

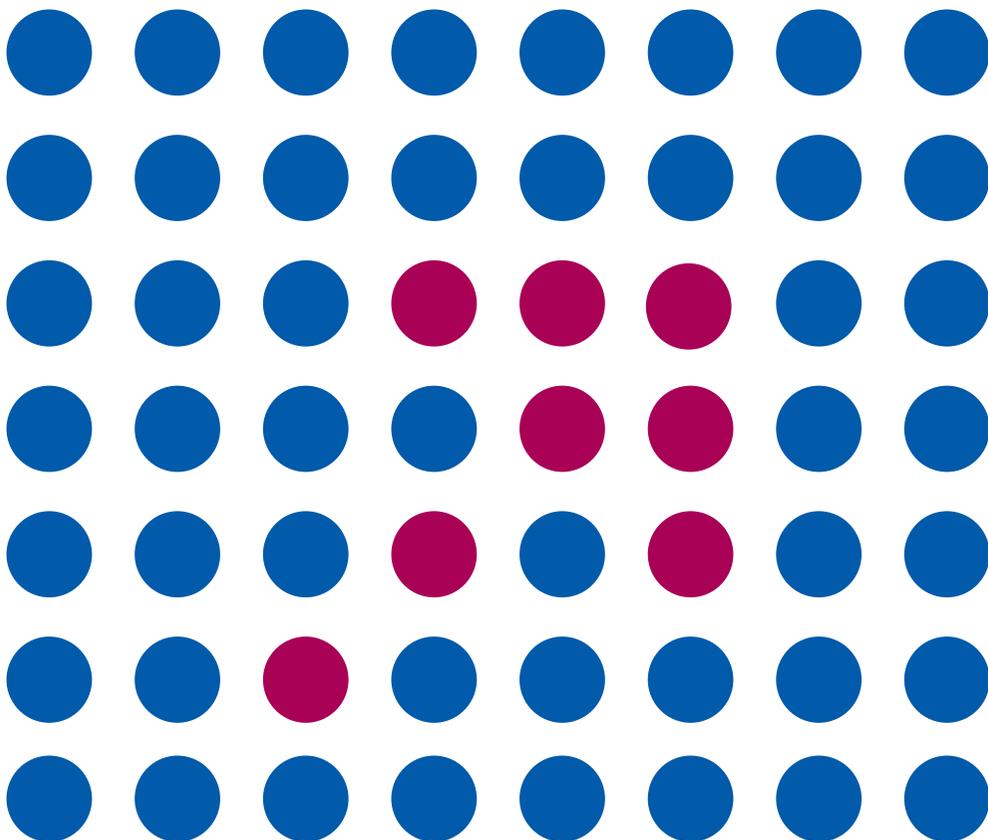


Supporting Choice

Supporting vulnerable service users in making choices

Edited by Claudia Wood

Report of the Social Market Foundation seminar
12 October 2004



The Social Market Foundation

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Senior Fellow at the King's Fund

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Liz Sayce

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Preface

This paper draws on contributions to an SMF seminar held on 12th October 2004. The seminar provided a forum for discussion of the major issues facing vulnerable and disabled people when making choices within public services, particularly in health and social care. Speakers reflected on the issues from various standpoints, ranging from the new approach the Government is taking in promoting choice in the NHS, to the value of choice as a means of greater independence from the user's point of view.

This paper restates the presentations given and summarises some of the main points which emerged from the discussion. It also attempts to draw some of the main themes together by way of conclusion and to identify areas for future debate and possible reform.

Our thanks go to all our speakers and to all those who attended. In particular, we would like to thank Lundbeck, whose kind support made this seminar and publication possible.



Introduction

The extension of user choice within our public services throws up many problems and challenges. Some are worthy of serious attention, and some are not.

Among the questions that we ought to take *very* seriously is that of how we are to extend user choice to those members of the community who face the greatest challenges in exercising an effective and informed choice. Many feel that, unless we take careful preventative measures, these individuals will be left with the poorly performing sectors within our public services, while those better equipped to choose will enjoy exclusive access to the best performing areas. This not only offends equity, it seems to strike at the very heart of what our public services are *for*. These services were set up to benefit all citizens, but it was the especial plight of the most vulnerable members of society that was foremost in the mind when resources were pooled and public provision was set in motion. If introducing user choice means we fail these individuals, the very *raison d'être* of our public services will have suffered a serious blow.

