Chance would be a fine thing

Reassessing risk in mental health

MindThink report 2
Participants

This report is based on a roundtable discussion held in March 2007. This report captures some key issues discussed at the seminar, and what Mind believes were some of the most interesting proposals for change. The views of participants varied and it should not be assumed that all individual participants would agree with all of its recommendations.

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Introduction

How do we balance consumer choice with adequate protection from exploitation? How do we weigh up the desire for personal autonomy against the duty of care and the need to manage risk in service provision? What would a principled approach to mental health policy – including the NHS Choices agenda, welfare reform, independent living and access to credit – look like?

On 6 March 2007, at the King’s Fund’s offices in London, Mind held a MindThink seminar to consider issues around our understanding of autonomy and risk in mental healthcare.

Discussion points and conclusions from the seminar are summarised in this report, which also suggests some ways forward for approaches to choice and risk in policy-making. The report is not exhaustive in its coverage of the issues and does not discuss the literature or evidence base. Its purpose is to provoke discussion, not pre-empt it; to inform and reconfigure debates on key issues, not to provide the final word.

Participants had different views on some issues. This report highlights the key ones and draws out conclusions on which there was some consensus. The recommendations are Mind’s own, developed from some of the most interesting proposals for change.

Unless otherwise stated, all quotes are from the transcripts of the seminar. Mind would like to thank all participants for their involvement and contributions.
“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... But avoiding risk altogether would constrain the choices people make.”
Department of Health (2007), Independence, choice and risk: a guide to best practice in supported decision-making

“Over-zealous efforts to eliminate risk, combined with low expectations of people’s potential, destroy freedom and autonomy and discriminate against people with mental health problems.”
Caroline Ellis, DRC

“Balancing autonomy and risk can only be achieved adequately by having a policy and legislative framework that ...engages the service user at all times in a shared endeavour. Creating the product of wellbeing demands the full participation of, and active control by, the service user.”
Christopher Heginbotham, University of Central Lancashire

“Policymaking in mental health reflects the attitude of service users as risky. Instead of allowing people with experience of the system to drive decision-making, there is a top-down approach where Ministers, civil servants, an unelected psychiatrist tsar and hospital boards are all in charge and service user-involvement is tokenistic.”
Tina Coldham, HASCAS

“There is nothing wrong with risk, so long as you know where it is, and you know how to manage it. Risk management requires a cool head and rational, evidence-based thinking. As a society, we don’t have a good record of managing risk. Instead of following the evidence, we follow our fears; we look for risk where we think it should be, where we think we can control it. So we locate risk in people with mental health problems and try to control them.”
Sophie Corlett, Mind

**Background and context**

The existence of the welfare state reflects society’s conviction that we have a duty of care towards citizens. Increasingly, however, the rhetoric of the market is creeping into health and social care services, through policies that champion personalisation, choice and autonomy. This could result in a significant shift in the balance of rights and responsibilities in our public services and raises some challenging questions for the mental health sector.

The personalisation agenda in the NHS has allowed patients to choose their hospital, provided them with extended GP surgery hours and increased rights to advocacy and advance decision-making. Mental health service users rightly demand not just flexibility in time and location, but a choice of treatment options and an alternative to pharmaceutical interventions.

In social care, direct payments and individual budgets are placing cash for care services – and the responsibility for spending it appropriately – in the hands of the individual. Likely outcomes could be the decline of local authority block-contracts for domiciliary care, meals on wheels and day centres, the creation of new markets for personal assistants and support brokers and, hopefully, more people living independent lives.

In an increasingly market-driven world – and one where the money for welfare is continually squeezed by economic conditions and an ageing, ailing population, financial capability (as well as spending power) can determine our life chances. This is because the decisions we make about spending can have profound implications for our wellbeing and opportunities, both now and in the future. It’s up to each of us to use credit wisely, save for old age, make shrewd decisions about which fuel suppliers offer the best deal and, for some, to spend our social care budget and perhaps employ our own carers through direct payments.
**Consumer, citizen or patient?**

Choice should empower service users. But giving people autonomy also gives them greater responsibility and the freedom to take risks.

It is interesting to compare the rights and responsibilities of individuals in financial markets (consumers) with those of individuals in the health and social care economy (patients).

At present, the mechanisms are underdeveloped in financial markets for managing the risks of unwise decisions, and providing support for consumers to make better decisions. Accountability rests with the spender rather than the lender – if we overspend, under-earn or get into debt, the right to credit, a bank account and other products and services can be forfeited.

Yet in mental health services, risk-management is big business. We start out from the principle that the State has a duty of care and that patients can have limited freedom to exercise choice and control over the way they live or the treatment they receive.

