative costs mean the minimum they can afford to charge seems disproportionately costly.
- 3.26** The cost of processing and settling compensation claims can be very time-consuming and costly for insurers and the insured alike. In response to recommendations in *Better Routes to Redress*, the Department for Constitutional Affairs has set up a working group of stakeholders, including insurers, to look at risk management and affordable insurance.

37. *Better Routes to Redress*, Better Regulation Commission, May 2004

A risk toolkit for the voluntary sector

Volunteering England has produced a toolkit on risk management for volunteers. It will be relevant for all settings where volunteers are engaged, including the public and private sectors. As well as addressing risk issues comprehensively, this very useful guide includes tips on how to keep insurance costs down and how to avoid compensation claims. It can be found at <http://www.volunteering.org.uk/Projects+and+initiatives/volunteeringandriskmanagement/Risk+Toolkit/>

Conclusion

This best practice guidance seeks to provide organisations and their workforces with a common approach to independence, choice and risk as the basis for working practice, through proper processes and agreements. This is consistent with the Government's broad approach to choice, and links in with a wide range of other current initiatives that are set out in Annex B.

Within a commonly agreed approach to choice and risk, there will always be scope for wide interpretation of the issues surrounding individual cases. For that reason, we have set out in Annex C some extra, more detailed, illustrative case studies based on real life case stories to assist practitioners and their organisations to develop their thinking. Comments on each case example suggest in broad terms how it might be appropriate to support people in their choices and tackle the issues that arise.

We have also referred in the footnotes to other initiatives and publications on choice which are relevant to the issues and which, on further reading, will contribute to the fuller picture within the broader context.

We very much want to encourage practitioners and organisations to embed this guidance into their policies, their agreements with other agencies, and their own cultures and working practices. In this way, we can help people to achieve their potential without their safety being compromised.

Annex A

A Supported Decision Tool

This tool is designed to guide and record the discussion when a person's choices involve an element of risk. It will be particularly helpful to a person with complex needs or if someone wants to undertake activities that appear particularly risky. It can be amended to suit different user groups.

It can be completed by the practitioner with the person or by the person themselves with any necessary support. It is important that, in discussing any risk issues, the person has as much information as possible (in an appropriate form) and fully appreciates and genuinely understands any consequences, to enable them to make their best decisions.

The tool could be adapted for use within existing needs assessment and care planning processes. It also has potential application for any organisation or individual providing advice and support services to people who are self-funders and ineligible for support from their local councils.

Using the tool

Practitioners need to:

- Ensure that the person has the right support to express their wishes and aspirations
- Assume capacity unless otherwise proven
- Consider the physical and mental health of the person and any specialist services they need or are already receiving

Issues for the practitioner to consider

When using the tool with the individual, consider carefully the following aspects of the person's life and wishes:

- dignity
- diversity, race and culture, gender, sexual orientation, age
- religious and spiritual needs
- personal strengths
- ability/willingness to be supported to self care
- opportunities to learn new skills
- support networks
- environment – can it be improved by means of specialist equipment or assistive technology?
- information needs
- communication needs – tool can be adapted (braille, photographs, simplified language)
- ability to identify own risks
- ability to find solutions
- least restrictive options
- social isolation, inclusion, exclusion
- quality of life outcomes and the risk to independence of 'not supporting choice'

Supported decision tool

1. What is important to you in your life?
2. What is working well?
3. What isn't working so well?
4. What could make it better?
5. What things are difficult for you?
6. Describe how they affect you living your life
7. What would make things better for you?
8. What is stopping you from doing what you want to do?
9. Do you think there are any risks ?
10. Could things be done in a different way, which might reduce the risks?
11. Would you do things differently?
12. Is the risk present wherever you live?
13. What do you need to do?
14. What do staff/organisation need to change?
15. What could family/carers do?
16. Who is important to you?
17. What do people important to you think?
18. Are there any differences of opinion between you and the people you said are important to you?
19. What would help to resolve this?
20. Who might be able to help?
21. What could we do (practitioner) to support you?

Agreed next steps – who will do what

How would you like your care plan to be changed to meet your outcomes?

