

JRF Programme Paper
Risk, trust and relationships in an
ageing society

**THE RIGHT TO TAKE
RISKS: SERVICE USERS'
VIEWS OF RISK IN ADULT
SOCIAL CARE**

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This paper:

- Gives voice to service users' fears and concerns about risk;
- Identifies additional risks to those commonly identified by professionals and policy-makers; and
- Explores how perceptions of risk and rights are significantly different for mental health service users.

The Joseph Rowntree Foundation (JRF) commissioned this paper as part of its programme on risk, trust and relationships in an ageing society, which aims to explore how risk features in the lives of adults who use care and support.

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Key issues

1. The landscape of risk in adult social care is immensely complex. The choices of one person may impact upon the life of another, and the path taken following a difference of opinion is likely to depend upon who holds the power. The language of risk is more often than not pre-determined by practitioners and does not reflect the concerns of service users.
2. Disabled people and service users identified some additional and different risks to those commonly identified by professionals and policy-makers. Fear featured powerfully in these conversations.
3. A significant fear for many people, particularly at this time of welfare reform and service cuts, reviews and reassessments, is the fear of losing their independence. Several people supported the view that the right to independent living for disabled people should be enshrined in law.
4. The profile of rights needs to be raised in an accessible and acceptable way, without necessarily entering into situations of conflict: we need to make the language of rights more commonplace.
5. Even within the broad community of people using adult social care services, different people have different levels of power over their lives, over the decisions made about them and the choices and risks they can take. We particularly saw this in relation to people in residential care and mental health services, but can also extend this understanding to people with severe learning or communication difficulties.
6. There is a particular need to reach into mental health and residential care services to raise awareness about people's human rights, and to find ways of enabling people to have these rights realised.
7. Key issues around perceptions of risk and rights are significantly different for mental health service users: people are perceived as a source of risk first rather than being considered potentially at risk in vulnerable situations; they appear to be overlooked by adult safeguarding practices; and their individual rights are compromised by the Mental Health Act 1983. There is a clear connection between perceptions of risk and access to rights: the more risky you are seen to be by others, the fewer rights you have access to.
8. Co-production, service user involvement and user-led approaches were proposed by several people as ways for ensuring that the vision of service users is encapsulated in any policy or service and the delivery, monitoring and evaluation of that service. User involvement in risk assessments and informed

decision making about risks surely should itself be a right.

9. Raising awareness among professionals and policy makers about the risks that service users themselves fear and experience may promote understanding of just how important it is that people are involved in the decision-making processes.
10. The role of regulation should be to promote and enhance a rights-based approach. Regulation should be centred on the views and experiences of the people using the service being inspected, reflecting their quality of life.

Introduction

This paper was commissioned as part of a JRF scoping programme on rights, responsibilities, risk and regulation in adult social care. The remit for the paper was 'to look across the landscape of adult (social) care and discuss service users' perspectives on salient issues associated with their right to decide about the risks they wish take in their lives, but also on their right to be protected from risks'. The focus of this paper is therefore on the views of service users, with the aim of addressing the absence of user voices in the debate about these complex themes.

The scope of this piece of work is potentially huge; it covers the broad landscape of independence, choice and control, from the small choices we make in life through to life-changing decisions and the experiences and feelings associated with danger, fear, abuse and safety. There is no easy continuum to construct around these themes to draw them together or make sense of them. Rather, we have an array of different experiences, issues and perspectives to take into account, some of which are potentially contradictory. Some patterns begin to emerge as we listen and begin to make sense of how one person's experience touches on another. Threads of power and powerlessness – the power to make decisions or to take the risks you choose – run throughout.

In the field of adult social care, there are many people, issues, organisations and regulatory bodies involved in discussions about risk and safety. Questions of responsibility, duty of care, adult safeguarding and capacity come into play. There is the concern about keeping safe those people society has come to perceive as 'vulnerable' and yet these same people – us – want to be able to live full and independent lives and take the risks that everyone takes in an average day. Some of us take far greater risks on a daily basis, or perhaps intermittently, than many non-disabled people ever take.

Perceptions and assessments of risk, then, are both an individual matter for each of us and yet at the same time, of concern to communities and society at large. It is a complex field fraught with decisions and choices that affect other people as well as ourselves. However, we rarely hear the voices of service users in discussions about risk.

In their UK-based scoping review of risk and adult social care, Mitchell and Glendinning (2007) found very few studies reporting only the views of service users. They suggest that this could reflect '*the state's role and pre-occupation with risk management*' rather than with exploring and seeking to understand service users' perspectives of risk. They highlighted the need for more research exploring user (and carer) perspectives. Their updated review (Mitchell et al,

forthcoming) reports a few additional studies on the experiences of people with mental health problems, people with learning disabilities and older people. However, significant gaps remain. This report does not attempt to fill these gaps; rather, it aims to shed some light on them in the hopes that we might understand them and fill them better in the future.

Methods

This report is based on the following sources of information, views and experiences:

1. Existing literature: where service users or disabled people are the authors or their views/experiences are genuinely represented;
2. Discussions with service users and disabled people from a range of different backgrounds and experiences; and
3. Personal reflections by the author.

Discussions took place with the following people:

- Tina Coldham, Mental Health User Consultant, Trainer and Researcher;
- Peter Campbell, mental health system survivor and activist;
- Doug Paulley, disabled activist living in residential care;
- Susie Balderston, Policy and Training Director for Vision Sense, a user-led organisation in the North East;
- John Evans, freelance disability rights consultant/activist (one of the founders of the independent living movement in UK and Europe);
- JRF Independent Living User Reference Group (nine members took part, including people with learning difficulties, people with experience of using mental health services, disabled people and older people).
- Jean Walker, older person, chair of Bradford and District Senior Power and the Bradford Older People's Alliance;
- Kay Sheldon, mental health service user and board member, Care Quality Commission;
- Ann Macfarlane, freelance consultant in disability equality and Independent Living; disabled woman and activist on older people's issues; and
- Sarah Carr, Senior Research Analyst at SCIE and mental health service user (co-author of 'Enabling risk, ensuring safety: Self-directed support and personal budgets' SCIE Report).

