Mental Health Policy in Northern Ireland: The Nature and of Extent of User Involvement

Deirdre Heenan

Professor of Social Policy, School of Policy Studies, University of Ulster, Derry, N. Ireland
E-mail: da.heenan@ulster.ac.uk

In a recent review of the mental health policies of its 42 member states in the European Region, the World Health Organization highlighted the need for further analysis of service user involvement in the policy making process. In the UK, a plethora of recent government policies and initiatives have stressed the importance of service user involvement in the design and delivery of health and social services. Their input is described as a fundamental requirement of a modern, flexible, responsive healthcare system. This paper reviews mental health policy in Northern Ireland, which has undergone a period of unprecedented activity and explores the extent to which service users have influenced the process of policy design and development. It raises questions about the extent to which a genuine commitment to and investment in user involvement has been achieved and comments on the prospects for the future.

Introduction

Over the past two decades, the principle of increased user involvement has become an established feature in legislation, policy and practice in the United Kingdom. The New Labour Government has placed patient and service user involvement at the heart of its health and social care reform programme (DOH, 2006, 2007, 2008). The policy focus is on a personal and responsive health care system that systematically listens to and actions the views of users. Involving recipients of interpersonal services in their design and delivery has been described as a fundamental and moral obligation (Hannigan and Coffey, 2003). Whilst there is a consensus in the literature that user involvement is desirable, there is also recognition that effective engagement is extremely difficult to define and achieve (Croft and Beresford, 1989; Henwood and Hudson, 2000; Carr, 2007). The debate over what constitutes meaningful involvement has dominated research with many highlighting the difficulties of moving from tokenism to genuine power sharing (Bowl, 1996; Barnes and Shardlow, 1997; Pilgrim and Waldron, 1998; Peck *et al.*, 2002). The nature and extent of involvement varies enormously: at one end of the spectrum the service user may be given some degree of choice over treatment options, whilst at the other end they may be involved in designing and delivering the entire service.

The World Health Organization (WHO), *Mental Health Declaration for Europe* (WHO, 2005a) and the *Mental Health Action Plan for Europe* (WHO, 2005b) identify the empowerment of service users and carers as one of the main priorities for the next decade. In the *Mental Health Action Plan for Europe*, the WHO member states committed themselves to ensuring the representation of service users and carers in the delivery and

planning of services by 2010. In November 2008, a WHO report, gave an overview of mental health policies and practices in 42 member states of its European Region (WHO, 2008). It identified great variation across countries and significant gaps in information in areas of strategic importance, such as user involvement. This paper explores the extent to which service user discourses have informed the design and delivery of mental health services in Northern Ireland and considers the impact of proposed changes in health and social care on mental health service users. Although the research is based in Northern Ireland, the issues identified and discussed are relevant to policy makers nationally and internationally.

Background

Historically, in Northern Ireland mental health issues have been afforded a very low priority with facilities and resources for the treatment and prevention of mental illness described as woefully inadequate (Heenan, 2006). Services are dominated by a 'medical model' of psychiatric care with a wide range of associated coercive powers. Service users in Northern Ireland have faced particular difficulties, including poorly resourced services relative to other areas of the UK, and the added burden of living in a divided society characterised by high levels of poverty, unemployment and social deprivation (DHSSPS (NI), 2004). The prolonged civil conflict in Northern Ireland has cast a long shadow on the mental health of the community in Northern Ireland (DHSSPS (NI), 2005a), with those with mental health problems among the most socially excluded in this society.

However, the past ten years has witnessed a period of unprecedented activity in the area of mental health policy and practice. Concern for the mental well-being of the population followed the publication of a plethora of research which highlighted the prevalence of mental health problems and stressed the need for radical action to improve the situation (Curran, 1998; Fay *et al.*, 1999; NIAMH, 2003; Kapur and Campbell, 2004). Alongside this, the signing of the Belfast Agreement in 1998 committed devolved governments to pursue an agenda based on equality, social inclusion, citizenship and human rights. This new political context and policy environment appears uniquely conducive to substantial progressive reform underpinned by partnerships between those who use the services and those charged with designing and delivering them, but to what extent has this been achieved?

Northern Ireland is one of the poorest, most deprived regions of the United Kingdom with very high levels of social and health needs (Moore *et al.*, 1996; Heenan, 2006; Kenway *et al.*, 2006). The prolonged period of political and civil conflict combined with the relatively high levels of poverty have taken their toll on the mental health of the population (Curran *et al.*, 1990; Fay *et al.*, 1999; Kelleher, 2003; O'Reilly and Stevenson, 2003). Post Traumatic Stress Disorder has been described as a specific and significant health need in Northern Ireland's adult population (Ferry *et al.*, 2008). In terms of the scale of the problem, research concluded that the prevalence figures for psychiatric morbidity in Northern Ireland were 25 per cent higher than in England (DHSSPS (NI), 2002a: 188). The 'human capital' costs associated with mental health, including numbers of people claiming incapacity benefit, unemployment due to mental illness and a reduced quality of life, were also found to be significantly higher (NIAMH, 2003). The numbers of suicides have been a particular cause for concern. The suicide rate in Northern Ireland is higher than in England and Wales, but lower than that in the Republic of Ireland and

Scotland. On average, there are 150 deaths per year in Northern Ireland due to suicide and undetermined intent (DHSSPS (NI), 2006a: 9).

