Nurse Education Today 34 (2014) 1175–1178

Contents lists available at ScienceDirect

Nurse Education Today

journal homepage: www.elsevier.com/nedt

Service user involvement in practitioner education: Movement politics and transformative change

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ARTICLE INFO

Article history:
Received 20 November 2013
Received in revised form 19 February 2014
Accepted 31 March 2014

Keywords:
Health and social care education
Politics
Service user involvement
Social movements

SUMMARY

This paper will attempt to celebrate both key developments and best practice involving the users of health and social care services in programmes of practitioner education in a UK context, and offer a critical appraisal of the extent to which such initiatives meet some of the more transformative objectives sought by service user activists for change. The approach is largely that of a discussion paper but we will illustrate some of the themes relating to movement activism with selected data. These data relate to earlier research and two specially convened focus groups within the Comensus initiative at the University of Central Lancashire; itself constituted as a piece of participatory action research. We conclude that universities represent paradoxical sites for the facilitation of debate and learning relevant to key issues of social justice and change. As such, they are places that can impede or support movement aims. Particular strategic responses might be more likely to engender progressive outcomes. These ought to include the presence of critically engaged academic staff operating within a scholarly culture that fosters forms of deliberative democratic decision making.

Introduction

Pedagogical practices supporting service users' contributions have grown significantly in recent times (McKeown et al., 2010, Terry, 2012). These are matched by a proliferation of policy rhetoric urging increasing levels of involvement in almost all aspects of the organisation and delivery of services (Barnes & Cotterell, 2012, McKeown & Jones, 2014). Such developments are international and extend across different disciplines (Towle et al., 2010) with a significant nursing focus in the UK. The idea of service user involvement is now essential to the lexicon of educators, policy makers and practitioners. This has undoubtedly become part of conventional thinking, urging promotion of autonomy, cooperation, recovery objectives and a humanising of care. The latter point demands particular attention in the face of a prevailing moral panic (Cohen, 1972) over perceived deficits in compassion and nurse education (see Odone, 2012).

Progressive developments have, therefore, been underpinned by the infiltration of ideologies of empowerment, citizenship and consumerism into policy prescriptions for wider governance and participation in the public sphere. Questions remain, however, regarding inherent contradictions or the extent to which the rhetoric is matched by actual practice-level or societal change. Proselytisers and naysayers for different types of involvement can be found amongst the diverse ranks of pedagogues, practitioners, service managers, service users and social movement activists. In this paper, service user and carer involvement in practitioner education will be located in an historical overview of UK government policy before turning to review the impact for practitioner education programmes. There then will be a discussion of the relevance of understanding such involvement through the lens of movement politics, drawing upon focus group data provided by participants in the Comensus initiative at the University of Central Lancashire. One intention is to move debate and discussion around the value of service user involvement away from anodyne and simplistic consumerist notions of voice, choice and public engagement onto a more dynamic politicised territory. That is not to say that progress cannot be made upon this territory, nor that consumerism has monopoly interest in matters of ‘voice, choice and engagement’. Rather, an uncritical stance towards the same can result in superficial, tokenistic or ‘tick-box’ forms of involvement instead of empowered change. All of this requires a critical look at the role of universities in nurturing or impeding the forms of social space which might better support the realisation of service users' demands for social justice and change across health care services and wider society.

Public Participation and Involvement Policies

UK government policy has discursively championed various approaches to citizen voice within health care with increasing emphasis

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http://dx.doi.org/10.1016/j.nedt.2014.03.016
0260-6917/

in recent times. That said, there is a dynamic history of interest in public participation stretching back many decades. Relevant legislation and policy sit within broader systems of governance that support consumer rights and democratic participation across the public domain. Involvement policies for health care organisations, in particular, resonate with empowerment ideals, seeking equality in the social relations between practitioners and service users. Latterly this is framed in the language of co-production. Gorsky (2007) describes a 200 year heritage for public participation dating to the implicit democracy of early mutual friendly societies and arriving at present day consumerist policies of service user engagement and involvement.

The turn to consumerism is of interest in that it coincides with the ascendancy of a global neo-liberal polity that threatens the survival of state welfare and health services. Interestingly, the same forces have ushered in increasing corporatisation of universities as part of the more general retreat from publically provided services (Rolfe, 2013). The rise of neo-liberal governance and associated privatisations and marketisation of health care provision has been in conjunction with assaults on welfare support for the most disadvantaged in society (Ramesh, 2012). Many such persons might identify as disabled or users of health and social care services (McKeown et al., 2013). Critics suggest that policies promoting public engagement and involvement are much too bound up with a wider mission of governance and social control (Cooke & Kothari, 2002).

It is within this broad political-economy that democratic deficits arise. Governments face crises of legitimacy, and new social movements appear, framed in issue based or identity politics; for example, various feminisms, gay activism and civil rights groups (Habermas, 1976, 1981). Hence, social movements have been constituted with regard to disability or service user identities. These make moral and political demands for, amongst other things, appropriate rights, better health services, and more inclusive, less-stigmatising communities (Rogers & Pilgrim, 1991; Brown & Zavetoski, 2005; Williamson, 2008). Arguably, service users who participate in involvement practices within universities bring with them, either partially or wholesale depending on prior affiliations, a number of the characteristics of movement activism (McKeown et al., 2010).

