

Part I: The Context

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1 Service User and Carer Involvement in Higher Education

I never thought that I would be involved with a university's teaching and learning – possibly sweeping the floor would have been the only way in.

1.1 Introduction

There has been a general trend over recent decades towards acceptance of the notion that the public ought to have a more participatory role in the state, and that people who make use of various services have a particular interest in decision making and planning as well as the nature of service they receive. This general consumerism has been influential in United Kingdom policy relating to health and social care, and in specific institutions of care delivery (DH, 2005, 2006a; HM Government, 2007). Often coming from a different ideological position, the same ends have been pursued by a burgeoning social movement of service users and community groups. Most recently, the notions of personalisation and personalised care have come to the foreground in analyses of service failings and prescriptions for reform (Carr, 2008). This trend is evident in the Darzi review of the UK National Health Service (NHS) and the growing adoption of individual budgets in the social care field in particular (HM Government, 2007; DH, 2008, 2009a).

The idea that people should have a say in the planning, delivery and evaluation of their care, and that their views should be respected and acted upon by practitioners, is almost taken for granted in the United Kingdom, and in other resource rich countries, such as Canada. A natural extension of this expansion of participation is to create and sustain similar opportunities for involvement in higher education institutions, where health and social care staff are trained, and where relevant academic research staff are located. This has been matched by a global interest in collaborative approaches to interprofessional learning and workforce development that also bring service users and carers in to the partnership and promote community engagement (Hargadon and Staniforth, 2000; Barr *et al.*, 2005; Freeth *et al.*, 2005; Meads *et al.*, 2005; Hammick *et al.*, 2009). Over the last few years, a great

deal of interest has developed in methods of developing and supporting such an endeavour. This has resulted in the production of numerous reviews, guidelines and position statements for involvement activity, in service delivery (Crawford *et al.*, 2002; Public Administration Select Committee, 2008), in research (Beresford, 2005b; Hanley, 2005; Involve, 2007), and in education and training (Wykurz and Kelly, 2002; Repper and Breeze, 2007; Tew, Gell and Foster, 2004; Branfield *et al.*, 2007).

A wealth of interesting initiatives has been developed across the range of universities with a stake in the education of health and social care staff and research in the field. These include involvement in all aspects of teaching and learning, such as curriculum planning, lesson planning, delivery of teaching sessions, course and module management, assessment of student progress and wider quality assurance processes (Downe *et al.*, 2007). Service users and carers have also been at the centre of various innovations in practitioner education, such as enquiry or problem-based learning (Dammers, Spencer and Thomas, 2001), e-learning and distance learning (Simpson *et al.*, 2008), and simulated patient sessions (Morris, Armitage and Symonds, 2005; Priestley, Hellawell and McKeown, 2007). This involvement extends into the arena of interprofessional learning and collaboration, which is transacted in both universities and the workplace (Meads *et al.*, 2005). In the United Kingdom, various professional reviews and regulatory bodies who have oversight of curriculum development have advocated both user involvement and interprofessional learning (DH, 2006b; GSCC, 2005).

Involvement in research can be at different stages of the process, but there have been few examples of extensive involvement throughout a research study, or, indeed, of completely user-led research, though this is growing (Lowe and Hulatt, 2005; Pitts and Smith, 2007; Sweeney *et al.*, 2009). In a context of wider community engagement, involvement in participatory action research approaches offers a promising route to more complete engagement, opportunities for authentic user-led research studies and opening up the civic role of higher education institutions (Hanley, 2005; Holdsworth and Quinn, 2006; Church, Shragge, Fontain and Ng, 2008).

The development of service user and carer involvement in universities has been piecemeal. New initiatives have evolved because of the activity of key individuals, rather than always being effectively planned and supported at the institutional level. Reflecting this, resources and funding are a perennial problem for a number of university initiatives and projects, raising real questions about sustainability. There are a few exceptions to the rule. In the United Kingdom, ring-fenced funding is available in relation to social work training and, despite its relatively low level, these monies have been valuable in developments associated with social work. A number of networks have grown up to support people interested in relevant work, for example the Developers of User and Carer Involvement in Education (DUCIE) network hosted by the Mental Health in Higher Education (mhhe) initiative. There have also been a number of international conferences and scholarly meetings focused on health and social care services user and carer involvement in universities, including the foundational *Where's the Patient Voice Conference* (Farrell, Towle and

Godolphin, 2006) and the University of Central Lancashire (UCLan) *Authenticity to Action Conference*.

International efforts to involve service users and carers in higher education settings are too numerous to list. Some examples from different international contexts that have had a systemic impact are noted here. In Australia an alternative approach has been the direct employment of a service user in an academic post, referred to as consumer academic, with the remit of encouraging greater consumer involvement within the Centre of Psychiatric Research, the provision of a consumer perspective and, ultimately, greater acceptance of consumer involvement by academics (Happell, Pinikahana and Roper, 2002). A number of United Kingdom universities have appointed development workers to academic posts to support user and carer involvement. Many of these appointments are of people with personal experience as service users, including notable examples at City University, London, and the University of Leeds, both in the United Kingdom. In Toronto, Canada, well developed relationships between Ryerson University and a range of community groups and individuals have led to a number of interesting collaborative developments. There is *A History of Madness* course open to all students of the university designed and taught by David Reville, mental health service survivor and community activist. In a lengthy partnership, mental health service users and academic staff have worked together to establish and evaluate a range of social businesses using participatory action research approaches (Church, 1997). In the United States, *Community and Physicians Together* is a joint venture between the University of California, Davis, a local health care provider and 10 community organizations in the Sacramento area. Doctors in training are allocated to community groups where people from the community assist in teaching them about their individual health needs and how best to make a difference to health at a community level. This initiative was awarded the Campus Compact Thomas Ehrlich Award for Civically Engaged Faculty in 2008 (Paterniti *et al.*, 2006). The Comensus initiative at UCLan has attempted to develop a systematic approach to user and carer involvement that covers a whole Faculty and reaches other university business and Faculties (Downe *et al.*, 2007). At Brunel University, London, Peter Beresford, mental health service user and activist, has held a chair since 1998 in the Centre for Citizen Participation, and has made a significant contribution to pushing forward issues of user involvement in both education and research in United Kingdom universities.