Record of any disagreements between people involved

Date agreed to review how you are managing

Signature

Signature

Annex B

Key links to wider initiatives

Better information, better choices, better health is a strategy for improving access for all to the quality, general and personalised information people need and want, to exercise choices about their personal health and healthcare.

A common assessment framework will aim to deliver a structured approach to multi-disciplinary assessment and care management across health and social services. *Our health, our care, our say* made this commitment, building on experience to date from implementing the Care Programme Approach, the Single Assessment Process (SAP) for Older People and Person Centred Planning.

Dignity in Care is a Department of Health campaign to ensure all older people are treated with dignity when using health and social care services. An important aspect of treating people with the respect that they have a right to, is to support them in having as much control as possible over the way they live.

In Control is a partnership between families, individuals, services, local authorities, Government and many other organisations. All these people are working together to define best practice in self-directed support and change the system.

The Individual Budget Pilot Project is a cross government initiative led by the Department of Health working with the Department for Work and Pensions, the Office for Disability Issues and the Department for Communities and Local Government. The central idea behind the individual budget concept is to provide greater choice and control for people needing support and to place the person who is supported at the centre of the process. People will be enabled to design their own support with the knowledge of what finance is available, and to manage the funding to provide that support. The concept builds on the successful features of direct payments and on other initiatives to develop self-directed support.

Link-Age Plus is a programme in eight local authority areas in England to apply the Sure Start principles of independence, choice and prevention in a renewed effort to tackle poverty, social exclusion, disadvantage and deprivation facing some older people. Funded by the Department for Work and Pensions, Link-Age Plus aims to provide a single gateway to services provided in the community – ranging from housing matters, social care and financial benefits to transport, health and volunteering opportunities.

My Home Life is a programme of initiatives to improve the quality of life of older people in care homes, by creating support for practitioners and accessible tools and information resources for care-home managers, staff and commissioners which can be used in their daily work.

Our health, our care, our say, the Government's White Paper, sets out a vision to provide people with good quality social care and NHS services in the communities where they live. As part of the agenda to give people more independence, choice and control over their lifestyles, the White Paper announced that a national approach to risk in social care would be developed. It also said that by 2008 it would expect everyone with both long-term health and social care needs to have an integrated care plan if they want one. By 2010, it would expect everyone with a long-term condition to be offered a care plan.

Partnerships for Older People Projects are currently running to help shift funding away from hospital care towards earlier, targeted interventions.

The self-directed support network is a national network to support local authorities and their partners to move forward with self-directed support. It runs in partnership with our work on Individual Budgets, direct payments and In Control. It will also help those local authorities not involved in the Individual Budgets Pilot to explore ways in which they can expand choice and control through personalised support.

The Supporting People programme is a grant programme providing local housing-related support to services to help vulnerable people move into or stay independently in their homes.

Supporting People with Long Term Conditions to Self Care – a guide to developing local strategies and best practice provides a set of common core principles to self care and explains how health and social care services can support people with long term conditions to self care through an integrated package which includes information, self monitoring devices, self care skills education and training and self care support networks.

Strong and Prosperous Communities, the Local Government White Paper, aims to give local people and local communities more influence and power to improve their lives. It is about creating strong, prosperous communities and delivering better public services through a rebalancing of the relationship between central government, local government and local people. Key to this is a new approach to performance assessment based on outcomes for people rather than concentrating on processes.

Annex C

Issues and solutions: some illustrative cases (based on real life case stories)

1. A person declines support

Jane, 18, lives in a supported scheme for young people and has epilepsy. Staff are concerned as she has been refusing to take her epilepsy medication.

There are complex issues when a person who has capacity needs support but declines it. As long as Jane has capacity, staff cannot force her to take her medication. The only times anyone can be made to take treatment is either when they are detained in hospital under the Mental Health Act, or if they lack capacity a decision can potentially be made in their best interests.

If Jane lacked capacity and the treatment was in her best interests, she could be made to accept her epilepsy medication. However, the use of any restraint would be prohibited, unless it was necessary to prevent harm to Jane, and as long as it was proportionate to the likelihood and seriousness of the harm if she did not take her medication. If it was considered necessary, the restraint should be for the minimum time needed to give her the medication.