This sample of 17 people includes disabled people, older people, people with learning difficulties and people with mental health problems. By observation only, the majority may be described as white British. Two people were Black African Caribbean. It is by no means a 'representative' sample of the population of people who might be covered by these issues. Rather, it is a selection of people identified through networking by the Programme Manager and the author; people who were thought to have something to offer to the debate, given their perspectives and life experiences. Their views are supplemented by reference to the publications listed in section 10. I have quoted people by name only where

they were individually interviewed, and with their consent; all other quotes are unattributed.

This report has not reached some people whose voices are seldom heard, for example: very frail older people or those with dementia living in residential settings; people with complex needs, severe learning difficulties or 'challenging behaviour' living in residential settings.

A personal note

My personal perspective on risk is most notably associated with my experience as a mental health service user with a history of self-harm. Within that context, I have found my personal perception of risk to fluctuate and, if I am honest, it has not always been entirely 'reliable'. Taking a risk with myself, my life, is part and parcel of the distress I experience. I may not have always understood the risk I have taken with my life when taking an overdose – believing that I am taking a minor risk when in fact it may have been life-threatening. However, the same can be said of the responses of services and professionals. I vividly remember being told to go home and to 'be empowered' by doing so after taking my first overdose in 25 years. I was living alone, frightened and felt myself to be very much at risk on that occasion. As we shall see later in this report, this experience of the vagaries of services is not uncommon.

Perhaps the single most significant experience in relation to the risk of self-harm in my life was the death of my friend, Helen Blackwell. Helen had frequently self-harmed in severe and serious ways, somehow managing never to be detained under the Mental Health Act (1983). There were times when I found her self-harm too much, too frightening, to deal with. And then one day, she took an overdose that ended her life. It is probable that she did not intend this; we shall never know for sure, but she gave every sign of expecting to be in hospital for a few days and of then resuming her life.

Over the next few days and weeks, the reality of the situation sank in for me too. With the help of my therapist and a new person in my life, I am happy to say that I have not self-harmed now for about three years. I can still feel angry with the mental health professionals, the crisis team supporting Helen, who did not detain her to keep her safe, knowing she was at serious risk of self-harm. Perhaps they had become almost inured to the risks she took with herself. However, I have to acknowledge that Helen would not have wanted to be detained; she had always worked to retain her independence and to avoid hospital admission as far as possible.

Our experience of risk is ever-changing – particularly as we and the people around us are ageing and changing too. During the course of this project, my aunt had a heart attack after a back operation. I found myself in the situation of arguing with hospital staff for her independence, whilst at the same time having to face the risks that both she and I might face in the immediate aftermath of the event.

As with many of the situations discussed during the course of my conversations with people for this project, these experiences illustrate the fact that thinking about risk often involves an engagement with complex dilemmas and an acceptance that there will not always be an ideal solution.

Risk

One of my first thoughts has been about the language of risk. The ways in which the word is used demonstrate the different ways in which we may think about risk in everyday life. If you consult with a financial adviser, it is likely that you will be asked about your attitude to risk. If you decide to go rock climbing, you will think about the risks in relation to the achievement and challenge, as well as the appropriate safety measures. Risk, it seems, can be as much about uncertainty or excitement as it is about danger.

In the social care environment, risk is usually used in association with potential harm. Practitioners' views of risk often differ from the views of people using services and the language used to express risk also differs (Carr, 2010). These perceived risks have implications for the safety and the independence of the individual, but they also have implications for the accountability of the care providers, perhaps for friends and family and for wider society. Consequently the risk arena becomes contested by a number of different 'risk agents'.

Risk is also used in variable ways across and between different groups of service users and disabled people. The risk of potential harm underpins much of the discussion, but is of particular concern in mental health, where people may fear for their personal safety at times of distress, but tend to have the emphasis placed on the harm they may present to others. A mental health service user and member of the JRF ILURG said:

'They are always more concerned about the risks to the public than they are about risks to yourself. I'm ten days out of hospital and at discharge they weren't talking about how I would be harmed, they were talking about how the public could be harmed.'

Risk of harm to self or others is what those who have the power to use the Mental Health Act (1983) are inevitably looking out for, as these are criteria for use of the Act. The downside of this for service users is the creation of a potential threat to independence and freedom that does not make seeking help an easy decision to make.

When talking about most people using social care services, 'risk' is more often about protecting people from various dangers in the world – keeping them safe in something that Doug Paulley refers to as 'Careland'. In Careland, there are different rules – you are not expected or allowed to do things that might hurt you or might risk your safety even if that 'safety' means risking your own independence and wellbeing. The debate enters the arena of choice and control:

whether you have the opportunity to do what you want to do, to be as independent as you can be given certain restrictions placed upon you by society's response to your disability, impairment or health status.

Wallcraft and Sweeney (2011) in SCIE report 47 articulated these differences in relation to social worker perspectives:

'Social workers' attitudes to risk vary according to the groups of people who use services... social workers often saw people who use mental health services as posing a risk to others, but for other groups, including older people and people with disabilities, they were more likely to see risk as part of normal life, needing to be managed, but having positive potential in terms of self-development'.

Another important issue here is the use of the term 'vulnerable'. Both in preparing the review of prevention in adult safeguarding for SCIE (Faulkner and Sweeney, 2011) and in conversations with people for this report, I came across a strong preference for the term 'at risk' and a focus on risky situations rather than on 'vulnerable' people. Given the right – or wrong – situation, we can all be vulnerable. Ann Macfarlane put this particularly well when she pointed out that use of the term 'vulnerable' can be a good way of denying people the right to take risks.