This book deals with alliances between universities and service users and carers at a number of different levels: people who have experienced significant use of health or social care services, those who care for sick or disabled relatives, those who choose not to use services for various reasons, those who experience stigma or social exclusion linked to a health condition or disability, those who wish to celebrate positive experiences and examples of good practice and those who have had negative experiences and need to address examples of poor practice. All have a stake in the activity of universities. This may be in terms of seeking influence or direct participation in the range of university business, or it may be in attempting to harness the resources of the university to support individuals and groups

to tackle concerns arising in the community. The most obvious means of engagement is involvement in the training and education of the health and social care workforce as a vehicle for effecting desired changes in service provision. Similarly, involvement in research activity can be potentially influential in making services better. At a more complex level, closer relationships between community participants and academic staff can begin to subtly or significantly transform working practices in universities and their inter-relationship with the community.

The primary reason for involving service users in the training and education of mental health professionals is the anticipation that it will produce practitioners capable of delivering improved and more relevant outcomes for users and their carers. (Tew *et al.*, 2004)

This premise has seen a number of universities in a range of countries setting up service user and carer involvement initiatives that strive to incorporate service user and carer perspectives in the education of future generations of practitioners (Barr, 2005; Church, 2005; Church, Bascia and Shragge, 2008). This range of involvement is often linked to wider community engagement activity, with the relationship between universities and their local communities of significant importance to all parties (McNay, 2000; Cone and Payne, 2002; Savan, 2004; Winter, Wiseman and Muirhead, 2006; Campus Compact, 2009). At this level, individuals and community groups will begin to have a strategic voice within universities, addressing key concerns, such as widening access or reciprocal use of resources, or academic knowledge and power may be mobilised to support community campaigns. In such a context, interesting questions arise concerning identity, with academic and lay identities open for transformation or entrenchment (Church, 1996; Spandler and McKeown, 2008).

Arguably, health and social care professionals need to be equipped to involve service users and carers in both personal and strategic decisions. An understanding of relevant social and political factors can be seen as crucial to this enterprise. For this to happen, future health and social care practitioners need to be given the skills as soon as possible within their training and should regard this involvement as standard and not merely as an add on to practice. In seeking full and empowered participation, service user and disability activists rally behind the clarion call of *nothing about us, without us*. This echoes the classic feminist stance, in which the personal is most definitely political.

1.2 The Politics of Health and Welfare

Conventional welfare provision in the United Kingdom has been criticised as paternalistic. This is taken to mean that interventions are carried out for the perceived good of service users by those seen as authoritative experts. Systems built on this premise have led to doctors, social workers and nurses being afforded status and authority, with service users and carers deferring to their specialist knowledge and expertise. At its worst, this approach leads to the service user or carer having

minimal input into any care regime, and feelings of disempowerment, confusion and uncertainty occur.

Means and Smith (1998: 71) suggest:

There is no simple answer as to what does and what does not represent user empowerment, since it is a contested concept. However, most would argue that it involves users taking or being given more power over decisions affecting their welfare.

Change within health and social care services is slow. However, two drivers have been significant in bringing the voice of service users and carers to the fore. These are:

1. The growth of consumerism, latterly associated with a personalization agenda.
2. The growth and status of a number of service user and carer movements campaigning for transformation of services.

In the 1980s and early 1990s public services in the United Kingdom and elsewhere became heavily influenced by the notion of consumerism. Users of services were seen as customers who could exercise choice about the care they received. The development of consumerism in the United Kingdom health and welfare context grew out of a prevailing neo-liberal political ideology strongly associated with the Conservative government of Margaret Thatcher. This New Right philosophy highlighted the need to promote individual choice, roll back the welfare state and expand the influence of the private sector within health and social care. Notwithstanding claims to the contrary, the advent of a New Labour government in 1997 did little to diminish the broad privatization agenda. There has been a progressive critique of these policies, particularly in relation to their lack of adaptability to health and social care. Consumerism has, however, opened up various empowerment strategies for service user and carer movements. It has done this by emphasizing that every individual is a citizen with a set of social, civil and political rights. Users and carers have carried out collective action congruent with this premise and, as a result, changes in legislation, policy and practice have come about. Whilst service user movements have to some extent taken advantage of the political opportunity afforded by the rise of consumerism, movement politics are more complex and, arguably, have much more in common with the progressive left and strands of anarchist political thought than with the new right. Those seeking organizational change within universities come up against various structural and cultural barriers that need to be understood and overcome.

1.3 Organizational Culture and Culture Change

The concept of culture within organizations has been thought of and defined in different, diverse and sometimes contradictory ways. For Geert Hofstede (2001: 9), culture is *'the collective programming of the mind that distinguishes the members*

of one group or category of people from another'. Diana Pheysey (1993: 19) also sees culture in this way, stating that culture is '*a programmed way of seeing derived from beliefs and values*'. Deal and Kennedy (1982) also ally themselves to these theories believing that '*a strong culture is a system of informal rules that spell out how people are to behave most of the time*'. Essentially, '*it is the way we do things around here*'. Robbins (2001) defines organizational culture as the social glue that helps to hold an organization together. Andrew Brown's (1998: 9) definition articulates well the interplay between inculcation of collective values and norms of behaviour in the culture of organizations:

Organisational culture refers to the patterns of beliefs, values and learned ways of coping with experience that have developed during the course of an organisation's history, and which tend to be manifested in its material arrangements and behaviours of its members.

Peters and Waterman (1982) claim that '*excellent companies are marked by very strong cultures*'. However, this is not necessarily the case. As Brown (1998) notes in his 'consistency hypothesis', strong cultures do not equate with high performance where inconsistency between the espoused culture and culture in practice is present.

Those who advocate culture management tend to assume that culture is a variable that is easily identified and manipulable. (Woodall, 1996: 27)

Jean Woodall implies that the management of culture is problematic. Brown (1998) agrees with Woodall's perception but states that the difficulties are of a relative rather than an absolute nature and that to manage culture requires '*the ability both to introduce change and to maintain the status quo*' (Brown, 1998: 161). This dichotomy can be evident in universities, where the espoused culture may welcome service user and carer involvement but established hierarchies, bureaucratic systems and processes, entrenched throughout these organizations, ensure that cultural change is difficult to realise. This issue is illustrated in Chapter 6, using the specific example of the Comensus initiative.