The concept of the ‘expert patient’ (a consumer, in other words) is gaining ground in the NHS. But the reality of compulsion in mental health services stalls progress. Can there ever be real choice in mental healthcare, when detention looms in the background as a threat for when things go wrong? And in social care, the mental health sector has been largely resistant to greater personalisation. In March 2007, just 3.5 per cent of all people receiving a direct payment were mental health service users.

Where does the balance lie between autonomy and risk? When should the State and the financial sector intervene, and when should they leave well alone?

**Capacity and risk-taking**

In the most recent survey of public attitudes to mental illness (2007), 44 per cent of those questioned felt that “a person who is mentally ill cannot be held responsible for their own actions.” Thirty-one per cent believed that “a person who is mentally ill is incapable of making simple decisions about life.” Such attitudes lead to a paternalistic system of care, aimed at heading off the risks posed by a person making poor decisions about their own welfare.

Mental health services are designed in such a way that too often they fail to encourage people to take control of their own wellbeing. Treatment decisions are often made without the involvement of the service user. Social care services may fail to address the diverse social, cultural and leisure interests of users, inadequate care can result in people being unwell for long periods and lead to long-term social exclusion.

There was widespread support for capacity-based solutions to this problem of risk management. Christopher Heginbotham and George Szmukler suggested it might be possible to abandon mental health legislation in favour of mental capacity legislation as a means of managing serious risk. Mental capacity-based approaches do not discriminate between people who lack capacity on the grounds of mental disorder and those who lack capacity for other reasons.

Caroline Ellis argued that a framework for positive risk-taking is enshrined in the Disabled Persons (Independent Living) Bill 2006, a Private Member’s Bill championed by the Disability Rights Commission. The Bill would introduce a capacity test into the Mental Health Act, similar to a capacity test favoured by Mind in proposed amendments to the 2006 Mental Health Bill. Where people retain the ability to make decisions for themselves, they would not be forced to take medication if they chose not to. Where capacity to make decisions is demonstrably impaired, refusal to take medication may be over-ruled in the best interest of the person concerned.

The Independent Living Bill also creates a legal framework for autonomy through enforceable rights to assessment, treatment, support and advocacy, driven by the individual rather than the authorities.
Re-conceptualising risk

A preoccupation with risk infuses our understanding of mental distress more than any other health condition. It has become a byword for a grossly exaggerated relationship between mental distress and violence, creating expectations of aggression where more often there is victimisation. In fact, research suggests that nearly 50 per cent of all violent crime may be associated with alcohol use, 18 per cent to drug misuse, and one per cent to mental illness. People experiencing mental distress are up to 14 times more likely to be a victim of violent crime than to be arrested for such a crime.

Participants agreed that it is the narrow interpretation of risk in public debate that can be so stigmatising, and prevent people with mental distress from having the same rights to determine the course of their lives. Risk is not just about the individual threats posed by one person to themselves or a wider public. There is risk in systems too; it is inherent in all of our services and policy decisions. Risk is part of the fabric of our lives. Risk is involved every time we buy a drink or take medicines or let our children out to play. Policy-makers, market traders, doctors and military leaders are all, in their different ways, involved in a continual balancing of risk and benefit.

There are perennial issues about how risk and autonomy are distributed. Minimising risk for one section of a community may result in unacceptable restrictions on the autonomy of others (for example, a total curfew on all young people to minimise the risk to older people from youth crime – or prohibition of alcohol). Potentially mental health policy could sanction huge restrictions on some people’s autonomy for negligible reductions in risk for others.

We can reclaim the idea of risk by re-focussing the debate on the risks that poor services and poor life chances pose to the half a million people living with severe and enduring mental health needs or the one in four of the population who will experience mental distress.

Policy decisions we as a society have made or supported have resulted in systemic failures in the delivery of services to people with mental health problems. They have led to serious obstacles to the rights and dignity of people experiencing mental distress.

“Without risk there is no autonomy.”

MindThink contributors suggested some of the consequences of failing to measure risk appropriately:

- Unmet need in primary care which leads to millions of people each year risking the loss of their jobs, their families and/or their health.
- Stigma which leads to victimisation and reluctance to seek help.
- Focus on acute care threatening to reduce the resource invested for preventative interventions, to stop people becoming unwell and losing control of their lives.
- Unsafe mental health wards, where abuse and fear are accepted or ignored.
- Inequalities in the mental health system, which mean that the colour of your skin, your gender, sexuality, culture, social class, age, religion or physical health, become important indicators of the likelihood of recovery, the kind of care you will receive, and the way your behaviour is interpreted.

