

COMMENTARY & ISSUES

□ JON GLASBY

University of Birmingham

□ PETER BERESFORD

Brunel University

Who knows best? Evidence-based practice and the service user contribution

Abstract

This paper reviews the assumptions underlying traditional medical research and critiques the concept of 'evidence-based practice'. In particular, it identifies and counters three basic tenets of this approach: the alleged need for objectivity in research, the notion of hierarchies of evidence and the primacy of systematic reviews. Instead, the paper argues for a new emphasis on 'knowledge-based practice', recognizing that the practice wisdom of health and social care practitioners and the lived experience of service users can be just as valid a way of knowing the world as formal research.

Key words: evidence-based practice, knowledge-based practice, user involvement

In recent years, there has been an increasing recognition that policy and practice in health and social care should be 'evidence-based'. In 1997, the White Paper, *The New NHS*, was clear that 'what counts is what works' (Department of Health, 1997). In particular, New Labour was adamant that 'services and treatment that patients receive across the NHS should be based on the best evidence of what does and does not work and what provides best value for money' (para. 75). This was to be achieved through a number of mechanisms including the dissemination of high quality scientific evidence through the national Research and Development programme, the introduction of new evidence-based frameworks for various health and social care services, and a new National Institute for Clinical Excellence (see over).

As part of this quest for evidence-based practice, a range of official bodies exist to explore and disseminate 'what works'. In the National Health Service (NHS), the UK Cochrane Centre was established in 1992 to facilitate and co-ordinate the preparation and maintenance of systematic reviews of randomized controlled trials of health care (www.cochrane.co.uk). It is now part of a worldwide network of centres, and a Cochrane review focuses on particular types of research evidence and on meta-analyses of studies. In the same way, the Centre for Reviews and Dissemination (CRD) was established in 1994 to provide research-based information about the effectiveness of interventions used in health and social care (www.york.ac.uk/inst/crd). In particular, the Centre focuses on systematic reviews of research which tend to prioritize particular forms of evidence in a hierarchy of study designs (see below for further discussion). More recently, the National Institute for Clinical Excellence (NICE) has been established by government in order to review the evidence and provide national guidance on health care and treatments (www.nice.org.uk).

In social care, where there is a natural tendency to look to the social sciences rather than to the physical sciences and to medicine, there has perhaps been less of a tradition of formal commitment to reviewing and acting upon evidence. However, even here, recent developments have seen the formation of the Campbell Collaboration as a sibling organization to the Cochrane Collaboration (www.campbellcollaboration.org). Focusing on the evidence base for interventions in the social, behavioural and educational areas, this body also emphasizes the importance of systematic reviews, but does include greater consideration of qualitative research than some of its NHS equivalents. At the same time, the Social Care Institute for Excellence (SCIE) produces guides and other publications which summarize the extent of our current knowledge on particular topics (www.scie.org.uk; see below for further discussion).

At face value, it seems difficult to argue against the claim that policy and practice should be evidence-based – who could possibly argue that what we do in public services should not be based on what we know to work? However, to claim that policy and practice should be evidence-based is a statement of a dilemma and not a blueprint for the way forward. For example, what constitutes valid evidence? Who decides? Do certain types of evidence seem to be treated as more legitimate than others? What happens when the evidence is fragmented or even contradictory? How much evidence

does there need to be before we can confidently develop and roll out a particular policy?