The assumption here is, of course, that vulnerable members of society will have more difficulty in making choices than those in other groups. We ought not to accept this assumption uncritically. It is an inspiring fact that many of those individuals that we might classify as belonging to vulnerable groups frequently make extremely serious choices, and they make them well. Moreover, they are exactly the right people to be making these choices. The needs of these individuals are complex, and change over time. They themselves are best placed to make choices about how to meet these needs at any given moment.

If individuals with complex needs are the right people to choose how service provision meets those needs, the question is how to engage the many vulnerable individuals

who *do* experience difficulty in making choices. It is important that we do so. Leaving these individuals to navigate their way through a system of expanded choice might well lead to the previously described inequity. However, expending effort on engaging these individuals holds out the prospect of a very significant goal – public services that are more sensitively tailored to people’s complex and shifting needs.

High quality information about the nature and range of choices available is a necessary precondition of *any* individual making an informed choice that accurately reflects his or her needs and preferences. This much is obvious. What is less obvious is how we tailor the provision of information to different groups of individuals, in order to enable them to make these kinds of choices. Many vulnerable individuals will be poorly served by the ‘traditional’ ways of presenting information, such as via leaflets or websites. Arriving at new methods requires creative thinking. Many of these individuals are in almost constant contact with certain key public services, and something like a long-term mentor, who can keep track of their needs and preferences, might be more appropriate. Such mentors would not only present information in an appropriate manner, they would also be there to answer questions and, crucially, provide moral and emotional support to individuals who are often marginalised and even stigmatised by society at large. The success of nominated ‘Patient Choice Advisers’ in the recent NHS London choice pilots suggests patients value such close collaboration and support.

Ultimately, making choice in public services a meaningful experience for vulnerable groups requires nothing less than a cultural shift in the way that the members of these groups are viewed. Too often the approach taken by service providers is paternalistic. Some might argue that vulnerable individuals are more likely than others to make bad choices. The answer to this must be: not if they are properly supported, they won’t. *Any* individual denied the proper support and information is liable to make bad choices over the provision of public services. Very few of us are medical or educational experts. The goal of tailored services for the vulnerable is simply too important to be given up on the spurious grounds that these individuals are not up to the task.

The value of this goal was the inspiration behind a seminar held at the Social Market Foundation on 12th October 2004. In this pamphlet, we present an edited version of the contributions made at this event. Each speaker brought a different expertise to the difficult challenges that must be faced in extending choice to the vulnerable in society. Professor Paul Corrigan, Adviser to the Secretary of State for Health, tells of how the NHS is actively trying to build on the skills vulnerable individuals have developed in managing their medical conditions, by extending choice in health care to these individuals. Professor Nancy Devlin brings her expertise as an economist to bear on the central question of information provision, and provides a useful analysis of how users might rank the ‘reputation’ of a public service. Dr. Tony Bayer, a practising clinician in geriatric care, provides invaluable insight into how certain medical conditions – and, just as importantly, certain clinical *contexts* – can make the extension of choice in health care a real challenge for some individuals. He reminds us how the nature of some medical conditions means that very specific kinds of support are required in order to make choice meaningful. The issue of culture shift is tackled head on by Liz Sayce of the Disability Rights Commission, who argues powerfully that we ought to move away from conceptualising use of public services by vulnerable individuals in terms of ‘managing risk’ to a view that stresses how choice can empower these individuals and enrich their lives.

The perspectives brought to bear are diverse, and usefully so. The themes raised, however, are marked by heartening overlaps. We hope these overlaps suggest a way forward in extending choice to those users of public services who are most in need of excellence in provision.

Claudia Wood

Speaker presentations

Professor Paul Corrigan, Special Adviser, Department of Health

The old administrative formula

The key question I would like to start off with is: how do we decide the needs of one vulnerable person, whose needs are quite different from other vulnerable people? The way in which this has been achieved up until now has been by employing bureaucratic administrative systems. We have believed that in some way it has been possible to create personalised services by constructing an ever more complex system with a formula for single mums, and another for ethnic single mums, and then another for mums with two kids, and so on. We have believed it is possible to create an administrative formula which will be sensitive enough to cater to individual user needs. However, we were wrong.