We might make more equitable decisions by taking a wider view of risk. System-wide risk assessment asks: “What do we consider to be essential provision in mental health services, and on what can we afford to compromise? Where are the risks for service users? Who are the winners and losers when spending priorities are decided? How are equality issues addressed? How ethical is a particular policy?”
“There is a striking inconsistency in public debate about risk and mental health. There is excessive anxiety about any risks that might be posed by people experiencing mental distress. At the same time, the risks posed to service users by poor or inadequate service provision are completely off the radar. Risk is conceived almost entirely in micro/individual terms, and hardly at all in macro/systemic terms.

“The debate about the reform of mental health law provides a good example. The lobby made a great deal of the figure from the Cochrane review that said that you’d need to coercively treat 238 people to prevent one arrest. But there is a further point. A good proportion of those 238 people would be exposed to significant risk inside the mental health system – for example, from unsafe wards or poor prescribing. Indeed, mental health legislation driven by grossly exaggerated public safety concerns could itself significantly increase the degree of risk experienced by people in the system.

“Same with the debate about individual budgets – people may not always make the best use of their money, and there is a risk there – but isn’t the bigger question whether greater control of budgets for service users will drive up standards of provision of social care and reduce the serious risks people are exposed to by poor and unresponsive services?”

Marcus Roberts, Mind

“We have an inconsistent approach to how much we are prepared to spend to reduce risk. The UK spends £1.3m per tractor death prevented, through enhanced tractor safety. Compare this with mental health: no one is prepared to spend a similar sum on one person in mental health services, to eliminate one death. Yet because people with mental distress are marginalised and not valued, governments are prepared to lock up 100 service users to prevent one incident.”

Christopher Heginbotham, University of Central Lancashire

**Flexible and accessible services reduce risk**

Mental health and social care services allocate scarce resources according to highest risk. In social care, eligibility criteria are based on a needs assessment and increasingly only those with ‘substantial’ and ‘critical’ needs are eligible for care. In mental health, enhanced care plans, assertive outreach, intensive home treatment services and provisions in the new Mental Health Act such as community treatment orders all work on the principle of directing resources to acute care to reduce the risks posed by those with the most severe mental health problems.

Nevertheless, people fall through the cracks in service provision. A series of homicide inquiry reports have concluded that the perpetrators were failed by the system. It is becoming a familiar story: individuals in crisis were refused help when they asked for it, risk was poorly assessed or those with complex needs were lost between drug and mental health services. Frustration, fuelled by the inflexibility and failures of mental health services, can make people more risky by making them less likely to engage. In many cases where people with mental health problems do pose a risk to others, the source of that risk is not so much the individual as these wider systemic failures – in particular, inadequate investment in, and provision for, timely assessment and treatment.

George Szmukler noted that risk-assessment tools cannot be relied upon to give particularly accurate measurements of the behaviour of an individual. Research suggests that using existing risk-assessment tools, for every person identified correctly as someone who will go on to commit a violent act, a psychiatrist is likely to identify as potentially violent a further 5,000 people who will not. What’s more, the likelihood of assumptions and prejudice deciding where we allocate resources is greatly increased when we take a narrow approach to risk based on sizing up individuals on themselves and others.

Participants suggested that risk assessment at population level – or consideration of the ‘macro-risks’ – in conjunction with individual risk assessment, could increase the likelihood of achieving successful outcomes. It may be that the best risk-management strategy for acute mental
health services is also the best therapeutic and ethical approach: more investment in evidence-based services; timely assessments where people are becoming unwell; and appropriate services that are responsive to service user needs because they involve service users.

By raising standards of care for all rather than pinpointing the most needy, the whole population will benefit. By providing choice or diversity in service, more people will be served. Investment in joined-up provision that tackles alcohol and drug-dependence and social deprivation as well as mental health needs would lead to fewer people falling through the gaps between services.

Such an approach could be more efficient and more ethical. It could also be better equipped to catch the high-risk cases – by being flexible, responsive, resourced and resourceful.

Positive approaches to risk-taking

Participants felt it was possible to re-conceptualise risk, by highlighting where cautious decision-making feeds upon and exacerbates low expectations, and threatens the aspirations of people with mental distress to take full control of their future.

Service user contributors emphasised that risk-taking is a vital part of the process of moving on and living independently. How can we promote positive risk-taking and stamp out risk-averse, over-cautious service provision which holds people back?

Mental health is lagging behind other disability sectors in embracing such positive risk-taking. Direct payments – a way of empowering service users by giving them budgetary control and choice over the services they pay for and use – have low take-up amongst mental health service users.