What are the risks?

For many of the people I talked to, the risk of **losing their independence** was of greater concern than many of the potential dangers perceived or apparent in their lives. It is noteworthy that some of the choices people make to maximise their independence appear risk averse, whereas others more directly represent asserting independence and even taking a risk. In other words, the assumption we often make that independence correlates directly with risk does not necessarily hold. Independence – having control over your life, having choices and being able to make decisions for yourself – is something to be preserved as well as fought for and can exist in a range of different environments.

For example, an older woman living alone related her choice not to leave the house on a snowy or icy day in order to avoid a fall that could potentially risk her independence. She talked of taking reasonable risks and of being aware of her limitations. Two people talked of hiring personal assistants privately rather than through an agency because the agency had strict regulations about manual handling. Appointing people privately allows greater freedom to ask people to help them in the ways in which they need it; for example, avoiding the use of a hoist for lifting. (Equally, this leads into the realm of responsibility: the health and

safety of PAs engaged in lifting is also of concern and now becomes the responsibility of the service user employing them.)

For many people, the potential risk to independence and quality of life is not apparently considered by social care services, or is not given the same weight as, for example, an assessment of the health and safety risks of going on a trip. What are the consequences to the individual of *not* taking a risk? There is not just the risk of reduced independence but also of **increased institutionalisation**. Ann Macfarlane further suggested that the risk in the longer term of *not* taking risks is to diminish a person's sense of self and self-worth.

At the basis of this is the fundamental and personal choice made by many disabled people over the last few decades to live independently in their own homes rather than in residential care. Increasingly, older people are making the same choice, where they can. John Evans spoke eloquently of the history of the independent living movement and of people's right to live an independent life, free of the institutionalisation inherent in living in residential care. John described the importance for him of having a back-up plan should anything prevent one of his personal assistants from coming to work:

'I have to be sure I've got the right support with me. It's my duty and my responsibility to get it right, to have the right personal assistance at all times. That would be my threat – people have accidents, get ill. I have to cover for that – it's something I have to be aware of, and come up with alternatives. I have to have it at the back of my mind all the time.'

For many people, maintaining independence often means managing issues that might appear small, but which could affect their quality of life to a significant degree. Often this appears to be the result of services imposing an institutional approach towards risk upon everyone, without much thought for the individual consequences. The difficulty of negotiating these issues often leads to considerable frustration, but could in theory be resolved with the use of common sense or relatively simple strategies. One example was given by a member of ILURG and concerned her mother, who had smoked since she was 11 and wished to continue:

'She went to a day centre two days a week for about nine months before she died; her dementia was still in the early stages but they would not let her outside for a smoke, which upset her. When we attended a review they said she was aggressive (mum was a very forthright person but not aggressive, even with her dementia). We as a family would have been happy to sign something to take responsibility for her being allowed

outside to smoke. I felt her human rights were affected – she was happy to take this risk and so was the family.'

Ann Macfarlane gave a few examples of this, when she described 'Experts by Experience' visits she had undertaken for the Care Quality Commission (CQC) and for its predecessor, CSCI (The Commission for Social Care Inspection). A woman wanting a biscuit was told by a nurse that it was almost her dinner time: 'it would spoil your lunch'. In order to get the biscuit, she had to resort to child-like strategies. Such an apparently small incident can both compromise an individual's independence and undermine their sense of self-worth.

Doug described the difficulties he faced in wanting to keep his electric wheelchair in an alcove outside his flat. He was told that it represented a fire risk and that he should keep it inside his flat – where it would take up a large proportion of the living space. In order to resolve this, he brought in the fire brigade to check the reality of the fire risk. They found in his favour and he is now able to keep the chair in the alcove.

Several people talked of the everyday risks they face simply in choosing to leave the house, go to meetings, or take part in the community. Three members of the ILURG talked of the challenges they faced attending meetings of the group, whether caused by disability, physical frailty or psychological challenges. Two members usually travel with a PA or supporter. One member of the group talked of the everyday risk of bone fractures in her decision to go out or stay at home, where she might be safe, but ultimately passive and powerless:

'My whole life has been about risk management... When you have brittle bones you really don't have much choice about that... In the end after having lots and lots of fractures I had to think about how to manage this risk. It is real - I do have all these fractures. The risk assessment stuff became something I had to take control of... What it taught me was that I can live my life, I can either live my life like this or I can accept I have the bones I have and risk is a major part of what I have to deal with every day on a minute-by-minute basis. I've got better at it as I've got older.'

The risks posed by contact with services arose in several conversations, particularly in connection with residential or nursing home care and mental health services. In both cases, power is the issue at the heart of the discussion. There is the potential for abuse to take place unobserved in all residential settings, and the potential for being treated or detained without consent in mental health services (under the Mental Health Act, 1983). The latter was felt to be a constant potential threat in the background (and sometimes the foreground) of the lives of

mental health service users. A member of the ILURG spoke of carefully measuring the information she gives to her GP for fear of the response if she told them how she was really feeling:

'Because I'm terrified of the Mental Health Act and I know services in my area are not sympathetic. At the very time you need help most I have to be very careful and then maybe not get the help I need. It's a real Catch 22.'

In two conversations, we touched on the powerful irony of being turned away by mental health services when you seek help, but then being forcibly offered help when you do not think you need it. A couple of people also talked about the vagaries of services; for example, hospitals being over-protective and concerned about discharging people, until they need a bed and then discharging them quickly without evidence of the same concerns.