Perhaps seeking to provide some certainty in the face of such complexities, the research textbooks and guidelines seek to provide a series of ground rules for 'good' research (and hence valid evidence):

- 1 *The need for objectivity in research*: a golden rule of many standard textbooks is that all research should be 'objective'. This is based on the view that things exist as meaningful entities independent of consciousness and experience and that rigorous scientifically based research can discover that objective truth and meaning (Crotty, 1998: 5). Such an 'objectivist' approach to research highlights the need for and possibility of research which is neutral, unbiased and distanced from its subject. The unbiased value-free position of the researcher is a central tenet of such research. By claiming to eliminate the subjectivity of the researcher, the credibility of the research and its findings are maximized. Research can therefore be replicated by other researchers in similar situations and always offer the same results. Research that does not follow these rules and that is not based on this value set tends to be seen as inferior, providing results that are less valid and reliable.
- 2 *The concept of a research hierarchy*: arising out of these claims about objectivity, much of the literature portrays different types of evidence in a hierarchy. This tends to place systematic reviews and randomized controlled trials (both approaches associated with science and medicine and both deemed to be the most objective approaches) at the top of the hierarchy, with qualitative research and expert opinion (including the views of service users and carers) further down (on the grounds that they are more subjective and sometimes even 'anecdotal'). As an example, the hierarchy set out in Table 1 is used in the government's *National Service Framework for Mental Health* (Department of Health, 1999: 6) as a means of grading and synthesizing the evidence, and is similar to those used by the NHS Centre for Reviews and Dissemination and other bodies committed to developing the evidence base for health care interventions. However, this approach has been criticized (Cohen et al., 2004) on three main grounds: randomized controlled trials and meta-analyses have not been shown to be more reliable than other approaches; they can only answer limited

Table 1 A hierarchy of evidence

<i>Hierarchy</i>	<i>Type of Evidence</i>
Type I	At least one good systemic review, including at least one randomized controlled trial
Type II	At least one good randomized controlled trial
Type III	At least one well designed intervention study without randomization
Type IV	At least one well designed observational study
Type V	Expert opinion, including the views of service users and carers

questions; and they do not include other non-statistical forms of knowledge.

- 3 *The importance of systematic reviews*: in standard research hierarchies, systematic reviews (including at least one randomized controlled trial) are usually the first category (and therefore the 'best' form of evidence), given precedence over other forms of evidence.

In contrast, this paper challenges these principles and the overall notion that policy and practice should be 'evidence-based' (in the current usage of the term). In particular, we argue that:

- 1 Objectivity is not a prerequisite for valid evidence (and can even be harmful in some circumstances).
- 2 There is no such thing as a hierarchy of evidence.
- 3 There is much greater scope for literature reviews that include a much broader range of material than would usually be the case in traditional systematic reviews.

Underlying each of these statements is a belief that what is currently constituted as 'evidence' is too often dominated by academic researchers (often influenced by the physical sciences and medical approaches) and neglects the views and experiences of people who use and work in health and social services. This, we argue, can be just as valid as more traditional, quantitative approaches, and neglecting these perspectives gives a false and potentially dangerous view of the world.

In exploring these issues, we draw heavily on the personal experiences of both authors through a number of research studies and through personal experience of using services. These include three main sources of ideas:

- 1 In 2003, the National Institute for Mental Health in England published *Cases for Change*, a narrative review of what works and what does not work in adult mental health (Glasby et al., 2003). In producing this review, the core research team included a social worker, a general practitioner and a mental health service user, and the 653 documents reviewed incorporated a much broader range of material than is normal for official reviews (ranging from systematic reviews and randomized controlled trials to user-focused qualitative research). This study is described in more detail below, including a discussion of the approach adopted and the lessons learned.
- 2 In 1997, the findings of the Citizens' Commission on the Future of the Welfare State, supported by the Baring Foundation, were published. This exploration of existing welfare state services and welfare reform was initiated, controlled, carried out, analysed and written up by a wide range of welfare state service users (Beresford and Turner, 1997). It was followed up by two studies, supported by the Joseph Rowntree Foundation, again initiated and undertaken by a wide range of health, welfare and social care service users, one exploring what service users wanted from the welfare state and the other reporting a series of local development projects to implement 'user-defined outcome measures' in social care (Shaping Our Lives et al., 2003; Turner et al., 2003). All these projects offered a challenge to traditional academic and medical research, prioritizing a different way of knowing the world.
- 3 Both authors are board members of the Social Care Institute for Excellence (SCIE) and, in part, applied for such positions as a result of their interest in seeking to understand many of the issues raised in this paper.