Staff would need to encourage Jane to take the medication, ensure she has all the information in an appropriate form, look at her fears and concerns and see if she is using it as a way of masking other issues she is having difficulty expressing. An appointment with her GP to help support this would be appropriate, assuming she agreed, along with suggesting she discuss the issue with other people such as her family, friends and relatives.

2. A person chooses to undertake risky activities

Mr L is physically disabled. He lives in sheltered housing and has support from care workers both to help him manage his home and to help him get up in the morning, bathe, prepare meals and go to bed. He goes out twice a week with a care assistant and enjoys playing bowls, but he would like to do something more active. Mr L has always wanted to ski and has heard about 'sitski', enabling disabled people to ski; he wants to try it.

There is a risk of injury if Mr L is supported to access sitski. If this risk is explained to Mr L and he understands and accepts the degree of risk and if he remains enthusiastic and makes it clear that he still wishes to go with his care worker perhaps to try out a

dry sky run, he should be supported to do so. Provided he makes an informed decision and his assessed needs are met in terms of support, he is consenting to the risk and no liability will arise if he injures himself in a skiing accident. His disability does not place him in a different position from a person without a disability who chooses to engage in extreme sports and suffers an injury as a result. If there is no negligence on the part of professionals, then the duty of care has not been breached.

3. Putting people into risky situations

Ms P has a learning disability. After leaving residential college, she returned to her parental home. Ms P wanted to live independently and her parents supported her wishes, subject to appropriate support being available to minimise her risk of exploitation and harm. Ms P now lives in a bed-sit. She is assessed as needing support on a daily basis to ensure that she does not become isolated and to help her develop strategies to reduce risk of exploitation and harm. Ms P's care plan includes a review in four weeks, as her parents are nervous about her exposure to risk and would like the situation monitored sooner rather than later. The review does not take place, despite requests from the family who express their concern that Ms P has become withdrawn and isolated and that the paid carer support has, in reality, been only intermittent. Ms P's mother subsequently discovers that her daughter has been befriended by a neighbour who, it transpires, has been sexually abusing her.

In this situation, the council risks litigation or an adverse finding by the Local Government Ombudsman. This is because they did not respond to the concerns expressed by Ms P's mother or carry out the timely review they had agreed to do. The council was alerted to the risk and did not act.

4. Complex cases giving rise to multiple risk

James, 23, has Aspergers syndrome. He lives in a supported housing scheme but isn't coping very well, refusing specialist support. He has had a few office jobs but has difficulty holding them down; on his payday, he tends to go on a drinking spree, often not returning home for a few days. He has been mugged and threatened on numerous occasions when he has been drinking.

James' parents think that he should be placed in a specialist residential service. They worry for his safety and his drinking binges, which have on occasions led him into trouble.

James wants to live independently and make his own decisions about how he lives his life, and refuses the idea of residential accommodation, he does not accept the diagnosis of Aspergers Syndrome.

There is a conflict between what James wants to do and what his parents think is in his best interests. He will not agree to meetings which involve his parents but is heavily reliant on them for support and they often pick up the pieces at the crisis points.

Managing a case with such complexity is not unusual in practice. The importance of ensuring James' wishes are respected and not overridden is crucial, however he needs to take responsibility for his decisions and work with services if he is to achieve his goals. Age appropriate specialist support for James to look at the things he wants to do would be a way to develop opportunities to build on his strengths and increase his confidence but ultimately only if he will agree. Arrangements would also need to be in place in case things go wrong, not leaving his family carers as the only fallback, and they would need a consistent and supportive approach and be involved as far as possible in helping him to achieve his goals. They would also need to respect his wishes about the specialist resource. They could be supported through independent specialist carer's services.

5. Supporting the individual while ensuring that the views of family members are represented

Simon, 19, is a fit, active young learning disabled man who enjoys being with others, and living with his extended family. Simon communicates verbally, and with good support is able to make his needs and future wishes known. Simon is starting to take more control of his life, particularly in making decisions about what he wants. Outside the home, Simon is able to make key decisions with staff who support him, but this is a challenge for Simon's family who are used to making decisions for him. Simon has expressed a strong desire to work towards living independently and has said that he would like to live with friends in a flat of their own. Simon has limited awareness of what it would mean to be independent, and he needs support to develop a wide range of skills – travel training, cooking and stranger danger etc. Simon's family have a number of concerns about how he would manage within a different environment. His mother has had difficult experiences with services, and she is reluctant to allow her son to be supported to live differently. Staff supporting Simon are confident that he can live independently with good support, but they are concerned that he will lose confidence and not be able to move forward without support from his family.