Several people talked of the significant risks associated with asserting their rights. Doug Paulley reflected on the risks involved in deciding to assert his rights in a residential care setting. He talked of the challenges he faced of being targeted with unpleasant treatment, something that ultimately resulted in a finding in his favour (by the local Adult Safeguarding Board) of 'institutional abuse'. He also mentioned the risk of endangering the wellbeing of fellow residents who may be targeted with the same treatment, as a result his decision to take action. He described this as a constant '*weighing up process*' – whether to act or not. Doug feels that there are many people in residential care who are not speaking up about their rights out of fear and who are consequently not receiving the care that is their right. He posed the question: 'Do you have a responsibility to assert your rights?' (on behalf of others who can't), but with the risk that doing so might affect you and your fellow residents. Another example was given by an older woman, a member of the ILURG:

'When people go into residential care they are entitled to 'pocket money'. They don't always get it, some of the homes keep that, saying that it's for toiletries. They don't get the choice of buying the ones they want. I know a woman who put up with it because she was afraid. Her quality of life was affected. There's a fear of asserting your rights.'

The risk of abuse was mainly discussed in relation to residential care where institutionalisation and interpersonal abusive treatment can occur unobserved, although a couple of people talked of the risks of financial abuse for older people. People living in their own homes are also potentially vulnerable to abuse – from family members, PAs or carers and others (Faulkner and Sweeney, 2011).

The risk of abuse was also mentioned in connection with the current awareness of accusations directed at disabled people of being 'benefits scroungers' or of 'faking it', accusations that have been highlighted by certain media coverage. This has heightened the risks for disabled people of taking part in their communities, threatening their ability to take part in everyday life, because of the reality of disability hate crime. People with learning difficulties are at particular risk of bullying and abuse in the community (People First Lambeth, 2007).

Indeed, some would argue that stigma and discrimination are the biggest risks to the lives of many disabled people, particularly people with mental health problems (Sheldon, 2010; Sayce, 2008) and people with learning difficulties (Lambeth People First, 2007). In addition, some people may also face the risks of racism and of other additional sources of discrimination, both in the community and, potentially, within services.

Particular risks experienced by people from marginalised groups were touched on by Nasa Begum in a SCIE consultation (Begum, 2005). For some of the people in these groups, in particular homeless people and refugees and asylum seekers, daily life circumstances were described as 'risky, unsafe and provisional', resulting in some very different perceptions of risk. The idea that people might worry if refugee and asylum seekers who needed social care took risks was considered to be quite strange. Some were more concerned about taking risks in relation to the restrictions placed upon them by their immigration status than any limitations they faced because of social care needs.

People from black and minority ethnic (BME) communities also face different levels of risk. The report *Inside Outside* (NIMHE 2003) suggested that people from BME communities are much more likely to be assessed as risky to the public and as a result, detained under the Mental Health Act (1983), given more drugs by depot injections, more control and restraint when in hospital and over-estimated as risky within hospitals.

Sarah Carr raised the issue of risk in relation to lesbian, gay and bisexual people in contact with services, particularly those with mental health problems. She highlighted the potential risks posed by services which have historically stigmatised people for their sexual identity, and the need for safe spaces that this creates for people (Carr, 2011).

Fear

Fear loomed large for many people, particularly in the ILURG group discussion. People talked of fears for their own safety, and of standing up for themselves or for their rights; but also mentioned that frontline staff are afraid of being held responsible should something happen 'on their watch'. Hence members of staff will often act defensively, but may also feel disempowered in a situation that does not support them to take risks with and for their clients. Nevertheless, the fear of retribution for service users in residential and mental health services is powerful, particularly for people who continue to need or live in that service. A member of the ILURG said:

'I can't tell you how many times people have phoned me up saying they are in a residential home or their relative is and I will get the whole sob story. And when I said 'why are you not doing something about it?' - she said because it might make it worse for my relation. People are afraid to assert their rights, they know what they should and shouldn't get. It's the same in hospital.'

People are frightened for themselves and for others, and others are frightened for them. Fear pervades personal relationships, often between the generations; parent and young child, adult children and older parents. Parents fear for their growing disabled child taking risks as they develop their independence, and adult children fear for the wellbeing of elderly parents who may be frail but still wish to be active and independent. Whilst editing this report in a café, I got into a conversation with an older woman who expressed her fears of going out after dark, which restricted her activity during the winter months.

Ann talked about a friend living in a nursing home, and the fear she experiences in trying to get her needs met. She is put to bed at 6pm every night, apparently due to staffing resources, which means that she spends as many as 14 hours in bed. She is too fearful to challenge this. A couple of times when she has spoken out about something, she has been 'punished' by staff. One example of this was staff putting her to bed in a position where she was facing the wall and could not see the television.

It is perhaps important to note that most of the people I spoke to are people keen to retain their independence in a variety of different ways. We should also respect the choices of people who opt for less independence and less risk taking. Some people, particularly as they get older and more frail, may feel safer by choosing less independence in residential or nursing home care. It may be a question of finding the right balance for the individual between independence and

isolation, risk and safety, as long as there is real choice involved. A member of the ILURG talked about her father, who had chosen a limited lifestyle at this point in his life.

'His world has now shrunk to the size he can manage, he doesn't want to take risks, his whole life is a risk because he couldn't cope with it. He is really content. Why would we interfere? It may not be a bad thing if people truly can't cope.'

However, without choice and alternative options available, it may not be possible for an individual to choose the level of independence and/or safety that they feel comfortable with.

Several people talked of the difference between the perception of risk and the reality of risk. Sometimes this difference is brought about by the level of knowledge different people are in possession of, but sometimes it is brought about by the nature of the personal relationships involved. An example of the latter is parents of disabled people or the children of older adults being overly-protective and wishing to curb their independence out of fear; perceiving a greater degree of risk than exists in reality.

The difference between perception and reality becomes of considerable significance in relation to the stereotypes associated with people from BME groups. As mentioned earlier, black mental health service users are more likely to be assessed as violent and dangerous than their white counterparts. Warner (2006) found that the concept of 'high risk' was associated with mental health service users who were seen as a 'close fit' to the archetypal risk figure of the young male with a diagnosis of schizophrenia or personality disorder and that this association was greater for black men.