The administrative formula approach has failed the vulnerable, because we have created a system supposedly serving their needs which is operated by non-vulnerable people. Unfortunately, people have been hanging onto the hope that if, in some way, the formula was right, a service would be created that would meet everybody's needs without them playing a part in its design or delivery. This is the essence of what I want to say today – that individuals have to play a role in creating their own service for it to truly meet their needs. For example, if, as a teacher, you have tried to *make* students learn, it's often an uphill struggle. If, on the other hand, your students want to learn, teaching them is infinitely easier. It is this relationship of

co-production that is so critical to personalised services and is key to responsive choice systems.

The new approach

Future policy initiatives will reflect this new way of thinking. First, the Department of Health's five-year plan demonstrates a different approach to engaging the 17.5 million people with long-term conditions in this country, by involving them far more in their choice of treatment. The Department has developed the *Expert Patient Programme*, where patients share their experiences with other patients, to help them express their preferences of treatment and navigate the system. The obvious thing about a long-term condition is that the person suffering from it knows far more about how to manage it than healthcare professionals, even though patients often have limited knowledge regarding medical systems and administrative procedures. The more patients know about this side of their care, the more choices are available to them, and that is what the Department is aiming for. If a patient is going to deteriorate with his long-term condition, then there will be a care manager to assist him with managing his condition. If the patient gets really quite ill, as 250,000 people are in the UK, then a community matron will help the patient navigate the system and enable him make independent choices for as long as possible.

In terms of elective care, the Department plans that by December 2005, a patient going to see a GP will be able to choose between four or five procedures, and by 2008 the Department hopes to provide completely free choice in this area. Another target set for 2008 is that people will not have to wait for their referral appointment for longer than 18 weeks.

Breaking down myths

I want to finish with some thoughts about life experiences and the vulnerable. The notion that choice is something external to vulnerable people's lives is just wrong. If you do suffer from a level of disadvantage or a level of vulnerability, then actually much of your life is spent making choices which might terrify some of us, because they are very difficult, and often limited, with very important consequences. If we rightly see choice in welfare services as integral to the other choices vulnerable people

make in their daily lives, then there is something not just patronising but also ridiculous about the notion that vulnerable people “cannot make choices”. They make them all the time. Sometimes they need support in making them, but then sometimes we all do. What we need to do is to design policies which provide that support without undermining independence.

Nancy Devlin, Professor of Health Economics City University, and visiting Senior Fellow at the King’s Fund

Choice and information from an economist’s viewpoint

In any discussion concerning the role choice plays in economics we must bear in mind that the starting point for most economic analysis is the notion of a perfect market, an important element of which is perfect information. Markets are not perfectly efficient until people have access to comparative information on prices and quality, and the ability for consumers to make important choices drives the outcomes of markets and market-places. The key assumption is that consumers can determine the quality of the goods before they consume. The vital question here is, to what extent does the healthcare market contain these same sorts of elements? And, therefore, what are the challenges in using quality and choices to drive changes in healthcare markets?

The character of the healthcare market

The variety of features in healthcare markets makes their functioning rather diverse, but a common element is that healthcare often relies on reputation. Consumers may not be able to tell the quality of care before they consume it – they may not even be able to tell the quality of a service *after* they consume it. A layperson finds it very difficult to determine the clinical quality of care they receive – they do not know how good their GP is as a diagnostician, for example. However, the role of GPs is very significant in conveying information and their impressions of the choices available: consumers will, even if they are well

informed, often look to their healthcare providers to guide their choices.

Another important aspect of healthcare markets is that the greater the number of providers in a given area, the higher the prices, which is completely contrary to economic theory. It can be explained, however, by a model of increased monopoly, which is set. If you are in an area with a small number of hospitals, for example, then as a consumer it’s very easy to obtain good information and experience over the years about the quality and characteristics of those providers. People learn from their friends, from their neighbours, from their GPs, from having consumed healthcare in the past. In a situation where there is a sudden increase in the number of providers between whom people can choose, obtaining adequate information on quality and comparative characteristics becomes a lot more complex.