Schein's (1985) levers for change advocate that managers should engage in actions in an attempt to manipulate their employees. Such manipulation is often met by resistance to change. Robbins (2001) differentiates between individual and organizational resistance to change. He cites individual sources of resistance as habit, need for security, fear of the unknown, economic factors, selective information processing and myopia. Organizational sources of resistance are structural inertia, limited focus on change, group inertia, threats to expertise, power relationships and established resource allocations. Some of these resistors to change are clearly apparent in universities; where academics are seen as the experts along with associated power imbalances.

Some universities have strong cultures and emphasise a clear mission. Whilst some authors celebrate strong cultures (Peters and Waterman, 1982) believing them to be a recipe for success, others argue that strong organizational cultures

can be oppressive and reduce innovation, making change difficult to accomplish (Flynn and Chatman, 2001).

The stronger the culture, the harder it is to change. Culture causes organisational inertia; it is the brake that resists change because this is precisely what culture should do – protect the organisation from willy-nilly responses to fads and short term fluctuations. (Deal and Kennedy, 1982: 159)

Ogbonna (1992: 8) agrees with this stance and argues that ‘the ability to manage culture implies not just a capacity to change and maintain it, but to create, abandon and destroy it as well’.

Adoption into core areas of performance may be a route to more profound organizational cultural change. As Pennington (2003: 251) states:

The truth is that culture change is driven by a change in performance. An organisation’s culture cannot be installed. It can be guided and influenced by the policies, practices, skills and procedures that are implemented and reinforced. The only way to change the culture is to change the way individuals perform on a daily basis.

For this change to happen, Pennington suggests five basic ideas for performance change: create a business related sense of urgency; focus on performance by setting specific goals, and measure everything; change systems and structures in addition to skills; make change a way of life; and, finally, create opportunities for ownership.

There is a risk that these approaches may result in enforced change that is not fully embedded in the values of organizational members. Despite the widespread acceptance of the validity of service user and carer involvement, it is possible that complex higher education organizations defy easy systematic integration of such involvement. Possible reasons for this might be the differing value base of stakeholders. Career bureaucrats, academics and lay participants may all have a commitment to increased user and carer involvement for entirely different reasons. In the university context, the various health and social care practice disciplines may also exhibit historically entrenched features of professional identity and socialization, associated with enduring claims to power that can operate to limit the realization of transformative goals (Luke, 2003). Significant cultural change can, possibly, only occur within the organization if all parties are authentically attached to altruistic and equity based values which would define a truly service user and carer led initiative.

1.4 Policy and Implementation

In the United Kingdom context, the agenda of authentically involving service users and carers in the development, delivery and evaluation of professional education in health and social care is gaining importance within services (DH, 1994a,

1998a, 2000a, 2001a, 2004a; NHS Executive, 1999) and with professional bodies such as the General Medical Council (GMC, 1993) and the General Social Care Council (GSCC/SCIE, 2004). This involvement has grown in prominence due to a combination of legislation and the recognition by professional bodies that, if future health and social care practitioners are to be prepared to work in user-led services (DH, 2005), then there is a need for their input within all spheres of training, from the clinical practice arena to the classroom.

Curriculum developers should recognise the important role of carers and users in advising on service provision and development. Consultation processes should be wide ranging and representatives of service users and carers should be involved where practicable in the development, delivery and evaluation of curriculum. (National Board for Nursing and Midwifery for Scotland, 2000: 4)

Involving service users and carers in the education of future health and social care practitioners provides students with a unique insight into lived experience, grounds education in reality, enhances the students' experience, provides an added dimension to teaching and empowers the service user and carer. Few universities have responded comprehensively to the call for involvement, and critics suggest that involvement in practitioner education has been inconsistent (Basset, 1999). This highlights the need to examine current initiatives and examine the scope, remit and effectiveness of such activity.

Health and social care policy requires service user and carer involvement in practice, research and education, but evidence of its impact, scope and the influence of such involvement need to be investigated. There is a growing body of literature surrounding service user and carer involvement in education and research in universities and wider community engagement (Repper and Breeze, 2007). The main focus has arguably been on literature documenting the experience of higher education institutions (HEIs) and their attempts to involve service users and carers in their scholarly activities, their successes and any barriers they have faced.

1.5 Representation

The vexed issue of representation and representativeness is a key focus of debate amongst interested parties, typified by challenges of contested meaning, and can be a potential avenue for service agencies or institutions to devalue or embargo the input of particular individuals or groups (Beresford and Campbell, 1994). Concerns around representation include issues such as how people can speak for others or from a general perspective, perceived credibility and validity around who is involved and questions over why these individuals are representative of the wider service user/carer populace. The British Psychological Society (2008: 18) discussed this notion within its 'Good Practice Guidelines' and decided that 'representativeness should be an aspiration not an obstacle'. This notion is also discussed widely by Robert *et al.* (2003: 63):

Professionals wishing to promote user involvement frequently express concerns about the representativeness of individual service users, sometimes suggesting that particular service users may be 'too well', 'too articulate' or too vocal to represent the views of users more general'.

Crawford (2001: 85) responds to this criticism by pointing out that 'this problem is not specific to those representing the views of service users. The same question could be asked of those representing the views of local general practitioners, psychiatrists etc.'

We would recommend that we accept un-representativeness as each person who has experienced services/or cared for someone who has experienced services has a unique insight and contribution to make.

Practical methods to combat this issue within education have been suggested by City University in its guidelines for 'User and Carer Involvement in Educational Activity'. These include:

- Users and carers nominating representatives themselves from their groups.
- The fostering of local relationships.
- Transparency and flexibility.
- Always involving more than one service user or carer.

1.6 Level of Involvement

Even though the agenda of involving service users and carers in the education of future health and social care practitioners is gaining in importance, achieving meaningful involvement is complex, defying simple remedies. The extent to which involvement is authentic and meaningful for participants is crucial, and a number of commentators have attempted to represent progressive stages towards more complete involvement. Arnstein (1969) introduced the concept of movement across a continuum of participation. Arnstein's 'ladder of citizen participation' includes (in descending order of power) – sharing, citizen control, delegated power, partnership, placation, consultation, informing, therapy and manipulation.