Personal relationships

As indicated in the preceding paragraphs, some people, particularly in the ILURG group discussion, talked about the complex association between risk and relationships. Whilst there was an association with fear, there was also an association with trust. If a relationship of trust existed between a person and their supporter, carer or personal assistant, reasonable risks could be taken that would promote or preserve an individual's independence. A member of ILURG talked of her family's concerns about her taking the journey to the meetings:

'Families can be very over protective, especially as you get older. I have a family who is very over protective, but now they daren't say anything to me because I say 'this is my life and I'll do what I want with it and if the day

comes when I need your help I'll ask for it'. After I had these operations I had to convince my family that I could do it, like getting down here. They've had to get used to it. I've said if anything happens to me at a meeting or on my way to a meeting you'll know I've died happily because I was doing what I wanted to do.'

She undertakes the journeys with a supporter, who noted:

'[She] has made her own risk assessment about travelling here. Having me with her – she's comfortable with that. She knows she can't travel on her own. We should be allowed to make our own assessments rather than people coming in and telling us what we can do.'

Sometimes, the issues are so bound up with family relationships that it is difficult for people to untangle the risks and see what might be important for an individual's independence.

'My mum was always saying 'don't do that you might break something' but she wouldn't do it for me... I'd been out to buy some confetti for mum for a wedding she was going to and she'd done this whole 'what if you break something' and I tripped over a paving stone and broke both my legs and my arm and I was in hospital for 3 months and it was one time when my mum could say 'I begged her not to go out'. But I said 'Mum, you did that every time I went out'. The risk assessment stuff became something I had to take control of. My mum never picked stuff up so I didn't trip over it. Interesting, her relationship with that.'

Jean Walker gave an example of a family putting pressure on an older woman to stay put in the family home, when what she wanted to do was move into smaller and more accessible accommodation. Ann talked of her over-protective mother who had a breakdown when Ann moved out and into residential care in order to satisfy her desperate need to leave home. Looking back on that experience, she wished that there had been some support for them to talk about their feelings and the situation they found themselves in.

In Kay's experience of interviewing people as a Mental Health Act Commissioner, researcher and now as non-executive board member of the CQC, it is often the quality of the relationship a person has with, for example, their key worker that makes the difference. Someone who genuinely listens and takes on board what the person has to say can build a relationship of trust and enable the potential for risk to be ameliorated:

'When I got a new named nurse, she formed a good therapeutic relationship with me and wanted the two-to-one sessions to finish. . . . I agreed to our one-to-one interviews being taped and then after a while the tape recording was not considered necessary any more.'
[Service user quoted in Sheldon, 2010]

Risks and benefits: finding a balance

Many people talked in different ways about 'weighing up' the risks of a particular endeavour, or of trying to find a balance between the risks and benefits involved in a particular decision or action. These might be quite small everyday decisions or they may be major decisions and life choices. In some day-to-day decisions, this could be quite a personal matter and might not reach the attention of services or professionals. However, for someone in residential care, this level of choice and independence was less likely.

Risk contributes to the process for assessing someone's right to services. A member of the ILURG talked of the complex balance she faced, between presenting enough of a risk to qualify for a service but not too much of a risk that she might be in danger of losing her independence:

'When I have a care assessment I have to be careful how I talk about that stuff... you don't get any service unless you are deemed at risk and social services put something in to stop you being at risk, that's the only basis on which you get a service. You have to play it carefully. You don't want to be so at risk that you get put in residential care or not allowed out or something but you need to be enough at risk to get a service.'

Some people's experience of this weighing-up process is that they are not allowed to participate in it – often it is being done by others on their behalf, as in the example of assessing the health and safety risks involved in going on a journey for a group of people in residential care:

Services are good at highlighting the downside of risk – but poor at thinking about the great opportunities that facing up to risk and finding positive solutions in a creative and mindful way could mean for people, their families and their communities... (Neil et al, 2008)

This takes us into the realm of risk assessment and decision-making, which people felt often takes place without them and by people who are not directly affected by the risk. This was referred to several times in relation to people in mental health services, whether they represented a risk to themselves or to other people (e.g. Langan and Lindow, 2004). Similarly, it was noted that people going through the safeguarding process often have all responsibility and even knowledge of what is going on taken out of their hands, as professionals react to a situation where someone has been abused (CSCI 2008).

Excluding people from decisions about their own risks has implications, not just for the accuracy of the assessment, but also for their dignity and human rights. In their article advocating a person-centred approach to risk, Neil et al (2008) state:

We feel it is important to remember people's rights, including the right to make 'bad' decisions, and to gather the fullest information and evidence to demonstrate that we have thought deeply about all the issues involved and made decisions together based on what is important to the person, what is needed to keep them healthy and safe and on what the law tells us.

Langan and Lindow (2004) showed how unreliable, inaccurate and out-of-date risk assessments in mental health can be, most of which did not consult with service users. Kay Sheldon said very much the same in relation to her experience with the Mental Health Act Commission, and of a survey of service users' experiences she carried out (Sheldon, 2010):

'The only time that robust risk management surfaced, by all mental health professionals concerned [was] to protect themselves from possible recriminations and accountability. Never, during all this time, did one person stand up and ask 'what are we doing to 'S'?
[service user quoted in Sheldon, 2010)

In the consultation report on *No secrets* (DH, 2009), people reported wanting help to deal with potentially and actually abusive situations in their own way. They wanted to 'do their own safeguarding, they wanted help with information, options, alternatives, suggestions, mediation, "talking to" and so on.' (p 18). *They did not want decisions made for them* [author's italics].

This highlights the importance of people who are at risk having training and/or regular practice in making independent decisions. Although most of the research and practice to improve decision-making skills has taken place with people with learning difficulties, the importance of having the knowledge, assertiveness and resistance to defend oneself might reasonably be considered to apply to all adults in potentially risky or abusive situations.