Research highlights particular challenges in applying direct payments to mental health, not least that service providers are facing a larger cultural shift. Clinicians fear that it is too risky to allow people with mental health problems to manage money, that the nature of mental illness means that the likelihood of things going wrong or people making unwise decisions, is somehow greater than for people with other kinds of disability.

Participants around the table acknowledged that we all make unwise decisions all the time. We are all pretty bad at managing our money, for example, but that doesn’t mean we shouldn’t have the right to choose to blow our weekly earnings when we should be saving for a rainy day. Decisions made by people with mental health problems should not be judged by different standards.

The Mental Capacity Act 2005 has enshrined in law a principled approach to assessing a person’s ability to make choices for themselves, and when others may intervene in decision-making. Where a person is deemed to have ‘capacity’ to make a particular decision - be it how they spend their money, whether they...
“The greatest risk to people with mental health problems is not the risks they pose to themselves or others but the attitudes of other people which can blight lives and crush aspirations, lead to poverty, marginalisation and/or social exclusion.”
Caroline Ellis, DRC

“Without risk there is no autonomy. My psychiatrist worries that my plan to go to Hungary to study and take my support worker with me is a huge risk on so many levels. He’s probably right. But I can’t progress in my academic career without doing this. I’ve got contingency plans for if it all goes wrong. And I’m prepared to shoulder the responsibility.”
Mike Walker, Mind Trustee

The creeping nervousness about public protection and managing risk in service provision is incredibly frustrating. Over-cautious services are not what service users want. But people like us who have fought to keep our services positively risky are forced to be risk averse to maintain funding.”
Jackie Lewis, Doncaster Mind

“There is a fear that people with mental distress will blow their money on all manner of inappropriate things, and the State shouldn’t be using taxpayers money to fund that. But the individual budgets pilots show that when you give people choice and autonomy, their aspirations are – in societal terms – sensible and responsible, and modest... they see getting back to work, building social networks, improving family relationships as the best use of their money.”
Gill Stewart, Norfolk County Council

“People using services need greater autonomy. But this needs to go hand in hand with more public education about mental illness. If the public don’t understand what mental illness and independent living are about, a media backlash could result, with stories about people using taxpayers money to go online dating or get pizzas delivered. People should absolutely have the choice of these things rather than using traditional day services or meals on wheels, but public understanding also needs to increase exponentially.”
Jane Harris, Rethink

engage in chemotherapy or follow the GP’s advice to quit smoking and start exercising – that person’s decision is final. Crucially, the law enshrines the right for individuals who have capacity to make unwise, bizarre or inconsistent decisions, and makes clear that such decisions are not a measure of a person’s rationality.

More often than not, it is inexperience or a lack of accessible information that makes for poor decision-making. We could all use more training in managing credit, careful budgeting and being market savvy. In fact we depend on support in almost all decision-making, be it someone to bounce an idea off, talk things through with, provide us with advice or caution against a certain choice.

When a person with mental distress is given money to employ their own support worker or purchase their own care, the biggest dangers arise where they do not have the advice, support and guidance to do this safely and within the law. Care has never had a visible price tag before and we see our health as an entitlement that comes to us at no cost – so deciding what constitutes value for money is tricky. Any new employer or consumer in a new market would be taking similar risks – it is important that a diagnosis does not overshadow this normality.

Proponents of independent living make clear that living independently is not about doing things alone. Rather, it is about ensuring people have a right to services and support systems that respond to individual need, and maximise a person’s potential to live life to the full.

Participants felt that the same principle might be applied to financial markets. All services need to see it as their role to build capacity in decision-making amongst people with mental health problems. Information and support for the most marginalised consumers is the way to increase financial autonomy, as opposed to a mental health-based risk-assessment exercise that would further stigmatise this group. Lenders should not give credit to those unable to repay it, and should evaluate the likelihood of all potential borrowers paying
back their debts, whatever their mental health. The lending industry also needs to be more responsible in considering the effects on vulnerable people of the high-pressure tactics it uses on people who get in to debt.

Do we want a market for health and social care?

How should health and care services be organised to provide for greater autonomy and choice? Allowing a purely market-based system to flourish – such as individual budgets might provide – may lead to unintended consequences. Participants raised a number of reservations about a pure demand-led economy for social care.

The initial reaction of many service providers has been fear that contracts will be terminated and funding slashed. This is not just self-preservation; some argue that the initial impact may be felt disproportionately by voluntary sector services which are funded on short-term contracts, rather than statutory sector services which might look to preserve their contracts. This is not a true reflection of market demand, where voluntary sector services are often preferred and receive high performance ratings.