Objectivity as a prerequisite for valid evidence?

What has been called 'objectivism' in research – that is to say a commitment to values of objectivity, neutrality and distance – can now be seen as just one strand of thought among a variety of

emergent approaches to research and the production of knowledge, despite its traditional centrality in medical research. A whole range of research approaches critical of such values and assumptions have emerged. All raise issues about the researcher's relation with the world. Some, notably feminist approaches, have highlighted the nature of the relationship between researcher and research participants, critiquing traditional 'scientific' epistemology as a means of domination by those with power in society. They reject the idea of 'objectivity' as a feasible constituent of any research (Harding, 1993).

The most recent and perhaps most relevant of such research approaches to our discussion here is that developing in emancipatory disability and service user controlled research. These are the research approaches which have been developed by movements of health and social care service users, including, for example, the disabled people's and psychiatric system survivors' movements (Lindow, 2001; Mercer, 2002; Oliver, 1992, 1996). Both reject positivist assumptions of 'objectivity'. Their concern is with making change and not only the production of knowledge, which is seen as insufficient justification for research. This is reflected in commitments to:

- Changed, more equal social relations of research production.
- The empowerment of service users.
- The making of broader social and political change.

They are offered as explicitly political (and partisan) approaches to research, prioritizing the achievement of the human and civil rights of service users and their increased say and choices over their lives and the services they are offered. They not only acknowledge the subjectivity of their own (and other research) approaches. They have also begun to challenge positivist assumptions about the helpfulness of being 'distanced' from their 'subject'. Thus, they not only challenge traditional assumptions of the deficiencies of service users designing questions and interviewing research participants. They also identify *gains* in doing this, for instance, in terms of these making more sense to the participants and eliciting different, fuller responses (Rose, 2001). Now both implicitly and explicitly, the advocates of such research approaches are questioning both the possibility of 'neutrality'

and 'distance' in research, and whether what have been seen as their 'merits' may actually be deficiencies (Beresford, 2003).

The problem of being 'distant' from the experience being interpreted has particularly been highlighted. This can lead to the distortion and misunderstanding of such experience, for example, as a result of:

- Unequal power relationships between researcher and research participant, resulting in either hostile or paternalistic understandings.
- Inadequate awareness on the part of 'distanced' interpreters of their own position in relation to other people's experience, cultures and perspectives.
- Discrimination relating to class, race, gender and other forms of difference.
- Commitments to ideologies, agendas and values which pull people away from valuing or being able to appreciate the other person and their experience.
- Socialization into and reliance on models of understanding which subordinate and pathologize people (for example, medical models of 'mental health') (Beresford, 2004).

An historically significant example of the problems inherent in such 'distance' was the 1972 Miller and Gwynne study of institutionalized disabled people. Disabled people's reaction against this research played a key part in the development of emancipatory disability research. This study rejected the experiential knowledge of disabled research participants, who said that they wanted to and could live with appropriate support 'independently' in their own homes. It asserted instead that this was 'unrealistic' and that they were inherently 'parasitic'. Subsequent changes in thinking, policy and practice based on the experiential knowledge of disabled people have fundamentally disproved this argument.

More recently, a range of gains from researchers being 'closer' to the issue under study have been identified and the benefits of researchers getting closer to the experience with which they are concerned have been explored. A number of ways in which researchers (without shared experience with research participants) can do this have also been suggested (Beresford, 2003; Mercer, 2002).

Hierarchies of evidence?