Tew, Gell and Foster (2004) developed this model of a continuum further in their 'ladder of involvement' and related it directly to mental health education (Table 1.1):

The premise is that for any initiative in which service users or carers are involved development will occur, hopefully advancing up the ladder. For instance, the process will move service users and carers from being passive recipients to fully engaged, equal partners in education. According to the scope and range of their involvement, different initiatives can be placed at different levels on the ladder. The literature describes a number of schemes that, whilst attempting full partnership, fall short of reaching this ideal. Typically, these initiatives tend to focus on classroom participation.

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Table 1.1 Ladder of Involvement (Tew, Gell and Foster, 2004: 54)

Level 1 No involvement	The curriculum is planned, delivered and managed with no consultation or involvement of service users or carers
Level 2 Limited involvement	Outreach and liaison with local service user and carer groups. Service users/carers invited to 'tell their story' in a designated slot, and/or be consulted ('when invited') in relation to course planning or management, student selection, student assessment or programme evaluation. Payment offered for their time. No opportunity in shaping the course as a whole
Level 3 Growing involvement	Service users/carers contributing regularly to at least two of the following in relation to a course or module: planning, delivery, student selection, assessment, management or evaluation. Payment for teaching activities at normal lecturer rates. However, key decisions on matters such as curriculum content, learning outcomes or student selection may be made in forums in which service users/carers are not represented. Some support available to contributors before and after sessions, but no consistent programme of training and supervision offered. No discrimination against service users and carers accessing programmes as students.
Level 4 Collaboration	Service users/carers are involved as full team members in at least three of the following in relation to a course or module: planning, delivery, student selection, assessment, management or evaluation. This is underpinned by a statement of values and aspirations. Payment for teaching activities at normal visiting lecturer rates. Service users/carers contributing to key decisions on matters such as curriculum content, style of delivery, learning outcomes, assessment criteria and methods, student selection and evaluation criteria. Facility for service users/ carers who are contributing to the programme to meet up together, and regular provision of training, supervision and support. Positive steps to encourage service users and carers to access programmes as students.
Level 5 Partnership	Service users, carers and teaching staff work together systematically and strategically across all areas – and this is underpinned by an explicit statement of partnership values. All key decisions made jointly. Service users and carers involved in the assessment of practice learning. Infrastructure funded and in place to provide induction, support and training to service users and carers. Service users and carers employed as lecturers on secure contracts, or long-term contracts established between programmes and independent service user or carer training groups. Positive steps made to encourage service users and carers to join in as participants in learning sessions even if they are not (yet) in a position to achieve qualifications.

1.7 Models and Approaches

1.7.1 Limited Involvement – The Ladder of Involvement Level 2

Service users and carers are frequently invited into universities to talk of their experiences of using health and social services in a dedicated teaching session. This is by no means a new phenomenon:

For the junior student in medicine and surgery it is a safe rule to have no teaching without a patient for a text, and the best teaching is that taught by the patient himself. (William Osler, 1905 quoted in Spencer *et al.*, 2000: 851)

Involving service users and carers in this way allows the student to listen to and recognise the unique experience of health and social care that people have had. It also brings to the fore the influence that social inequalities and stigma have on patients lives. The recognition of the persons' own definition of their experiences can be seen as both empowering and validating (Campbell and Lindow, 1997).

Wood and Wilson Barnett (1999) set up a small research project to include mental health service users in classroom work. The outcomes from the research indicated that those students who had experienced service users and carers in the classroom were less likely to use jargon, more able to empathise, and more likely to view service users as individuals, and not patients with medical labels. In a report on the development of a course for cancer nurses, Flanagan (1999) recognised that user involvement in the classroom leads to greater empathy. This is borne out by Spencer *et al.* (2000) who stress that direct student-service user contact can enhance a student's ability to understand the actual experience of ill health.

Costello and Horne (2001) carried out an evaluative study involving the use of patients in the classroom. One student stated, 'It was beneficial to listen to a patient telling you about actual experiences rather than a teacher telling you about hypothetical ones'. Another reported, 'You received answers that you would not find in a text book'. From the data, 56% of the respondents indicated that a great deal had been learnt from the session, and 85% of the respondents agreed that the involvement of service users helped them to gain a greater understanding of their problems.

Despite the undoubted enthusiasm amongst students in this study to hear first hand of the service users' experiences, this involvement could be deemed as tokenistic. When mapped against the 'Ladder of Involvement' it would be characterised as limited (Level 2). Beresford and colleagues (2006: 327) speak of the dangers of tokenism within social work education:

On many social work courses the most that might happen could be one session led by service users, often with little support from the college, when they were encouraged to talk about themselves and their problems rather than their views and ideas about what social workers should be doing.

While low levels of involvement can be criticised as tokenistic, the research undertaken by Khoo and colleagues (2004) on the impact service users have on Masters students' educational experiences found evidence that reasonably simple involvement of service users in a classroom setting can pose effective learning challenges for students. The study was carried out in two phases. In phase one, a short questionnaire was sent out to students. In phase two, a sample of ten respondents was interviewed. From the questionnaire 79% of respondents rated the contribution of service users as good to excellent. Collectively, user involvement

was found to convey a number of benefits for course participants. Students reported that the service user sessions:

- Helped ground practice in reality.
- Raised awareness of issues and of user perspectives.
- Provided a focus on partnership.
- Challenged existing approaches.
- Challenged participants' personal views of the world.
- Raised participants' confidence as practitioners.
- Enabled informed change.

Some of these observations suggest the transformational potential of service user involvement in the classroom, beyond the sort of tokenism highlighted by authors such as Beresford. It follows from Beresford and colleagues' (2006) commentary that the meaningfulness of this involvement depends upon adequate planning and support, elements that are also amenable to a participatory approach.

Scheyett and Diehl (2006: 436) recognise the incongruity between the ethos of partnership in professional practice and the role of partnership in social work education:

Social work educators, if we are to act in congruence with our values, must examine the extent to which we practice partnership, self determination and empowerment in our curriculum development and in the educational process itself.