Informing choice

Choice of provider seems to be a key policy theme at the moment. It seems that a lot of initiatives are driven by meeting targets, which is fine, but that we also need to think more broadly about what it is we are seeking to achieve with increased choice. Are we prepared to allow people to choose treatments that are not cost effective? Are we prepared to allow choice if those who take up the choice are only those who are better educated or have higher incomes? A way in which these issues can be resolved is by working out what elements of service provision patients care about when they are making choices, and how we can support them in making those choices. There are important questions concerning how patients can obtain information, what they care about, and how consumer opinion can best be recorded. For example, three quarters of the public say they are already confused by the amount of conflicting health advice available. In this way, information can both encourage and limit choices, and so we need to think about not just what information is required, but the way in which it is conveyed. The way information is presented can have an enormous influence on the real choices available for patients. Evidence suggests there is only limited use of comparative information by consumers, and most rely on their GPs for guidance. Ensuring this comparative information is accessible

and more easily used by patients will give them greater independence in making choices, so that relying on a GP's guidance is also a choice, not the only option.

Inequitable outcomes

A pilot was undertaken to give patients who had waited six months for secondary care the opportunity to choose a range of other providers, both in the public sector and in the private sector, to reduce their waiting times. We surveyed nearly 2,000 patients regarding their preferences between alternatives, which implied different travel costs, different timings of the appointment, how long they would have to wait for treatment, etc., and the most important factor for those patients surveyed was *the reputation of the hospital*: patients would actually be prepared to wait longer to avoid going to a hospital which had a worse reputation than their existing hospital. We also found that people on high-income levels were far more sensitive to reputation than people with low incomes. We clearly need to reflect on how to produce more equitable outcomes in the healthcare market.

One way to do this might be to examine what a hospital's "reputation" means to people. Our survey was using a very simplified version of "reputation", without addressing what it actually meant. We really need to unravel the term to identify what aspects of a "good reputation" are most important for patients. Do patients simply rely on what they have heard about certain hospitals? Is it linked to the way the hospital fits into the community? On the basis of our results, we could hypothesise that where information on reputation is available, those on higher incomes will migrate towards hospitals with the better reputation. If information on reputation is not available, then those on lower incomes are more likely to accept hospitals where they can get quicker treatment.

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Dr. Tony Bayer, Senior Lecturer and Acting Head of the Department of Geriatric Medicine, University of Wales College of Medicine

Choices limited by medical condition

Geriatrics, as a profession, often has negative connotations, which may be a symptom of ageism. Ageism is now banned from the NHS in England, but in practise what has actually happened is that ageism has been replaced by a system where choices are limited by the medical condition a patient suffers with. If someone has cancer, then there are a lot of options and choices open to them. There are a large number of drugs, and a large number of targets which should be met. Cancer is a very strongly age related condition and is responsible for 20% to 30% of deaths among old people. If you look at heart failure, there are slightly fewer choices available, and there might be slightly fewer resources. If you look at Alzheimer's disease or dementia then, again, one in three people are going to die with dementia, but the patient will certainly not have access to comparative information on services and he will really have to fight for a choice of provider. So it really depends on what label you are given. For example, the second most common cause of dementia is a stroke or blood supply problems, but there are many stroke rehabilitation services around the country that are closed to people with dementia. So it is the medical condition a patient has, and the label he is given, which determines the choices available to him. If a patient has a label of "dementia", "vascular dementia" or "stroke related dementia", then a lot of doors are closed to him. If a patient has the label of "stroke" or "cerebrovascular disease", there are far more choices and options available.

Choices limited by healthcare specialism

Choice also depends on which parts of the health service a patient comes into contact with. If a patient with dementia is treated by a neurologist, then he is likely to have sophisticated investigations and probably a very good diagnosis, but

unfortunately he will not have too many options regarding the type of care he can receive. If a patient is treated by an old age psychiatrist, his access to sophisticated investigations will be limited, but he will have much better access to ongoing support and community services. Similarly, both a neurologist and an old age psychiatrist will not provide their patients with much access to complementary or alternative therapies, which a lot of people want, particularly for chronic conditions where there is no real medical cure.