Although many researchers and policy makers advocate a hierarchy of evidence, the *Cases for Change* review cited above argued that no one research method is automatically better than another. Instead, a research method is only helpful and appropriate if it fully answers the question that is being asked. Thus, if we want to test the effectiveness of a new drug, we may well wish to use a randomized controlled trial to explore the success of the new treatment and any possible side-effects. We may also draw on health economics to weigh up the cost of the drug against its benefits. However, if we want to know how best to improve access to social care services, we might ask current workers (about possible barriers and what might help to make services more accessible) and ask (previous) service users (how it felt making contact with social services and how this process could be improved). We might also observe social services area offices to watch what happens when new people come into the building for the first time, focusing on the physical location and accessibility of buildings, the behaviour and approach of office workers, the quality and atmosphere of the waiting room, and so on. In addition, we might also want to propose some changes as a result of our findings, then repeat our research to see what impact our work might have had and whether or not our hypotheses were correct.

Similarly, if we want to know what it is like to be admitted to a mental health hospital and whether this helped or hindered service users, we would ask them what this process felt like and the impact they believe it had on them. In cases like this where the issues are likely to be very personal and difficult, we would suggest working with service user researchers who might be able to develop a greater bond and rapport with research participants as a result of having been through similar experiences themselves.

In the *Cases for Change* review (Glasby et al., 2003), the research team deliberately set out to include a broad range of material in order to provide as comprehensive an overview as possible of mental health services. This included systematic reviews and randomized controlled trials as well as qualitative research and studies focused on the experiences of users and practitioners. At the start of each report, we summarized the types of evidence found using the categories from the *National Service Framework for Mental Health* (see Table 1) so that

readers could see the spread and nature of the research. However, we did not state which category individual studies fell into, as this would imply a hierarchy which we did not feel was appropriate.

Hardly surprisingly, this produced a different response than if we had used a traditional research hierarchy. As an example, our hospital report found 37 documents, many of which came from traditional 'type IV' and 'type V' categories (see Table 2). As a result, the chapter would have found no material at all had it relied solely on systematic reviews. By broadening to include quantitative surveys we gained a degree of insight into the pressures on acute beds and the high rates of inappropriate admissions and delayed discharges. By including professional opinion, the study was able to consider good practice guides produced by official bodies such as the Royal College of Psychiatrists or the Department of Health. By including the views of people who had observed inpatient settings, we gained an insight into what neutral observers feel about hospital services. This included a very powerful description of the views of social work students, who had spent time on acute wards and were shocked by the 'institutional aimlessness, poor staff-patient relationships, a narrow approach to mental health and a lack of attention to civil and human rights' which they found (Walton, 2000: 77). However, by including user-focused surveys and qualitative research we were able to report some very widespread concerns from current and former service users about the negative nature of life in acute care and the impact of this on people's mental health status. As an example, one national survey by the mental health charity, Mind, provided an alarming insight into life on the ward (see Table 3). This and other user-focused studies painted a

Table 2 Different types of research into mental health hospital services (Glasby et al., 2003)

<i>Type of Evidence</i>	<i>Number of Articles</i>
Type I	0
Type II	3
Type III	0
Type IV	16
Type V	18

Table 3 Service users' experiences of acute care (Baker, 2000)

<i>Description of hospital services</i>	<i>% of patients (n = 343)</i>
People who needed an interpreter did not get one	64
Difficult to get a restful night's sleep	60
Users do not have enough time with staff	57
The ward was untherapeutic	56
Not enough access to food	45
The ward had a negative effect on user's mental health	45
Ward atmosphere was 'depressing' and bleak	45
Not enough access to drinks	31
Ward atmosphere was unsafe and frightening	30
Illegal drugs were being used on the ward	30
Toilets were not clean	26
Users experienced sexual harassment	16

distressing picture of untherapeutic, unsafe and dirty wards, the easy availability of illegal drugs, insufficient interaction with staff, inadequate access to food, drink and fresh air, high levels of boredom, a lack of respect for patients, a lack of information for service users and carers, high staff vacancies, low morale and insufficient privacy (see, for example, Baker, 2000; Ford et al., 1998; Goodwin et al., 1999; Higgins et al., 1999; Warner et al., 2000; Watson, 2001). Where people said that they had experienced discrimination or where they claimed that they had been physically or sexually abused, some felt that their complaint had not been taken seriously because they had a mental health problem (Glasby et al., 2003).