Interestingly, the more radical cohorts of any service user movement would find themselves critical of simple consumerism, but opportunistically taking advantage of policy initiatives to more assertively take up a place in the public sphere (Deber et al., 2005, Clarke, 2007, Cowden & Singh, 2007). The working out of such developments in the higher education sector is arguably in tension with more progressive developments in public engagement.

Service User Involvement in University Settings

Nursing and other practitioner education have willingly taken up the challenge of bringing service user and carer involvement into universities. This mission has also extended into associated research and community engagement practices (see McKeown et al., 2010). Regulatory bodies such as the Nursing and Midwifery Council (2010) have stipulated common standards for pre-registration nurse education that refer explicitly to the desirability of involving service users and carers in programme design, delivery and assessment. An extensive literature provides detailed description, commentary and inquiry into such involvement covering student selection, face to face teaching, curriculum planning, course validation and evaluation (see Wykurz & Kelly, 2002, Felton & Stickley, 2004, Basset et al., 2006, Beresford et al., 2006, Lathlean et al., 2006, Repper & Breeze, 2007, Brown & Young, 2008, Morgan & Jones, 2009, Towle et al., 2010, McKeown et al., 2010, Dix et al. 2014). In tandem with this focus on teaching and learning has been a concomitant increase in involvement in research practices (see Church, 2005, Hanley, 2005, Involve, 2007, Frankham, 2009). A consequence of these developments has been that various quality assurance and grant approval systems are now geared up to take account of levels of involvement and participation. Inquiry into the motivation of service users to get involved in education programmes reveals that a desire to 'make a difference' to health and social care services is prominent along with interests in widening access to higher education (McKeown et al., 2012). Despite this growth in participation, neither an actual impact upon services has been confidently demonstrated nor are relevant study designs easy to conceive, implement or resource (Repper & Breeze, 2007, Rhodes, 2012).

Government policy and professional interest in service user involvement are open to wide-ranging critiques. Various commentators have posed criticism of the key concepts and language associated with involvement, which is clearly understood differently by different people, groups or institutions (Beresford, 2005). Arguably there is a lack of attention within policy prescriptions to detailing ideas for how best to implement involvement (Duffy, 2008) and thoroughly address service user demands for the organisation of services (Connor & Wilson, 2006). The terminology can be challenged for being implicitly disempowering, insufficiently acknowledging other diversity issues, or uncritically defining people in terms of pathology (Lewis, 2005). Furthermore, involvement practices can fetishise unrealistic or un-called for ideals of representativeness (Beresford, 1994) or inadequately face up to issues of tokenism (Carter, 2009, McKeown et al., 2010). These shortcomings fail to consistently value service user views as valid commentary on services; with some voices being too easily discounted or ignored. Similarly, profound questions can be posed over the extent to which models of service user involvement in any context can escape powerful constraining forces such as tendencies to incorporation and co-option (see Beresford, 2002, Lewis, 2005, Pilgrim, 2005, Carr, 2007). Conversely, efforts have been taken to exemplify progressive values of participation, cooperation and authenticity within involvement practices. Such concerns have been influential in the construction of various evaluative tools which account for levels of partnership (Arnstein, 1969, Tew et al., 2004, Tritter & McCallum, 2006).

Activist Identities and the Academy

Given the politicised and contested territory on which service user involvement must take place, it has been pointed out that service users can be viewed as social movement activists (Brown & Zavetoski, 2005). In effect, they take their place along-side a diversity of groupings including, for example, disability rights movements, patient and carer groups, and psychiatric survivor collectives, who all, variously, assert progressive political claims for a better world (see Crossley, 2006, Spandler, 2006, Beresford & Branfield, 2012). Hence, when 'user involvement' programmes are organised in university settings, the social space of the academy becomes to some extent colonised by service user activism.

Such experiences were confirmed in research carried out as part of the establishment of our Comensus initiative (McKeown et al., 2010, 2012) and two focus groups specially convened for the purpose of inquiring into matters of motivation and identity ($n = 12$ service users). Comensus coordinates and organises service user and carer involvement in various aspects of the work of the University of Central Lancashire. The majority activity supports teaching and learning relating to health and social care. Other inputs include involvement in community engagement, research and strategic developments, such as those concerning disability access. Comensus has developed its own democratic structures, including the Community Involvement Team, a group of around 20 individuals who are the autonomous decision making centre of the initiative. The wider network comprises hundreds of service users and carers and scores of affiliated community groups.

Comensus was initially organised as a participatory action research project, with ethical approval for all data collection granted via the university's ethics committee. Latterly, two focus groups were organised to specifically enquire into questions regarding why people elect to participate in Comensus, what sustains their involvement and