Choices limited by information

Therefore, a patient's choice is determined not only by his condition, but also where he comes into contact with the service. It is also obviously going to be determined by what the patient is told. Twenty-five years ago it was common for practitioners not to tell patients that they had cancer. Nobody would defend such a practice now, but returning to dementia – Alzheimer's disease – recent research suggests that about 50% of people with Alzheimer's disease are not actually informed of their diagnosis. There are clearly double standards here. If a patient does not know what is wrong with him, if he does not know the implications of the diagnosis, and if he does not know what the prognosis is, then it is very difficult for him to make informed choices. One of the reasons why patients with certain conditions are not told their diagnosis is because professionals feel inadequately trained to break such news, and are nervous about it. They may also have relatives or carers asking them not to tell the patient the diagnosis. Clearly there may be a conflict between what the patient actually needs and what the family, and often the potential carers, want. This is most obvious where a patient wants to stay at home and be looked after, whereas the person who must take this responsibility – the daughter, the husband or wife, or whoever has found the role of carer thrust upon them, are actually looking for respite and may want the patient to go into care. As a healthcare professional I must make the choice concerning whose needs I actually address.

Supporting user choice

If an old person is moved into residential or nursing home care,

then choice is totally removed from the situation. Once an old person goes in to a residential nursing home it is almost impossible to leave, because the old person's house is often sold and there is limited availability regarding round-the-clock care provision. A person tends to lose a lot of choices available to them, and many choices can only be made if permission is asked of the nursing home staff. Advocacy is one way of ensuring patients in such situations have the greatest range of choices available to them, but advocates tend to work in particular areas, such as residential nursing homes or hospitals – they do not tend to follow an individual over a long period as he navigates the system and is faced with various choices at different times. People with chronic conditions are going to have needs that stretch over months and years, and having an advocate for today's choice, and who then disappears, really is a very limited source of help. Rather than advocates, many people might actually prefer a mentor – somebody who not only represents their interests, but who will also be supportive and have time to explain the choices available, and who follows a patient with a long-term condition throughout the stages of his time in the health and social care system. Unfortunately, the idea of mentors has not caught on.

Liz Sayce, Director of Policy and Communications, Disability Rights Commission

The value of choice and independence

For disabled people, choice and control have been the defining features in the improvement of disabled peoples' quality of life. About a quarter of a century ago the seeds of the disability movement were sown when a group of people with physical impairments, living in residential care, made their opinions known about how they wanted their lives to change, and they set up a newsletter. They resisted the notion that when you are physically or mentally disabled, other people must make decisions for you. The direct payments system is an example of how

people are bucking this assumption: Rather than social care staff turning up to provide a patient with assistance at their convenience, the patient actually holds the budget and employs assistants to arrive at the patient's convenience, which gives him much more control over the support he needs to live his life, the way he wants to live it. Direct payments allow a person to be spontaneous – being spontaneous if you are subject to the vagaries of bureaucracy is often next to impossible.

It is unsurprising that direct payments were originally proposed by disabled people themselves, and subsequently translated into policy. However, there are some areas where it could go further. For example, just under 8,000 people received direct payments in 2002/03, of whom only 736 had a learning disability and 132 had a mental health problem. In other words, direct payments have been made more available to some groups of disabled people than to others. There is some pioneering work underway to resolve the issue of how to make the direct payment system more equitable, by making it work for people who may need extra support in handling their finances and care plan, but these examples of good practice need to be spread. The other way in which direct payments might be extended is by applying it more widely. Currently the system only functions with personal assistance in the home, but the Prime Minister's Strategy Unit is looking at disabled peoples' life chances and exploring whether there might be other funds which could be passed to the individual so that he can take control over other aspects of his care.