The challenge for services is how to support the interests of the individual and ensure that family carers are involved in decision making, are supported and valued. This involves a complex set of negotiations on the individual's behalf – the family carer needs to feel confident that the service being suggested or provided is consistent and of sufficient quality to minimise risks and keep their family member as safe as possible.

Good practice would be for Simon's community care assessment to be informed by person-centred planning with him, the views of his family carers, especially his mother, a risk assessment and an assessment of his mental capacity to make the important decisions under consideration here. A consistent practitioner, who would work out a careful plan with Simon, and his family, is highly desirable, ensuring there were manageable milestones and stages to work towards his goals with risks discussed and minimised.

The building of the relationship with Simon's extended family and in particular with his mother would be essential if his desired outcomes were to be realised. It would place Simon in a very stressful situation if his family were not involved. They would need to be convinced that he would be supported in a way which would give him the best chance of achieving his desired outcomes.

If Simon lacks the capacity to make a decision about where he should live, but is able nonetheless to express a preference, then his views need to be taken into account, as do those of his family members, particularly those currently caring for him. If there is a conflict between the family's views and those of Simon, or if there is no possibility of getting consensus within the family, the final decision must be made on the basis of Simon's best interests, bearing in mind all the factors set out in section 4 of the Mental Capacity Act 2005.

If there is still no resolution, his case may need to be referred to the court to make a best interests declaration. Currently the application would be made to the Family Division of the High Court. Once Part 2 of the MCA is implemented, by October 2007 the Court of Protection will become responsible for resolving best interests disputes.

6. Finding a positive solution to risk with the person and their family carer

Warren, 18, lives with his girlfriend, and has a very supportive family. He took an overdose of paracetamol after an argument with his girlfriend. Police found him nearby, and took him to hospital under Section 136 of the Mental Health Act. The assessing team, which included his GP, did not think it necessary to admit him for an assessment. A risk assessment was undertaken; though Warren had been diagnosed with ADHD (attention deficit hyperactivity disorder) in the past, he had no previous mental health history, and he agreed to accept treatment from his GP. The following day, there was an argument between his girlfriend and a neighbour. Police were called; Warren became agitated and jumped out of the first floor window. Police caught up with him and took him to hospital, again under Section 136. From the assessment that followed, it was discovered that Warren's close friend had recently died of cancer and he was still coming to terms with this. He had become agitated because the police

were there; his family confirmed that he often uses the window to leave the house (he works as a roofer) and therefore this was not seen as a high-risk situation in itself.

Consideration was given to admitting him under Section 2 of the Mental Health Act for an assessment but Warren was very much against it, saying that he would not be able to remain 'cooped up' in one place. Warren's parents agreed that he would not be able to remain in one place without force and were happy to support him at home.

At first there seemed to be significant risk issues, but the team had to weigh up the risks to Warren from being admitted to hospital against his will. They also had to consider the impact of his ADHD, the risk of compulsory treatment, and the likelihood that he would not benefit from care.

Following careful discussion with Warren and his family to gain an understanding of the current situation and the context, they agreed it was in Warren's best interests to go home with support; that the risks for him being detained against his will far outweighed any risks to him returning home. They recommended that he have psychological support, to help him work through the loss of his friend. The fact that Warren was willing to go home with support from his parents and his GP, and accept further help from the team as required, meant that the risks were reduced and managed and the plan had a good chance of succeeding. The team worked closely together to achieve the most positive outcome for Warren.

7. Using Assistive Technology to Minimise Risk

Mr E, 81, has dementia. He is living at home supported by his wife. At night, Mrs E sleeps separately, as her husband frequently gets in and out of bed to look out of the window and check if it is day or night. He is prone to falling and therefore causes her great concern. Both Mr E and his wife want him to continue to live at home, with her supporting him. Neither wants strangers in the house to help. However, if the situation continues, Mrs E's health will deteriorate and she may not be able to continue to care for Mr E. This means he may need to move into residential care.