Often this comes back to the culture and ethos of services. Trainers doing skills development with people with learning difficulties found that, if they returned to a service with a non-receptive culture, their skills would soon flounder. If, however, they returned to a service that encouraged them to make regular day-to-day decisions for themselves, they would be more likely to be able to use their skills to protect themselves if the opportunity arose (reported in Faulkner and Sweeney, 2011).

Susie Balderston of Vision Sense advocates the use of Circles of Support for disabled people. She gave many examples of where this can be 'risk-enabling'. One was of the value of having a circle that goes beyond parents and carers to consider taking positive or exciting risks, for example skydiving or embarking on a sexual relationship. Where parents might be inclined to be over-protective, other people in a person's life might encourage and support them to try things. Equally, a discussion with friends and others engaged in relationships might help the person to see how relationships work for others and hence strengthen their own ability to engage in a mutual relationship (having a safeguarding role should a relationship become exploitative or abusive).

'There is an example of a man with learning disabilities who had loads of tattoos. This resulted in him going before the safeguarding panel – social workers were concerned about the risk he was putting himself in. They set up a Circle of Support with a PA who also had tattoos, talked to him and went with him to the tattoo parlour. It turned out that he was often at the tattoo parlour and the workers were not sure how to deal with him. Now they have it in his support plan for him to spend four hours a week in the tattoo parlour, showing people the designs, making tea etc. He is now less at risk than most people – having some very tough bikers on his side! It has entirely changed his relationship with the tattoo parlour – without the Circle of Support, this would never have happened.'

There may be the potential to use this approach in other fields. However, some people have reservations about circles of support if they are organised by professionals on behalf of service users and do not reflect a genuinely person-centred approach. There are other models with similar characteristics to this; for example, family group conferences for older adults at risk. In discussing a person-centred approach to risk, Allen et al (2008) also talk of focusing on the individual and 'building an alliance of supporters' around them, effectively a circle of support.

'Risk enablement panels' have been identified as emerging practice in relation to personalisation and self-directed support, as a way of helping with complex decisions that may arise in signing off a person's support plan (Carr 2010). The emphasis here is on shared decision making with transparent shared responsibility, including the service user and their carers, family or friends and in line with the Mental Capacity Act (2005). A risk enablement panel should only be convened as a last resort. However, I did not come across anyone with direct experience of a risk enablement panel. Carr (2010) concludes that the promotion of choice and control implies the need for changes in the way risk is understood, managed and negotiated with people using services.

Rights

'Rights have to come first and the dignity to be able to take risks.' (John Evans)

A rights-based approach

For some people, there is no question that a rights-based approach is one of the ways of tackling this whole arena. In particular, John Evans talked passionately about the potential of the UN Convention on the Rights of Persons with Disabilities (to which the UK is a signatory), particularly article 19 on the right to independent living. He feels that the right to independent living for people with disabilities needs to be enshrined in law. The UNCPRD has huge potential advantages for disabled people. The difficulty is fitting it within the framework of our national legislation, which is something that all signatories are expected to do. Sooner or later, he believes, people will be able to use the Convention to challenge certain decisions or things that are happening in their lives.

Several authors advocate a rights-based approach towards risk and risk assessment, decision making, adult safeguarding and care and support in general (Sheldon 2010; Whitelock 2009, Neil et al 2008). But what does it mean to take a rights-based approach? Sheldon (2010) argues that risk management in mental health should be based on promoting and protecting our rights:

'We should have our rights explained, including our human rights. Risk management should not compromise our rights to dignity, privacy and respect.'

Whitelock, also writing about mental health, argues for a shift in focus away from viewing safeguarding as protecting 'vulnerable' people from abuse, towards the principle of upholding everyone's human right not to be subjected to inhuman or degrading treatment. Speaking on behalf of mental health charity Mind, she advocates a rights-based approach to adult safeguarding (Whitelock, 2009), the key to which is that all professionals involved in adult safeguarding ensure that service users are fully involved in the process:

'A rights-based approach to safeguarding recognises that people have the right not to be subjected to inhuman or degrading treatment (Article three of the Human Rights Act 1998 (HM Government, 1998)) but also the right to respect for a private and family life (Article eight).'

In reality, as we have seen, standing up for your rights can be frightening and can result in negative consequences. A wholesale shift in policy and practice must be necessary for this situation to change.

Advocacy must surely be one way of enabling people to express their views and assert their rights. However, advocacy services have come under pressure in recent years to respond to Government policy demands to become more professionalised and to conform to a particular model (Henderson, 2004). Certainly this is true in mental health where the introduction of Independent Mental Health Advocates (IMHAs) has meant a fight for survival by independent local advocacy groups and networks who wish to adopt a community-based, user-led, model (Simpson, 2011).

'The challenge for advocacy schemes in the future is to retain that independence whilst at the same time securing long term, secure funding for their activities.' (Henderson, 2004)

Arguably, the introduction of IMHA has strengthened the presence of advocacy for people detained under the Mental Health Act (1983). However, Action for Advocacy recently estimated that up to 5,000 people with mental health problems are currently being denied their rights in relation to advocacy. They recently called upon the Government to implement the 'right to advocacy' for all users of social care services'¹.

Differential rights

Disabled people and mental health service users do not have the same rights that many citizens take for granted. Many are excluded from jury service, do not have equal access to voting, education and employment opportunities or standing for public office; and many disabled people – particularly those with learning difficulties and/or mental health problems – experience unequal access to primary health care (Morris, 2005). Sayce (2008) cites an example of a deaf woman being denied the right to adopt a cat by an animal welfare charity on the grounds that she would not be able to hear if it was distressed. The acquisition of a label can both unlock access to certain services and benefits and, at the same time, erect barriers to some significant rights and opportunities.