1.7.2 Growing Involvement and Collaboration – The Ladder of Involvement Levels 3 and 4

Involvement which goes beyond occasional teaching sessions is happening within some education establishments. Flanagan (1999) engaged users and carers in the design of continuing and higher education in cancer care nursing within the University of Leeds School of Healthcare Studies. The design team met over a number of months within course design meetings, and *'the lessons from this particular example of public involvement were positive for all parties'* (Flanagan, 1999). The study goes on to conclude that, for all the good intentions of professionals, there is no substitute for the direct involvement of service users and carers. These valuable insights and perceptions were seen to be essential in the education of future cancer nurse specialists.

Dammers, Spencer and Thomas (2001) used real people in problem-based learning. 69 students over a two-year period studied a problem-based learning module attached to the undergraduate medical curriculum at Newcastle University Medical School. All completed a questionnaire. In response to the question, 'Was there any particular added value in having real as opposed to paper cases for the problems?', all the students expressed positive value in having service user involvement. The Newcastle team conclude that the use of active participants in problem-based learning should be considered more widely.

Arguably, including service users and carers in education should be a true partnership with engagement across all aspects of the curriculum. Authors have identified that there is a need for both organizational and individual commitment if the inclusion of users and carers as experts is to be more than a token gesture or a sop to political rhetoric. Tew and colleagues (2004: 57) point out that:

...achieving effective service user and carer involvement involves a significant commitment of time, along with relationship building, strategic planning and problem solving skills; all of this needs to be underpinned by appropriate funding and an infrastructure for support.

The Open University (OU) came to similar conclusions, and went further by exploring power imbalances in a narrative describing the production of a mental health course. The Open University designated resources, including time and money, for service user involvement in the production of an Open University course on mental health. This involvement provided educators with many dilemmas, as they had to work to fulfil academic criteria whilst balancing this against sensitivity and respect for service user perspectives. Jim Read, a notable movement activist wrote about this process:

Decision-making was all too often based on money and power, rather than sensitivity towards the people who would most be affected. It also stirred up my concerns about working with academics, who I perceived as potentially over-concerned with a false notion of balance as opposed to listening to the voices of oppressed people. (Reynolds and Read, 1999: 423)

The course team had differing views as to the extent and format of service user contributions. Service user members of the group commented that to include service users and not take on board what is said was tokenism. Service users became angry and the situation became stressful. Over time, with negotiation, compromise was reached. The course team commented that they learnt to be more sensitive to power relationships and to be clear about the decision making process.

Simons and colleagues (2007) took a slightly different approach to inclusion and carried out an observational study to evaluate the development of a Service User Academic Post and its impact in terms of social inclusion. A service user was employed by the university to take the involvement agenda forward. This post would have the same status, terms and conditions as for any other educator, although the job title was unique. The findings from the study indicated that, although the post was intended to be integrated into the teaching team, the post holder was not actually involved in 'normal educator activities'. This singled the post holder out as being different. On the positive side, fellow academics pointed to the symbolic power of the existence of the post in the institution. They remarked that appointing a service user moved the institution 'beyond rhetoric to action', and demonstrated that the academic team were willing to 'put our money where our mouth is'. The importance of building relationships in the team was also stressed:

The user academic would make sure there were user/carers strands through everything. She was good at that because she did actually form good working relationships with most

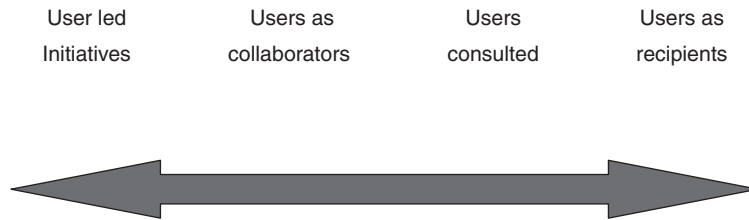


Figure 1.1 Continuum of participation – services and education. Reproduced from Lathlean *et al.* (2006: 734) with kind permission of Elsevier.

of the team. So she was able to say, ‘Where is the user/carers bit in that, then?’ (Educator 2, in Simons *et al.*, 2007)

The findings from this study recognised that user involvement had a positive effect on student learning and that the user academic also had a positive impact on the academic team.

A very similar project has been developed by the University of Melbourne, which employed what it called a Consumer (Service User) Academic into the Centre for Psychiatric Nursing Research and Practice. Melbourne believed that the involvement of a consumer academic would change the culture and ethos of the taught courses. A questionnaire was distributed to 25 post-graduate nursing students to assess the impact of the post. Findings were typically positive.

The majority of the students endorsed the concept of ‘consumer academic’ involvement in psychiatric nursing academia. This finding may be particularly significant in terms of accepting new teaching approaches to mental health nursing. (Happell, Pinikahana and Roper, 2002: 248)

Lathlean and colleagues (2006) reported on three initiatives that were reviewed within a symposium and which had the linking feature of moving across a continuum of participation. This continuum moves along a horizontal plane from the right hand side, where users are passive, to the left hand side, which promotes consumer-led initiatives (Figure 1.1).

One of the three initiatives reflected upon was Happell’s Consumer Academic post previously reviewed. Lathlean and colleagues viewed this method on their continuum as involving a service user as a collaborator in the delivery of education.

This symposium also reviewed an initiative which has developed a strategy for the inclusion of an external user and carer reference group. Members of the group negotiated the strategy for involvement, which included curriculum advice, planning and delivery of curricula at pre and post registration stages, and review of research proposals. Lathlean and colleagues viewed this approach as being located towards the left hand, more progressive, wing of the continuum, where users are collaborators rather than passive recipients. The final approach considered at the symposium was a study focusing on the participation of mental health service users in the clinical practice decisions of mental health student nurses

undertaking their nurse training. This study focused on three key concepts: anti-oppressive practice; contact theory, which proposes increased contact with groups of people leads to more positive attitudes; and moral development.