Reforms needed in the NHS

Enabling choice for people with disabilities is particularly significant for the NHS, because disabled people are such high users of health services. The latest figures from the DWP showed there are about 10 million disabled people in this country, which is about one in five of the population. However, when you look at the users of the health services the proportion of disabled people is much higher – about a third of the users of the health service have some form of disability. We are simply not going to meet the general patient choice targets if we do not address the fact that a large proportion of these patients have long-term conditions or impairments. At the simplest

The latest figures from the DWP showed there are about 10 million disabled people in this country, which is about one in five of the population. However, when you look at the users of the health services the proportion of disabled people is much higher

level, we have to make services and information accessible to people with different requirements because of their disabilities. One simple initiative we carried out with the Department of Health was to produce a leaflet for staff in hospitals called *You Can Make A Difference*. It pointed out basic issues such as the fact that somebody might need information in a different format if they have visual impairment, or someone with learning disabilities might need a slightly longer appointment. If someone is coming in to hospital it is worth finding out whether they have any particular requirements – they might need to be assisted, they might find it difficult to walk, they might find it difficult to sit, etc. These are very basic considerations, and in a way you would expect the health service, or any service, to be aware of these issues, but often they are overlooked. In fact, outside of the disability specialist services, the NHS is not very good at providing individualised, flexible customer care for people with different types of disability.

Tackling inequality

There are, therefore, many issues to consider regarding how to make choice work for disabled people, and this is important because there are so many disabled people using the health service. Choice needs to extend beyond the kind of elective surgery and acute care a patient requires – it must also include control over the services the patient needs on a day to day basis, allowing him to manage his own condition and allowing health

and social care to work for the patient, so he can live the life he wants to live. There are however a few provisos within this assertion. The first is that given the levels of inequality that exist between some groups of disabled people and non disabled people, it is difficult to see how choice alone can drive the greater equity we are aiming for. To give an example, there was one study that found that people with learning disabilities were 58 times more likely to die before the age of 50 than the general population, which is an extraordinary figure. It was not due solely to additional health conditions linked to learning disabilities – the research found that people with learning disabilities have much higher rates of early death from preventable illnesses, like respiratory disease. This is because it has often been left to individuals with learning disabilities to go to their GP with their health concerns, of their own volition. Training, checkups, outreach, etc. on their own would be inadequate to drive the sort of change needed to address this inequality in life expectancy.

The history of equalities law suggests that using individual redress, that is, bringing individual cases under legislation – race relations law, sex discrimination law, etc., will also not produce the sort of systemic change required to address this and similar issues of inequality. Far reaching change can only be brought about by systemic investigations, recommending measures which the Equalities Commissions can implement across the board, in the same way as the Commission for Racial Equality is currently doing in the police force. Under the Race Relations Amendment Act, people do not wait for racism to

Working practices must change – if the patient has explained that they need a longer appointment due to their learning disabilities, this fact should be logged and the patient ought not to have to explain this again

occur and then expect the individual to get redress. Instead, it has been stipulated that public organisations have a duty, positively, to promote racial equality. There is a disability bill which we expect will be announced in the Queen’s Speech, and which we hope will implement similar rules for disability. So, in addition to individual choice mechanisms, we need a systemic approach which supports the individual in making choices and erases inequalities between disabled and non-disabled service users. For example, when a person with learning disabilities visits their GP, the Department of Health must look into adequately training GPs and receptionists to meet that patient’s particular needs. Working practices must change – if the patient has explained that they need a longer appointment due to their learning disabilities, this fact should be logged and the patient ought not to have to explain this again.

Moving away from a culture of “risk management”

So the first proviso is that systemic improvements as well as, not instead of, choice, are necessary. Second, we need to dispel the notion that health and social care services targeting disabled people are about managing risks faced by vulnerable people. In the introduction to the 1999 National Service Framework for mental health, the then Secretary of State said most people with mental health problems are not a risk to anybody else, they are really only a risk to themselves. This says an awful lot about how much emphasis was placed on managing risk in health and social services at that time. This was combined with a lot of public concern about people with mental health problems in the community.

Disabled people, both mentally and physically disabled, are tired of always being associated with risk, even in the most mundane areas of their lives. For example, there was a judicial review a year ago in which two women with learning and physical disabilities challenged a local authority that had a blanket ban on manual lifting and handling because this manual lifting and handling would be a risk to the backs of the care staff. This has led to ludicrous situations where disabled people are not able to live in their own homes or live independently because care staff are under instruction not to do any lifting – not even to help a patient into a hoist to help them into the bath, even

when they have the appropriate equipment. Relatives aged 80 are expected to lift their own spouse in and out of bed while a 22 year old care assistant stands by, under instruction not to help.