People in residential care do not have the same tenancy rights as people in other rented accommodation. The only equivalents to this are homelessness hostels or

¹ See:

<http://actionforadvocacy.org.uk/articleServlet?action=display&article=2006&articletype=3>

holiday lets. The only way to challenge an eviction order is by using the Human Rights Act 1998: the right to a home and family life, Article 8. It is only since the 2008 Health and Social Care Act that people in care homes are protected under the HRA. However, people funding themselves independently still do not have that right.

Peter Campbell spoke about the fact that mental health service users do not have the same rights as other people because there is the possibility of taking away our freedom and our physical integrity through the use of the Mental Health Act: detention and treatment without consent. *'We don't even have to have lost capacity for it to happen':*

'My difficulty is that people with a mental disorder have a different set of rights. We are second class citizens, we can be locked up, we can be treated against our will. So to talk about independent living is a bit inappropriate for us as a group – well, not inappropriate, but misses the point.'

There is not the space here to examine these issues in depth, but clearly this raises important issues about the circumstances in which a person's rights can be compromised by the risk they are believed to present, primarily to other people but also to themselves. Referring back to the evidence about risk assessment in mental health (that it is frequently out-of-date and inaccurate), we might conclude that it is all the more important to involve people in the risk assessments made about them, as well as to ensure that people are made aware of their rights.

Responsibility

The promotion of choice and control, of more creative and positive risk-taking, implies greater responsibility on the part of the service user at the centre. It is quite significant that many service users and disabled people assume that it is their own responsibility to keep themselves safe (Department of Health, 2009), that:

'Understanding what made them safe required understanding them as people – understanding their personalities, their experiences, their family relationships, their wishes for the future and their past histories of choices.' (Dept of Health, 2009: 2.11).

Much of the discussion about responsibility for this report was implicit in the dialogue about 'finding a balance' or maintaining independence. However, a number of people used the word spontaneously in connection with the control they assumed over their own lives. John Evans talked of it being his responsibility to ensure that he has the right assistance, that he keep his home safe for himself and his PAs and the responsibility he has in the community when driving a powerful electric chair:

'I have to be sure I've got the right support with me. It's my duty and my responsibility to get it right, to have the right personal assistance at all times.'

'It's my responsibility in the community or wherever I go. I could quite easily knock people over, cause all kinds of damage. I have to take that on board. If something happened it would be me who would be responsible.'

Ann similarly talked of the importance of being a responsible employer. Like John, she employs her own PAs rather than going through an agency where the rules about manual handling are prohibitive, but this means that it is her responsibility to negotiate with her PAs about what they feel comfortable and safe with.

A member of the ILURG talked of taking responsibility for her own risks and risk management, after a childhood of receiving mixed messages and living with fear. Doug asked whether you have a responsibility to assert your rights in a setting where other people might not have the capacity to do so, but all are equally affected.

A couple of people, in describing their experiences of hospital care, talked of an 'all or nothing' approach to responsibility: one minute, you are entirely the

responsibility of the institution and they are protecting or preventing you from risks, and the next minute they have handed responsibility back to you and you are on your own without support:

'My mother had a hip replacement and we were expecting her to be in hospital for a few days; then all of a sudden they decide to discharge her with no plan, no needs assessment, because they needed the bed. I rang the hospital and said she's not ready to come out, she has no walk-in shower... They ... suggested she use the swimming pool but "tell her to be very careful with her crutches". It immediately became our responsibility. Yet before it had been all "you can't do this until you can manage the stairs"...

In conversation with Ann Macfarlane, we talked about the responsibility that those of us who are 'out there' and speaking with people in positions of power assume on behalf of those who are not, or those who cannot, do so. We agreed that we have a responsibility to try to reach out to and speak on behalf of people whose voices are seldom heard.

The Role of Regulation²

'The regulation we need is the one that's lacking, the one that ensures good quality standards of treatment, support, enablement - that also protects the rights of the individual, that they are not going to get abused - that takes it beyond social care to the police etc when you're talking about hate crime.' (John Evans)

Regulation of services

Four of the people I spoke to expressed particular concerns about recent changes to the Care Quality Commission. Three of these were looking at the CQC from the outside and commenting on its lost or compromised powers. One, Kay Sheldon, a board member of the CQC, had recently expressed her concerns publicly about the leadership, management and culture of the CQC. At the time of writing, Kay is officially recognised as a whistle-blower.

Doug sees regulation as useful as long as it is specific, as this makes it easier for a service user to make sense of and to use; the clearer and more specific the regulations governing a service, the easier they are to raise and to challenge. Recent changes to regulation have resulted in standards becoming more medical and simultaneously more vague, which he sees as a backward step as they are now more open to interpretation. He feels they should be more relevant to social care and that there should be more frequent inspections. For Susie, the issue is about the centralisation of the CQC – no longer having local inspectors with whom to threaten local service providers, people who you can contact easily, is a big backward step for her.

For John, the CQC needs a complete overhaul. He is concerned that it no longer involves service users in the inspection visits as well as the fact that it has lost some of its power and specificity, as a result of merging with health care to achieve universal standards:

'It would be a good piece of work to establish a good framework for the CQC to remedy the weaknesses, not just for a particular session but to establish a framework, some robust standards and safeguarding principles to make things happen. And then there's effective monitoring long term. That's where it all falls down, putting it into practice. That's why the co-production shouldn't stop in the planning stage but should go through to the roll out.'

² This section refers to the regulatory services in England.

Kay has publicly expressed her concerns about the way in which the CQC is being managed, and therefore how effective it is, to the Mid Staffordshire Public Inquiry. The CQC has moved towards a compliance/enforcement model, where once it was concerned with assessing quality of care. Hence it is assessing services to see if they meet essential standards of quality and safety. These universal standards have been combined across different care sectors and this is proving unsatisfactory; however there are signs that this will be changing to re-introduce sector-specific standards.