The outcomes of the inquiry have been to identify, from a service user and student perspective, professional values which respect the individuality of the person; behaviours and actions which share power and reflect belief in individual potential; and cultural aspects within organisations which enable shared learning and full participation in decision-making. (Lathlean *et al.*, 2006: 736)

This programme has been rated by Lathlean as ‘users as collaborators’ on the involvement continuum. However, with reference to the ‘ladder of involvement’, the initiative might best be categorised in the ‘growing involvement’ stage, as there is no clear support programme in place.

Despite the many excellent examples of service users and carers being involved in universities, many of which are featured elsewhere in this book, a review of the relevant literature has been unable to identify any research papers reporting on initiatives that fit Tew and colleagues’ Level 5 Partnership Stage. To explain this anomaly, the next section turns to evidence in the literature that has identified barriers to full involvement.

1.8 Barriers to Involvement

There are a number of barriers to authentic service user and carer involvement in education. These were recognised at a United Kingdom workshop held in Derby in June 2003¹, and reviewed in Basset and colleagues’ (2006) seminal paper *Service User/Survivor Involvement in Mental Health Training and Education: Overcoming the Barriers*. Within this paper 10 specific barriers to authentic involvement are identified:

1.8.1 Hierarchies that Exclude

Basset and colleagues identify the hierarchical nature of higher education institutions with built in ‘pecking orders,’ where only authoritative forms of expertise are valued. Lecturers and academics are deemed as the experts. The inclusion of service users and carers challenges these notions of expertise, and may risk the loss of some authoritative power for some individuals or groups.

The notion of service users as teachers challenges the perceptions of the role of mental health lecturers as the experts. (Felton and Stickley, 2004: 91)

¹ In a similar vein a workshop held in Nottingham in 2005 brought together key development workers for service user and carer involvement. This meeting also identified various impediments to involvement (Chapter 8)

Felton and Stickley cite the work of Paolo Freire (1971) in examining the nature of power in the culture of pedagogy. Arguably, whether it is recognised by academics or not, the maintenance of power is important for teachers in order to maintain status as a dominant group. This has significant implications for the involvement of service users in education in terms of the threat they may represent. Basset (1999) takes up the tokenism charge again, in arguing that much service user and carer involvement is based on appropriation rather than partnership, as power structures remain unchanged.

It would seem that higher education institutions may be culturally resistant to a challenge to their power base. In order to move beyond tokenistic responses to the consumerist challenge, service user involvement requires a change in structure that can only be realised or sustained by those who have power, and who are prepared to share it, or even to let it go altogether.

1.8.2 Stigma and Discrimination

Universities are not free from the forces of discrimination. Service users may be seen as ill people who need 'looking after'. This view does not support equal power relationships, but rather fosters paternalistic approaches. The predominant medical model of some disciplines and the professional mores learnt earlier in academic careers might reinforce this.

As noted above, the project undertaken by Simons and colleagues (2007) identified some problems with stigma and discrimination. The title of 'User Academic' labelled the worker and stigmatised the role, which was in direct contrast to the aims of integrating and valuing people equally. The User Academic was not integrated into everyday normal educator activities. This also led to unintended discriminatory behaviours. Some questions as to whether special employment practices were required for the post holder as a vulnerable service user were raised. However, usual systems for staff were bypassed.

The use of mental health service users in higher education by some academics can be resisted because of discrimination and stigma.

All the lecturers saw a potential difficulty with the capability of service users in the classroom. For some this included the unpredictability of individuals with mental health problems and their possible inability to cope with the demands of working in education. (Felton and Stickley, 2004: 95)

An uncritical acceptance of this belief reinforces the process of excluding service users from education.

1.8.3 Validation and Accreditation Processes

For Basset and colleagues (2006), validation and accreditation processes usually involve sets of meetings where point-scoring and bullying are not uncommon, and free deployment of jargon and acronyms are the order of the day. They note that, when service users or carers are invited into these forums, the academic

culture prevalent in the running of the meetings, and the inaccessibility of the format, often precludes participants from contributing in a meaningful or authentic way.

Despite the rhetorical support for user and carer involvement, active participation cannot take place without support mechanisms that appropriately prepare service users and carers. Indeed, properly empowered participation could lead to modifications to university processes and meetings so that they become more inclusive and user friendly for all those attending. This would, of necessity, involve changes to the behaviour and communication styles of many participating academics. Fiona O'Neill (2002) recognised this, stating that *'it is unlikely that active involvement can take place without appropriate preparation of both professionals and users'*. She goes on to say that *'apart from the capacity building aspect of training activities, joint training of lay representatives and professionals provide a way of facilitating partnership working and learning from each other'*.

1.8.4 Academic Jargon and Put-Downs

Educators, researchers, health and social care professionals are notorious for using academic jargon and professional terminology. This can lead to service users and carers feeling stupid, excluded and unable to fully participate in involvement opportunities. Basset and colleagues (2006) suggest that, to be successful, institutional staff need to speak the language of service users and carers. In support of this, Susie Green (2007) comments that service users should not be plunged into the murky unfathomable rhetoric of organizational and health service jargon. The solution is to recognise and accommodate the fact that there are different, but equally valid, cultures and ways of learning and understanding.

1.8.5 Clever People/Clever Excuses

Basset and colleagues further believe there are many excuses for not including service users and carers. People who work in higher education erect their own barriers to inclusion. Excuses such as *'they will feel out of their depth'*, *'we don't want people to feel they have let us down'*, *'there is not enough time to include people'* and *'they are not representative of our clients'* come up often. This passive resistance to inclusion is just as damaging as direct resistance, in that it creates a subtle undermining of the inclusion agenda.

Felton and Stickley's (2004) research also cited fixation on a notion of representativeness as a barrier to involvement, with four of their participants thinking that service users should be representative for user involvement to be valid. This notion is based on the rationale that individuals should be representative of users of the service as a whole to be able to give a valid user perspective. In response, Crepaz-Keay, Binns and Wilson (1997) point out that by being involved and immersed in educational culture, these users cannot be representative in this sense

of the word, as the majority of service users do not have this level of involvement experience. As Tritter and colleagues (2004: 23) note:

Users, like professionals, will provide input based on their own experience. Being too concerned that involved users are representative, or that all possible users are involved, can get in the way of ensuring that users' views are being used to shape services.