However, often it is about risk to self – the Disability Rights Commission have examined a huge number of legal cases where young disabled people have been excluded from going on school trips because they might put themselves at risk, and the school is not prepared to take that risk. In one case, a young person was forbidden from going up the stairs in a school on a specially adapted wheelchair because it was a health and safety risk, therefore, he was excluded from the entire sixth form college. His education suffered because of the emphasis on reducing and managing risk in health and social services. Health and safety is of course important, but perhaps even more important is for people with long term conditions to be able to participate fully in their communities. If services are risk averse, they entrench dependency amongst their users.

Fortunately, we are beginning to see some very positive moves away from this kind of “risk averse” approach. For example, the Social Exclusion Unit recently recommended that day services for people with mental health problems should be transformed, to move away from low activity day centres and more towards open employment schemes. The point is that choice and independence for disabled people will never be achieved with an excessive emphasis on vulnerability and risk prevention. This only leads to health and social care authorities making decisions for people, underestimating what they can do and not providing the support on patients’ own terms for them to fulfil their potential as citizens. In short, choice is crucial for disabled people. It needs to be extended. This can only be achieved with systemic approaches to addressing inequality and challenging the risk-averse culture in health and social services.

Points arising from the discussion

- There was general support for the need for longer appointment times with GPs to allow GPs to fully explain the choices open to a patient with a mental or physical disability. This would coincide with the need for greater use of advocacy/patient mentors to support them through series of choices.
- It was noted that public trust in GPs had been sustained at a very high level for a number of years, and so any reformed health systems would do well to keep the GP as “prime navigator” of patient’s choices, as this was where the patient’s trust lay.
- Questions were raised as to whether GPs would actually have the time to take on a greater navigator/patient mentor role, and that they might need support from other healthcare professionals.
- The opinion was expressed that ageism was alive and well in the health and social services, which was not helped by many services being defined by age bands. It was felt open choice for people of all ages would only be achieved if some of those age barriers were scrapped.
- There was a consensus that identifying how people attribute “reputation” to hospitals would be a key way in which to reduce inequality between high and low income groups in exercising choice. It was felt that the star system of rating hospitals was a new addition to a long history of hospitals building up local reputations over time, and sometimes these two factors did not overlap. The government had to acknowledge that what they rated as a “good” hospital might not coincide with the opinions of the surrounding community who had been attending these hospitals for generations.

- The Mental Capacity Bill was welcomed as it started with the assumption that an elderly patient, or one with dementia, did have the capacity to make his own decisions and choices. This would clarify the debate regarding who should be making those choices – the patient’s family, carer, doctor, or himself. Clearly there would be cases where the choice would fall to these third parties but the patient was still empowered by this Bill. It would act as a guideline for nurses and doctors faced with the common dilemma of when opinion between patient and carer conflicts.
- Questions were raised surrounding the issue of trust and information – it was accepted that people on the whole trust their GPs and some may not want to make choices themselves but rather leave it to their GPs to make decisions for them, but it could not be assumed that everyone felt the same. Trusting your GP does not mean you do not want additional information regarding healthcare services in order to make your own judgements or corroborate your GP’s opinion. It was felt the NHS had a paternalistic approach to sharing information with patients, assuming patients would not want detailed comparative information and did not want to make complex decisions.
- It was felt the term “vulnerable” often conjured up risk of abuse and the need for protection, which often limited choice. This term should actually identify those who needed more time to have choices explained, those who needed information presented to them in a different way, etc.
- To reduce inequalities healthcare professionals have to think more about the way they present information and guidance on choices so that it can be understood and be accessible to people of different cultural backgrounds, ages and disabilities. This is not a case of just packaging the information differently, but about the personal relationships between the GP/mentor and the patient which would allow the former to connect with the latter and ensure every patient, regardless of background, could make informed choices.