There are potential benefits to having clear standards so that people know what they can expect from the service they are receiving. However the relationship between the experiences of people using services and the regulatory process is unclear. Regulation can impact on the balance between risks and rights; enforcing safety can impact on the quality of care and rights. For example, the removal of ligature points in a non-acute mental health unit led to curtains being removed and windows fixed shut, which compromised dignity and made the unit unbearably hot in summer.

Kay feels that this (new) approach needs to be monitored and evaluated with significant input from service users: is it meeting the needs of the people using the services? Both John and Kay are in agreement here: that social care regulation and the regulator need to be monitored and evaluated from a service user perspective. Both mentioned the role of co-production in rolling this out, and Kay mentioned the potential of user-focused monitoring (see Kotecha et al, 2007 for more information).

Adult Safeguarding

The consultation report on *No secrets* (DH, 2009), found that people are concerned about the balance between safeguarding and personalisation, between choice and risk. The consultation found that safeguarding can be experienced as '*safety at the expense of other qualities of life, such as self determination and the right to family life*'. Systems to assist in this include ensuring people have informed choice and introducing support systems for direct payments.

CSCI (2008) found that people wanted the discussion about safeguarding to focus on respecting people's rights and wellbeing, rather than to take an unduly paternalistic or protective approach towards abuse and protection. This approach was seen as complementary to personalisation, although there was some concern about the situation facing people purchasing their own care.

According to the SCIE review of prevention in adult safeguarding (Faulkner and Sweeney, 2011), if people are to protect themselves from abuse, they need to be aware of what abuse is, to be informed about their rights and to have the skills and resources to be able to deal with it. They need to have the information, knowledge and confidence to take action. Wallcraft and Sweeney (2011), found that the evidence about user involvement in adult safeguarding was scarce and that there are a number of barriers to user involvement in safeguarding, including concerns about risk and fears of causing harm to those involved.

Mental health charity Mind (Whitelock, 2009) points to the systemic failure of the NHS to engage with adult safeguarding, which means that institutional abuse in mental health is widespread and unchecked; dealt with internally rather than referred to the police or adult safeguarding teams. Safeguarding, then, is a complicated tool; it can be protective, but it can also place an individual's independence at risk if used clumsily.

Conclusions

The landscape surrounding risk and rights remains immensely complex. The choices of one person can impact upon the life choices of another, and the path taken following a difference of opinion is likely to depend upon who holds the power. There is often no ideal solution to a complex situation, but rather a series of compromises to find the best fit. The culture and ethos surrounding risk and rights, both in wider society and within individual services, is risk-averse, with a tendency to blame individuals when something goes wrong. Whilst there are policies about whistleblowing, the overpowering culture is for individuals to fear standing up for their (or other people's) rights.

This consultation reached a fairly small number of people, many of whom are actively involved in campaigning or influencing local or national policy and services in different ways. Even though the paper does not claim to be 'representative' of the whole spectrum of views on these issues, it does give voice to some important fears and concerns.

Although they identified many of the same risks, disabled people and service users identified some additional and different risks to those commonly identified by professionals and policy-makers. They also talked about fear. A significant fear for many people, particularly at this time of welfare reform and service cuts, reviews and reassessments, is the fear of losing their independence. This suggests that individual assessments and reviews need to have independence as their starting point. Several people supported the view that the right to independent living for disabled people should be enshrined in law.

The profile of people's individual and human rights undoubtedly needs to be raised in an accessible and acceptable way. Many of these conversations demonstrated just how difficult it is for people to assert their rights when in situations of powerlessness, which raises the question of how we as a society raise the profile of everyone's right to equal rights. The challenge is how to enable people to assert their rights without necessarily entering into situations of conflict; to make the language of rights more commonplace.

There is a particular need to reach into mental health and residential care services to raise awareness about people's human rights, and to find ways of enabling people to have these rights realised. Mental health and residential care services seem to be the Cinderella services where people's rights are concerned – other people aren't having a ball, but at least they have been invited!

One of the themes to emerge from this consultation is that the key issues around perceptions of risk and rights are significantly different for mental health service users. People are perceived as a source of risk first rather than being considered potentially at risk in vulnerable situations. They appear to be overlooked by adult safeguarding practices, and their individual rights are compromised by the Mental Health Act 1983. There is a clear connection between perceptions of risk and access to rights. The more risky you are seen to be by others, the fewer rights you have access to.

Co-production, service user involvement and user-led approaches were proposed by several people as ways for ensuring that the vision of service users is encapsulated in any policy or service and the delivery, monitoring and evaluation of that service. User involvement in risk assessments and informed decision-making about risks surely should itself be a right. Raising awareness among professionals and policy makers about the risks that service users themselves fear and experience may promote understanding of just how important it is that people are involved in the process.

Different people have different levels of power over their lives, the decisions made about them and the risks they can take. We particularly saw this in relation to people in residential care and mental health services, but can also extend this understanding to people with severe learning or communication difficulties. Different methods need to be employed to enable people to take part in decisions about their lives and the risks they wish to take if they face these challenges.

Another perspective on power is the relative power differential between people in quite powerless positions; for example, a care worker who has little power or status nevertheless has the power to affect a service user's quality of life in quite significant ways. As we have seen, apparently small issues can assume a considerable significance for someone who is powerless and dependent on care.

A reading of the literature alongside the views of those who had some experience of the regulatory bodies suggests that the role of regulation should be to promote and enhance a rights-based approach. Regulation should be centred on the views and experiences of the people using the service being inspected, reflecting their quality of life. It should not be risk-averse; ensuring safety should not adversely impact on quality of care. Several people were of the view that the regulatory bodies should involve people who use services in developing and carrying out regulatory activities and in monitoring their effectiveness.

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