An assessment carried out by a psychologist established that Mr E's level of dementia and cognitive disability meant that he could still read, appreciate the pattern of letters and make sense of the words. The psychologist referred Mr E to an occupational therapist who completed a full assessment of his environment and his independent living needs, and was able to arrange for assistive technology to support him to remain independent. Mr E was provided with an electronic calendar which displays whether it is morning, afternoon, evening or night time. Now when Mr E wakes it is often enough for him to look at the clock and when it shows it is night he knows he should not get up and disturb his wife.

Mr E was also provided with a pressure mat with a portable linked doorbell facility. The pressure mat is placed by his bed and the doorbell peripheral is placed with Mrs E in her bedroom- when Mr E steps on it the doorbell sounds.

8. Using direct payments or individual budgets to support choice and manage risk of isolation

Rashide lives alone and has personal care needs that necessitate three carer visits each day. He has also been assessed as having needs around isolation, the risk of which could have a harmful effect on his well-being.

Before he was in receipt of direct payments, Rashide was provided with care from an approved agency. He was unable to choose who came to support him and when. This meant that at any one time he could have as many as six different people coming in to his home. Sometimes he was put to bed at 8pm well before he would have wished, because services were not able to respond to his individual choices. With a direct payment Rashide has been able to employ personal assistants who support him at the times he chooses and whom he feels comfortable with. Prior to him receiving an individual budget through a pilot site, Rashide used to attend a day service once a week. Although he liked the company of other people and the staff, he wouldn't have specifically chosen this as a means to address his social isolation. With an individual budget allocation, he is now able to use the money to attend a photography course with support from his PA. Not only does this mean he meets other people who share this interest, but Rashide is participating in community life and making new social networks. The risk of Rashide being isolated is no longer a concern.

9. Using the supported decision tool in the residential care sector

Grace, 90, lived until recently in her own home. After numerous falls and with failing eyesight, Grace decided with her daughters that it would be best for her to move into residential accommodation with 24-hour support. Grace has lived in the same area for the past 70 years, and it was important to her that she chose a care home nearby so that she could attend church and meet up with friends for lunch afterwards. When Grace went for an introductory visit, she was asked to describe what was important to her, and she told staff that although she had had falls, she still wanted to be able to go for a walk every day to the local park. She also said that she wanted to have a glass of sherry before dinner as she had been for years, because this enhanced her enjoyment of food. Grace also said she wanted to bake a cake occasionally, something she has been unable to do for years.

Whilst there were risks associated with Grace going for a walk each day, Grace and her daughters felt that this was an important part of her independence and well-

being, and they were willing to take responsibility for her having the assistance of a volunteer to accompany her during the week and family members at the weekends to reduce the risks. Grace agreed to be referred to a falls specialist, to ensure that all advice was incorporated into her daily routine. Her wishes for a glass of sherry before dinner were considered appropriate to her sense of enjoyment and well-being. With failing eyesight and falls, baking was considered a 'risky' activity, but it was agreed that this could be accommodated by setting up a weekly baking group among the residents with staff support. Her friend was happy to continue to take her to church and bring her home as before. These decisions and the reasons for them were all recorded in Grace's care plan.

The supported decision tool helped Grace to identify her choices and staff to provide creative thinking and solutions to enable her to continue to participate socially in her community and to remain in control of her life. In this way, Grace was supported to make choices and helped to manage the risks, enabling her to make a successful transition from home to residential care with dignity. Grace's daughters were impressed with the way her choices determined her care plan, and although they knew not all risks could be eliminated, these were managed effectively, and they felt that staff were supportive and took a proportionate approach, focusing on Grace's goals and quality of life as well as her safety.