1.8.6 Classifying Knowledge

Basset and colleagues also discuss how the academic world is focused on knowledge, evidence and rigour. Service user and carer involvement is not delivered in this way. Input is experiential, often coming from the heart, aiming for shared emotional connections that will enable change in practice. Teaching is also often aimed at a certain level with pre-set conditions attached. Involving service users and carers enables them to contribute in a way that is unique and individual. This is the very point of the exercise. It is not necessarily amenable to definition at level 2 or 3 of a degree programme. Arguably, it has as its strength the power to move students emotionally, enabling them to reflect on their knowledge and practice no matter what level their academic programme.

It is only through the use of patient experience knowledge, where patients are enabled to share their illness experiences with health-care professionals, either in practice or through educational processes, that theoretical knowledge firmly grounded on practice knowledge becomes the basis for effective nursing practice. (Warne and McAndrew, 2007: 228)

1.8.7 Individual, not a Team Approach

The desirability of achieving a better trained practitioner workforce more in tune with progressive principles of team working because they have studied and trained together is a key element of worldwide social care and health service modernization policy agendas (WHO, 1987; Hargadon and Staniforth, 2000). Despite this, many of today's higher education institutes are split into schools and departments, creating structural impediments for teaching and learning to cross the boundaries of different professional groupings. Basset and colleagues highlight how this can cause difficulties for service users and carers who may want to contribute widely. Cooper, Braye and Geyer (2004) identified such difficulties with interprofessional education at both pre and post registration levels. Although interprofessional learning is a key component for pre registration social work and nursing education and, in some cases, medical education, there can be problems fitting it easily into the established academic worlds where systems, resources and practice have arguably been set up to meet the needs of different professional bodies. Conversely, where efforts are taken to overcome such barriers, interprofessional learning can be successfully implemented and becomes a vehicle for addressing other partnerships, including the involvement of service users and carers (Meads *et al.*, 2005; Barr *et al.*, 2005). Indeed, with reference to the aforementioned study of interprofessional learning, Cooper and Spencer-Dawe (2006) report

improved learning outcomes when service users contributed to teaching compared with practitioners alone. Benefits for involving service users included understanding links between personal experiences and theoretical material, a better appreciation of team working principles and the need to locate service users at the centre of care.

1.8.8 Gaining Access in the First Place

Basset and colleagues' paper points out that individual academics may not know how to access service users and carers who wish to get involved. Conversely, service users and carers may not know how to get involved within higher education. This can lead to the few that do manage to become engaged being over-used, becoming burnt out and, ultimately, being disregarded as 'the usual suspects'. This can severely limit the range of service user voices heard.

The Fran Branfield and Shaping Our Lives (2007) report on user involvement in social work education speaks of how service users can internalise negative assumptions about what they can and cannot achieve. *'Some service users lack the confidence to believe they can participate. For some people it is a huge mountain to climb'*. Gina Tyler (2006) reports on her personal experiences of how some workers offer inauthentic gestures to involve people: *'Involving service users in a tokenistic way achieves nothing other than ticking boxes and fabricating figures, which are then used to measure counterfeit involvement'*.

1.8.9 Bureaucratic Payment Systems

Universities often have finance departments incapable of paying service users and carers on the day, in cash, and in a way that will not affect any benefits they may be claiming. The bureaucracy and audit trail needed to claim items such as travel expenses can preclude some service users and carers who may need reimbursement for outlaid expenses as quickly as possible. Turner and Beresford (2005) found that service users and carers who claim benefits are unclear as to which payments and how much they can be paid, worry about receiving payment, find it difficult to gain appropriate advice, worry about paying taxes, worry they will lose their benefits and find negotiating the rules of payment too daunting to take part in involvement opportunities.

1.8.10 Lack of Support for Trainers/Educators

Bennett and colleagues highlight the need for support, including briefing, debriefing, resources and information. Unfortunately, such support is often not available, leaving the service user vulnerable and often having to deal with emotional distress after reliving what are sometimes traumatic life experiences.

Beresford (2005b) believes two essentials need to be in place for successful service user involvement: access and support. Access includes structured ways to

get involved and to get your voice heard. Support is whatever is needed to make the process comfortable. O'Neill (2002), Tew, Gell and Foster (2004), Simpson and Benn (2007), Tyler (2006), Stevens and Tanner (2006), Tew and Hendry (2003), Miller and Walters (2006) and a number of other authors all recommend support is given to service users and carers to ensure that they are prepared, feel confident, gain new skills and become empowered as part of the process of involvement. A supportive infrastructure is also seen as necessary to ensure that getting involved within a university does not unduly put service users and carers under pressure or stress.

1.9 Innovation in Teaching and Learning: An Example

One means of addressing barriers to involvement is in the deployment of innovative teaching and learning technologies. There is relatively little published work specifically focused upon user involvement in e-learning, but one clear example is Simpson and colleagues' work around supporting enquiry-based learning with a user-led e-discussion group at City University (Simpson *et al.*, 2008; Simpson and Reynolds, 2008). Here, Alan Simpson describes how their particular approach to involvement in e-learning was developed and observes how it was received by participating students and service users:

It is always a challenge trying to come up with ways to get mental health nursing students to think about what it is like to be a mental health service user. How do you get them to try and understand what it is like to have a mental health problem or to be admitted to a psychiatric hospital? And, more importantly, how do you get those students to reflect on their own attitudes and behaviour and encourage them to have positive, constructive relationships with service users?

Increasingly, service users are being invited to take part in the education and training of healthcare students and staff in a variety of ways (Simpson, 2006), but we were very excited when we had the idea of getting our students to communicate online with people who had personal experience of mental health problems and services.

We knew a lot of people, including service users, used online discussion and message boards to discuss things, but could we make it work as part of an educational project? As far as we could find out, this had not been tried before, so we couldn't nick anyone else's ideas.

A small group of us, including Ian Light – a service user lecturer who sadly died following the completion of the study – created a secure project site complete with sample discussion threads on the University's web site and put together some publicity materials before making contact with local user groups.