For the research team, these were important findings which demanded an urgent policy response. However, when we began to submit papers to journals (particularly when we chose medically focused journals) we encountered a number of objections based on our approach. In particular, some reviewers were worried about the classification and quality of the studies included, adding that more

mention should be made of 'Cochrane and other systematic reviews of randomised controlled trials'. For others, some of the material included was 'idiosyncratic', the search was 'limited in scope', there was no meta-analysis, the review was unscientific and the study failed to meet minimum criteria for undertaking a systematic review. With the last comment, one of the reviewers kindly included guidance on meta-analyses of randomized controlled trials.

Interestingly, these same objections were not encountered when submitting to more social science/qualitative research-orientated journals (where reviewers felt that the approach was 'acceptable' and 'methodologically sound' and where a number of papers were published). This raises two fundamental issues:

- 1 Why do academics from different backgrounds have such divergent views about what constitutes valid research?
- 2 What is more important – an academic commitment to a particular way of knowing and researching the world, or the alleged abuse, extreme boredom and poor quality care that some service users say they experience in mental health hospitals? Surely our first priority should be to explore in greater detail whether these accusations are true, not to argue about underlying methodological concerns. Of course, this is an overly simplistic statement in so far as deciding whether or not something is 'true' prompts exactly the same methodological and philosophical issues raised in this paper. However, what is important here is not just a discussion about research methods and valid knowledge, but the danger that these debates could serve to obscure rather than illuminate some very real concerns about current service provision.

By utilizing a hierarchy of evidence, *Cases for Change* might have been more methodologically acceptable to a number of peer reviewers, but it would have rejected service users' experiences of hospital as 'anecdotal' and as less valid than other forms of knowledge. Crucially, it would also have failed to highlight these fundamental problems in acute care or to ask for a policy response. Viewed from this angle, the definition of valid knowledge becomes more than an academic argument – it becomes a fundamental issue of human and civil rights, of the quality of care we provide to people when they are at their most vulnerable and, in extreme cases, of life and death.

The primacy of systematic reviews?

Above, we set out our concerns about the focus of systematic reviews on particular types of evidence and the danger of neglecting other potentially valid ways of knowing the world that do not fit our preconceived hierarchies. In addition to including a broad range of service user-focused studies, however, *Cases for Change* also sought to move beyond the boundaries of a traditional systematic review in a number of other ways. First and foremost, the study incorporated the views of service users at every stage of the project. This included:

- 1 A collaboration between two university departments (the University of Birmingham's Health Services Management Centre and the Department of Primary Care and General Practice) with SUREsearch (a body of mental health service users who conduct user controlled research).
- 2 The involvement of a service user in the interview after our bid was shortlisted.
- 3 A mental health service user as a member of the expert panel advising the research.
- 4 The involvement of local service users and carers in defining initial search terms.
- 5 The recruitment of a mental health service user to work as a core part of the research team, helping to draw out and understand key themes across all topic areas, but taking specific responsibility for reading the literature and producing the report on user involvement.
- 6 The inclusion of critical commentaries at the end of each report, written by individual practitioners and service users in different parts of the country. These were designed to provide an individual response to our findings from someone with experience of the mental health system, and had a key part to play in the project (see below for further discussion).
- 7 The active involvement of the service user researcher at the launch conference and in further dissemination.

Although literature reviewing is often portrayed as an objective task, with different research teams capable of replicating the findings of any given review, we believe that all research is inherently subjective (see above for further discussion). As a social worker by training, one of the research team tended to view findings through a social work lens,

often identifying and prioritizing different themes and issues to colleagues from a different background. Having service user involvement in the study therefore meant that a user perspective was included in these debates at every stage alongside the different viewpoints of other members of the team. In addition, having a service user as part of the team made other team members try to consider how service users would think and feel in mental health services and when reading our report. It made us challenge our own assumptions, consider our language and be very honest and open with ourselves about our attitudes and values. As health and social care professionals, this process also helped us to reflect on the way in which the services for whom we work/have worked treat some of their service users and how this may feel.