Equally, there are fears that market forces may in this case favour the cheapest services rather than those of the highest quality. They could also fail to recognise minority needs. It is not yet clear how to reconcile individual demands with the need for equity, diversity and accessibility. One service user suggested that individual budgets may benefit an articulate, white, middle class male service user who knows what he wants, feels confident in asking for it and is less likely to face conflict with his psychiatrist. People with greater communication needs, less capacity, less support or less confidence may struggle to navigate a market-based system. Older service users may be more comfortable with day centre and domiciliary care services to which they have grown accustomed or which they have received for many years and may reject such an approach.

“What we need is a banking system that recognises but doesn’t stigmatise customers with mental health issues. It would be good to see safeguards against erratic spending that the customer is in control of, such as flags on bank accounts that alert bank staff to the need to query unusual spending behaviour, which the customer can have removed without leaving behind a ‘footprint’.

“Banks also need a more human element in their response to customers with mental health issues. For example, advisers in the specialist debt collection units at Royal Bank of Scotland receive mental health awareness training and use this to work more effectively with the customer who is experiencing debt. Where a person’s mental health condition is identified as relevant, and standard processes not appropriate, the customer is referred to a specialist team within the bank trained to help customers with more complex issues.”

Sue Christoforou, Mind

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Chance could be a fine thing: Things to think about

How do we foster a principled approach to risk assessment and risk management? Can we turn a risk-averse clinical culture into one that values positive risk-taking? How do we create greater equality in access to financial services? In the afternoon, workshops looked at translating contributors’ aspirations into realistic policy recommendations. Opinion varied, but a number of proposals emerged that suggest a pragmatic approach to shifting the balance between risk and autonomy. Mind believes these proposals should be taken up and explored by the relevant policy bodies and practitioner communities:

1. **Policy and legislation should be co-produced by policymakers and mental health service users**

Tokenistic service user involvement sends out a signal that people experiencing mental distress should have less say in their care than the Government and their doctors and carers. This undermine confidence and self-esteem, it makes people feel that they are not valued and it is potentially a source of stigma. There should be nothing to fear from engaging service users in policymaking – the more that people with mental distress feel ownership over their care, the better for therapeutic relationships, health outcomes and most importantly, people’s sense of empowerment and autonomy.

> “living independently is not about doing things alone.”

2. **Policy and legislation should promote the principle of the right to independent decision-making unless a person lacks capacity and poses a risk to themselves or others.**

Contributors suggested a range of possibilities for embedding a capacity-based approach to compulsory treatment in law and felt there should be public debate about this. Radical solutions – abandoning the Mental Health Act entirely – were proposed alongside more piecemeal ones, such as amending current legislation to introduce a capacity test. Contributors acknowledged that both of these solutions seem a long way off. However, all agreed that the principles instilled in the Mental Capacity Act provide a good starting point for a change in our understanding of mental distress and decision-making capacity.
3. **Discriminatory attitudes need to be challenged**

A nation-wide initiative to tackle stigma is a key step to shifting the balance. The media needs to be encouraged to take more responsibility for its coverage of mental distress. Exaggeration of the relationship between violence and schizophrenia should be challenged through public awareness campaigns. New Zealand’s ‘Like Minds, Like Mine’ campaign used positive role models such as sports stars to challenge perceptions and prejudice. The £18 million Big Lottery-funded Moving People programme provides an opportunity to do the same in England.

4. **Decision-makers should put a value on the function and success of a service not just by individual outcomes but by what the risks and opportunity costs are to all service users**

We need to consider the risks we impose on people with mental health problems in unsafe and non-therapeutic wards and in situations which hamper recovery or fail to prevent crises. Policy-makers and NICE, the body that makes recommendations to government about which health interventions should be provided on the NHS, should consider the large-scale risks. Risk impact assessments should be routinely carried out alongside cost/benefit analysis as a transparent way of integrating the two approaches.

5. **More research is needed about the impact of wholesale reform of the social care system through individual budgets. Who will be the winners and losers?**

Giving people more say over their care is an exciting way of increasing people’s autonomy. But direct payments and individual budgets, until now, make up a small percentage of the social care market. We need more evidence about how the system will look when they are the norm, and what the risks might be. A principled approach to system change would mean local authorities retaining some core funding for essential services and ensure that there is equity in access and outcomes for service users.

6. **Banks should take responsibility for improving people’s financial capability, rather than simply taking a punitive approach to those who get into debt**

Support systems should be evaluated and tailored to need, and some may be tailored specifically to the needs of people with mental distress. These might include education in financial literacy in schools, Citizens Advice information, and ‘reasonable adjustments’ provided by lenders to ensure that all customers can borrow appropriately.