After giving presentations at three mental health day centres, we recruited 12 service users keen to take part. About half of them already used the internet, the others were new to computers and e-mails but training, support and payment

were all part of the deal. Around the same time we invited a group of 34 second year mental health nursing students to take part in the project and all agreed. As we intended to evaluate the study (Simpson *et al.*, 2008), everyone was given written information and provided written consent to take part. Information about the number of e-mail messages read and sent was automatically recorded and 10 of the 12 participants (83%) and 13 of the 34 (38%) students, selected to reflect the range of students, were interviewed by an independent researcher. Once everyone had been trained and knew how to use the discussion forum, the students sent e-mail questions to the service users on six topics linked to a scenario they had been given. They were encouraged to respond to the questions and it was hoped that spontaneous discussions would develop between and amongst the participants. The students also had to use traditional library resources to research their subjects. All contributions were monitored by the project team, who very occasionally intervened mainly to encourage participation. After six weeks, the service users were invited to attend presentations by the students on what they had learnt. The project was an overall success with all students and service users interviewed overwhelmingly positive about the online discussion forum. They valued the discussions, would happily take part in a similar project again and would recommend it to others. They supported increased use of online discussions in healthcare education and had suggestions for topics that could be covered. Students described the contributions of the service users as 'responsive', 'brilliant', 'excellent', 'fantastic' and 'effective'. Their learning had clearly been influenced to some extent in that four of the six groups of students drew on the discussions in their presentations, with two groups focusing their work on the online interactions. They found that the online forum gave them an insight into personal experiences, improved their communication skills and provided motivation to work on psychiatric wards. Above all they had acquired an understanding of the service users' experiences of admission to hospital and about the feelings aroused by being spoken to or interacted with in a particular way.

I think just an idea of, just an impression of how it is to be on a psychiatric ward, that is mainly what kind of things I asked about ... how they found the atmosphere. What were their fears and what they found to be ... the most worrying aspects of being in hospital? (Student)

Others identified hearing first hand experiences of the impact of mental illness and distress and reflected on how this could influence their clinical practice.

I have learnt that maybe in future when I go on my placements, to put some of the things I have learnt on board ... communication skills or during admission ... that kind of a thing, so these are the kind of things I have learnt and I try as much as possible to implement in practice and improve more. (Student)

Over half the students (58.8%) logged on and read messages from service users and fellow students. However, it became clear that there was a 'visible' group of 15 (44%) contributing to discussions, with 14 (41%) playing no active part online, despite using the technology during the practice weeks. The tendency not to post e-mails reflects the common experience of any online discussion forum, where 'passive' membership ('lurking') often outweighs active participation, but it also reflected concerns expressed during the study that students lacked confidence in communication.

In contrast, the majority of the service users played an active role online. On average they sent more messages than the students and were more confident in using computer technology than most students. They were keen to take a leading role in the online community and valued contributing to the education of future nurses and of challenging stereotypical and stigmatising views of people with mental health problems. They also learnt things themselves from taking part in the discussions.

The service users were generally positive about the input of the students and thought they asked some good questions, but would have appreciated more discussion on a range of other topics. Others expressed frustration with the limited way in which students asked questions and failed to follow-up responses, although they also cited positive examples.

But then you had some who were really good, like the one about being admitted onto an acute ward and your experiences and I said about mine and someone wrote saying well how could it have been better, what would you have liked to have happened, which I thought was really positive. (Service User)

There was an awareness that some of the students were hesitant about probing too far, which had led some service users to offer encouragement.

I know there was one or two students that felt they were not confident enough to ask us, or they did not want to cause us any offence and we e-mailed back, don't worry about it cos like we have had worse. . . I can understand where they were coming from but I think we are made of tougher stuff than that, yeah? (Service User)

Service users spoke of gaining confidence in using computers. Being valued and taken seriously was in itself rewarding and empowering, but above all was a hope that they might be contributing towards positive change in the attitudes of staff and the delivery of mental health services.

Some of the discussions were very emotive for the participants but they were able to positively reframe their survival of difficult life experiences. Several explained how they had benefited from talking about their experiences online as the distance and anonymity afforded by the forum was an advantage, perhaps suggesting the supportive potential of online communities.

The use of an online discussion forum involving mental health service users and students is both possible and highly desirable. Online interactions enabled users to discuss their previous experiences, explain the impact of their care and

treatment and encouraged students to consider and reflect on the implications for their own practice.

There is considerable scope to develop similar initiatives across health and social care education and it is clear that service users could and should be at the forefront of that development. Future joint projects between service users and educational researchers might attempt to analyse the impact of online discussions on attitudes and healthcare behaviours in the workplace, because that, of course, is where it really matters. The Bradton virtual community e-learning resource being developed by colleagues at the University of Bradford and University of Central Lancashire, United Kingdom, has relied upon service users and carers as peer researchers and developers to produce a range of video stories, grounded in personal experiences of health and social care services. Participants in this initiative report some misgivings that the electronic resource does not promise to replace opportunities for face-to-face contributions to teaching and learning. Conversely, they can also see the value of so-called re-usable learning objects. For some individuals, their physical or emotional condition is such that delivering lengthy teaching sessions or revisiting material for multiple student groups might prove exhausting. The video material is a useful alternative, as it can supplement or even replace direct teaching sessions. Others with life limiting conditions have spoken movingly of the possibility of legacy effects, where their contribution to student learning lasts beyond their death.

1.10 Conclusion

The involvement of health and social care service users and carers in teaching and research endeavours within universities has become much more prominent. The notion of hierarchies of participation, as presented in the various ladders of involvement deployed for evaluation purposes, reflects an acute concern on the part of participants themselves and key academic staff that particular initiatives evidence 'true', 'genuine' or 'authentic' involvement. Aspirations for partnerships are backed up by numerous examples of best practice guidelines and a critical literature, often authored by service users, focused on how best to shape and support new working.

Honest reflection reveals that most involvement activity falls short of full partnership working, and there are few examples of completely user-led projects. These observations confirm the fact that various institutional and cultural factors can act as barriers to the adoption of best practice, but there is sufficient knowledge now about the existence and operation of these impediments for willing participants to take steps to overcome them or minimise adverse effects. Wider socio-political and structural factors are also of interest in considering the potential for success, and it is these issues that are turned to in Chapter 2.