Annex D

Glossary

Assistive technology	See Telecare and Telehealth.
Better Regulation Commission	An independent body which provides advice to government, from business and other external stakeholders, about new regulatory proposals and about the Government's overall regulatory performance.
Care Programme Approach	Arrangements between health authorities and social services departments for the care and treatment of people who have mental health problems in the community.
Commission for Social Care Inspection (CSCI)	The single independent inspectorate for all social care services in England.
Commissioning	The activities that local authorities and Primary Care Trusts undertake to make sure that services funded by them are used to meet the needs of individuals fairly, efficiently and effectively.
Direct payments	Payments given to individuals so that they can organise and pay for the social care services they need, rather than using the services offered by their local authority.
Director of Adult Social Services (DASS)	A statutory post in local government with responsibility for securing provision of social services to adults within the area.
Fair Access to Care Services (FACS)	Guidance issued by the Department of Health to local authorities about eligibility criteria for adult social care.
General Social Care Council (GSCC)	The social care workforce regulator. It registers social care workers and regulates their conduct, education and training.
Healthcare Commission	The independent inspectorate in England and Wales that promotes improvement in the quality of the NHS and independent health care.
In Control	A partnership of central and local government and the independent and voluntary sectors. It aims to put disabled people in control of their own lives through the power of self-directed support. This involves giving people control of a personalised budget.
Independence, Well-being and Choice	<i>Independence, Well-being and Choice: Our Vision for the Future of Social Care for Adults in England</i> is a Green Paper setting out the Government's proposals for the future direction of social care for adults of all ages in England.
Independent sector	An umbrella term for all non-statutory bodies delivering social and health care, including a wide range of private companies and voluntary organisations.
Individual budgets	Individual budgets bring together a variety of income streams from different agencies to provide a sum for an individual, who has control over the way it is spent to meet his or her care needs.

Local Area Agreement	A three-year agreement that sets out the priorities for a local area agreed between Central government, represented by the Government Office, and a local area, represented by local authorities and Local Strategic Partnerships and other key partners at local level. The primary objective is to deliver better outcomes for local people.
Local Strategic Partnership	A single non-statutory, multi-agency body, which matches local authority boundaries, and aims to bring together at a local level the different parts of the public, private, community and voluntary sectors.
Multi-agency Public Protection Arrangements	A framework for protecting the public from potentially dangerous offenders by means of individual agencies working together to draw up a risk management plan drawn up for the most serious offenders.
National Minimum Standards (NMS)	National Minimum Standards (NMS) are standards set by the Department of Health for a range of services, including care homes, domiciliary care agencies and adult placement schemes. The Commission for Social Care Inspection (CSCI) must consider the NMS in assessing social care providers' compliance with statutory regulations.
Our health, our care, our say	The <i>Our health, our care, our say</i> White Paper sets out a vision to provide people with good quality social care and NHS services in the communities where they live.
Partnerships for Older People Projects (POPPs)	A two-year programme of work led by the Department of Health for local authority-based partnerships to lead pilot projects to develop innovative ways to help older people avoid emergency hospital attendance and live independently longer. The overall aim is to improve the health, well-being and independence of older people.
Person-centred planning	Person-centred planning discovers and acts on what is important to a person from his or her own perspective and contributes to their full inclusion in society.
Self care	Individuals take responsibility for their own health and well-being. This includes: staying fit and healthy, both physically and mentally; taking action to prevent illness and accidents; and the better use of medicines and treatment of minor ailments.
Self-directed support	This means people co-design the support they need in their lives and have control over what that support is – often a key lever for this is giving them control over the funding for their support.
Social inclusion	Social inclusion is tackling social exclusion, which happens when people or places suffer from a series of problems such as unemployment, discrimination, poor skills, low incomes, poor housing, high crime, ill health and family breakdown.
Strong and Prosperous Communities	is the Local Government White Paper which aims to give local people and local communities more influence and power to improve their lives.

Telecare	A combination of equipment, monitoring and response that can help individuals to remain independent at home. It can include basic community alarm services able to respond in an emergency and provide regular contact by telephone as well as detectors which detect factors such as falls, fire or gas and trigger a warning to a response centre.
Telehealth	This provides means of monitoring a person's physical signs from their own home, such as blood pressure, temperature, pulse and rate of respiration, oxygen saturation and glucose monitoring.
Voluntary and community sector	An 'umbrella term' referring to registered charities as well as non-charitable non-profit organisations, associations, self-help groups and community groups, for public or community benefit.



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