Core themes

A number of common themes arose during the seminar and the general discussion which followed. This was heartening, given that our diverse range of speakers included a government special adviser, a clinician, an academic, and a lead figure in the promotion of disability rights. These common elements included:

The need to make choice in health and social care more equitable

Tony Bayer pointed out that a person’s access to choice varied according to a) the condition he was labelled with, b) the specialist he was treated by and c) what he was told. Liz Sayce believed the difference in access to Direct Payments by different groups of disabled people, and the inefficiency with which the NHS catered its services to those with special needs, were the root causes of inequitable access to choice and independence in health and social care. Similarly, Nancy Devlin pointed out that her research seemed to show that difference in socio-economic and educational background affected patients’ choices and ability to choose. This was due to a lack of clear information regarding health services and a consequent reliance on an undefined hospital “reputation” and guidance from GPs.

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The importance of clear and accessible information

All speakers placed great emphasis on the level of information provided and the way in which it is presented in facilitating choice amongst vulnerable groups. Nancy Devlin believed that the healthcare market was almost unique in the way in which users relied on “reputation” and other people’s opinions to guide their choices rather than using objective comparative data. Tony Bayer also demonstrated the power of information in healthcare by reminding the audience that at one time, it was deemed acceptable not to tell terminally ill patients they had cancer, and that similar situations still arise amongst patients with dementia on a daily basis. Liz Sayce added that despite one third of NHS users being disabled in some way, health services had a poor record in ensuring information was accessible to all (with the use of different formats, longer consultation times, specially trained staff, etc.).

A need for greater personal support in making choices balanced with the value of user empowerment and patient independence

Paul Corrigan emphasised that new policy initiatives were balancing supported choice with patient independence, by pioneering schemes whereby patients would be able to help each-other navigate administrative systems and, when a patient became very ill, specialised staff, such as care managers, would ensure the patient could exercise choice for as long as feasibly possible. Paul also made the distinction between help with the administrative system, and with a patient’s own care and treatment. He believed that people with long term illnesses and disabilities were best placed to know how to manage their own conditions, and it was more important for them to have help with the navigation of the bureaucracy of the health service. This echoed Tony Bayer’s call for a greater use of “mentors” who would support patients as and when they needed in care homes or hospitals, and also supported Liz Sayce’s view that more disabled people needed to be given the independence to manage their conditions as they saw fit with the wider use of Direct Payments.

All speakers agreed, however, that the empowerment of the vulnerable user to manage his own care had to be tempered

in certain situations. Tony Bayer, as a clinician, described the difficulty in balancing the needs of an elderly or mentally disabled patient with the needs of his carer or family. Similarly, Liz Sayce cited the figure that the mentally disabled were 58 times more likely to die by age 50 than the rest of the population, often due to preventable diseases. Both suggested that legislative changes to clarify where such patients’ rights lie would help both those treating them, and the patients themselves, in asserting their right to choose their own method of care.

Conclusion

The common ground that was uncovered between government, practitioners and disabled rights campaigners during this seminar is a source of great optimism. Policy initiatives to engage patients with their own care, the Direct Payments scheme, and forthcoming legislation on disability discrimination suggests that stakeholders on all sides of the debate are moving in the same direction concerning the promotion of choice amongst vulnerable groups. However, the fact that common areas of concern arose amongst the speakers and the audience alike – in particular the need to address inequity in terms of access to choice not just between the disabled and non-disabled, but also between groups with different forms of disability, suggests that there is still some way to go before health and social care services promote equal access to choice of provision amongst all users. The SMF hopes, over the next year, to investigate the issues raised in this seminar, and further the work of promoting equitable outcomes through supported choice amongst all health and social care users with a series of seminars and interim papers to develop and discuss possible reforms and initiatives to achieve this goal.

How vulnerable or disabled groups can be supported in making informed choices in health and social care, whilst preserving their independence, is a key element to new health policy initiatives. In a seminar held at the SMF in October 2004, experts from different sides of this debate came together to reflect on the issues at stake in the promotion of user choice amongst those with special needs or limited capabilities.

It was heartening to find that all of the speakers – from the Department of Health, from the NHS frontline, from academia, and from the Disability Rights Commission, believed user choice was especially important for vulnerable groups in promoting their independence and recognising their right to manage their own condition or disability as they saw fit.

The range of concerns and sources of optimism that emerged as each of these individuals reflected on the future of supported choice, provided a clear picture concerning where progress still has to be made in facilitating equal access to choice in the health and social care sectors.



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