Also crucial to *Cases for Change* was the inclusion of 'critical commentaries' at the end of each report, written by service users, practitioners and managers in different areas of the country to give a personal response to the report findings. Underlying this approach was an assumption that the published literature is only one form of evidence and that different people in different areas may well have different views and experiences. Thus, a hospital manager was able to read our hospital report and agree with many of our findings, but also to highlight some of the more positive developments that were under way which had not filtered into the literature. In the report on partnership working, a mental health service user who had sat on the board of an integrated trust was able to broaden the debate in most of the literature (which often focuses on the process of partnership working) to consider outcomes for users and carers. In addition, a black service user reading our discrimination chapter supported a number of our findings but objected to our suggestion that mental health services used to be single sex, but became mixed in the 1970s as this was felt to more accurately reflect ordinary life in the community. For this person – an Asian woman – mixed sex provision was not 'normal', and much of the literature in this area is written from a white UK perspective. As white UK researchers, this is not something that had occurred to us when conducting the literature review, and the insight offered by this critical commentary was an important one with which we agree entirely now that it has been pointed out to us.

Underlying all these approaches (and fundamental to our belief in the need to move beyond traditional systematic reviews) was a subtle

but crucial change in the title of the project. Initially, the study was commissioned to identify 'The Case for Change' in mental health, but this quickly evolved into 'Cases for Change' as the team realized that there was no one answer to 'what works', but rather a series of different voices and perspectives (some of which appear to get heard more often than others when service reform is being discussed).

New ways of knowing the world?

In place of traditional research hierarchies, 'objective' medical research and systematic reviews, this paper argues for a new understanding of what constitutes valid knowledge. Such an approach would recognize the contribution of traditional medically focused, quantitative randomized controlled trials and systematic reviews, but would see these as only one of a number of potentially useful ways of understanding the world and shaping health and social services. This should include the practice wisdom or 'tacit knowledge' (Collins, 2000) of practitioners and the lived experience or 'human testimony' (Lindow, 1999) of service users and their families. Such an approach – which we term 'knowledge-based practice' rather than current 'evidence-based practice' – would involve an alternative set of principles to those set out and critiqued in this paper:

- 1 The 'best' method for researching any given topic is that which will answer the research question most effectively.
- 2 The lived experience of service users/carers and the practice wisdom of practitioners can be just as valid a way of understanding the world as formal research.
- 3 For some research questions, proximity to the object being studied can be more appropriate than notions of 'distance' and 'objectivity'.
- 4 When reviewing existing evidence on a topic, it is important to include as broad a range of material as possible.

Of course, such propositions are only the beginning and raise a range of questions that will need further work and exploration. In particular, how can we best utilize the results of diverse forms of knowledge, and how can we judge the accuracy and quality of such knowledge? However, as our previous discussions suggest, perhaps one way

forward is to acknowledge that with any proposed policy change there will rarely be a single 'case for change', but rather a series of 'cases for change'. With this recognition, our traditional quest for quantitative, 'objective', systematic knowledge will need to be replaced with a more questioning approach which constantly asks which stakeholders may be able to contribute to the debate, whose voices usually get heard in such debates and who decides what constitutes valid knowledge.

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□ Jon Glasby is a qualified social worker and a senior lecturer at the University of Birmingham's Health Services Management Centre. Research and publication interests include community care for older people and the interface between health and social care. *Address:* Health Services Management Centre, University of Birmingham, Park House, 40 Edgbaston Park Road, Edgbaston, Birmingham B15 2RT, UK. email: J.Glasby@bham.ac.uk □

□ Peter Beresford is professor of social policy and director of the Centre for Citizen Participation at Brunel University. He is chair of Shaping Our Lives, the national user controlled organization and a long-term user of mental health services. □