In line with other regions of the UK, Northern Ireland has pursued a policy of developing community-care alternatives to hospital care (Prior, 1998; Wilson and Daly, 2007). Whilst the six large Victorian mental health hospitals have remained open, the number of patients in psychiatric beds has decreased quite dramatically, falling from over 5,400 hospital beds in 1965 to 1,500 by the 1990s (Prior, 1988). However, within health and social care, mental health issues have generally been afforded a low priority with problems of under-funding and inadequate services. In 2002, the share of the Health and Personal Social Services budget spent on mental health was 9.3 per cent compared to 11.8 per cent in England (DFPNI, 2002). Recent research highlighted the relatively low levels of spending on community based services (26.3 per cent lower average spend than in England) and suggested this was indicative of a lack of commitment to this approach (NIAMH, 2007). To-date policy change has been reactive rather than proactive and innovative initiatives led by service users have been relatively short term and community-based. Greer (2004) has highlighted the unusual nature of health and social policy making in Northern Ireland. Until devolution, political power was almost entirely in the hands of managers and officials within the civil service, with minimal input from community sector which had neither the resources, nor the expertise to influence policy making.

The centre piece of mental health legislation in Northern Ireland is the Mental Health (Northern Ireland) Order 1986. This order is closely based on the Mental Health Act 1983 of England and Wales and the Mental Health (Scotland) Act 1984. Initially it was broadly welcomed and hailed as progressive compared to the previous legislation (Kirwan and Kirby, 2002; Manktelow *et al.*, 2002). It stated that mental health professionals should, where possible, pursue the least restrictive alternative to hospital admissions and use coercion only as a last option. Yet, despite this commitment to adopting a more liberal approach, the level of involuntary admissions to hospital has been substantially greater in Northern Ireland than in England and Wales (Wilson and Daly, 2007). The number of involuntary admissions to hospital for assessment has risen from 1,028 in 1993 to 1,686 in 2006 (MHCNI, 2007: 7). Wilson and Kirwan (2007) suggest that this increase may be explained by a number of factors including a lack of suitable community alternatives to compulsory admissions, a risk adverse culture in health and social care and a consequence of the programme of de-institutionalisation. A review of the human rights issues involved in mental health law, policy and practice in Northern Ireland concluded that the legislation was inadequate and not fit for purpose. It recommended that more comprehensive legislation governing people with mental health needs should be considered a priority, as aspects of mental health law did not meet the standards required by current human rights law and standards (Davidson *et al.*, 2003).

This 1986 Order established the Mental Health Commission, designed to protect the interests of those with a mental illness. In the Guide to the Order, it is described as an independent multi-disciplinary body with investigative, inspectorial and advisory functions the role of which is to protect the rights and welfare of mentally disordered people and to safeguard staff involved in their care and treatment. Despite its broad remit, there has been some concern that the work of the Commission has been constrained by resource limitation, which has meant its role has been confined to monitoring the compliance with legal documentation, visiting hospital and community facilities and providing advice. The Commission's key objective is to protect the rights of the service user,

but, as it also provides informal advice to service providers, this could constitute a conflict of interest. Despite its focus on safeguarding the needs and rights of the service user, relatively few users and carers have been appointed as Commissioners or are involved in the management of the Commission (Davidson *et al.*, 2003).

Mental health policies

Since the 1990s in Northern Ireland and the rest of the UK, successive health and social care policies and strategies have included a commitment to increase user involvement in the design and delivery of services. Whilst there is no robust legal imperative which sets out the nature and extent of what is required, there has been a raft of guidelines, codes of practice and recommendations, which have progressively strengthened the voice of the user. In 1991, a number of Charters set out minimum standards around patient and user consultation. In 1997, the *Regional Strategy for Health and Social Well-being 1997–2002* stated that 'that should be meaningful consumer involvement at all levels of service planning, commissioning and provision and support for development of user led groups and services' (DHSS, 1997: 10). In 2004, *A Healthier Future: A Twenty Year Vision for Health and Wellbeing in Northern Ireland 2005–2025*, had 'involving people' as a key theme and advocated that 'planning and delivery of services be person and community centred' (DHSSPS (NI), 2004). Articles 13 and 14 of the 2007 *Health and Social Services (Reform) (NI) Draft Order* proposed a statutory duty of personal and public involvement (PPI) and consultation on health and personal social services (DHSSPS (NI), 2007a). To date, however, there has been relatively little research on service user involvement in Northern Ireland. In his recent study of stakeholder participation, Duffy (2008) highlighted the particular difficulties in Northern Ireland and concluded that progress to date was slow and uneven. Whilst there were some examples of good practice, many of those consulted had negative experiences of involvement with large-scale social care providers. As Tait and Lester (2005) have noted, despite its benefits and political encouragement, user involvement is essentially a minority activity, accepted as beneficial but rarely practiced. The Northern Ireland public health strategy, *Investing for Health 2002* (DHSSPS (NI), 2002b) contained a commitment to promote mental health and well-being at individual and community levels. Mental health was the issue most frequently highlighted as a priority for action throughout the consultation process for Investing for Health, but it has been associated with a distinct lack of action and a lack of tangible outcomes.

The *Bamford Review*

In 2002, in response to increasing concerns about the level and scale of mental illness, the health minister in the newly devolved administration established the most comprehensive review of mental health and learning disability. The *Review*, which followed similar exercises in England and Scotland, became known as the *Bamford Review*, concluded in 2006. It published a series of ten detailed reports with almost 700 recommendations. The considerable majority of recommendations related to DHSSPS responsibilities, but some also referred to broader issues, such as human rights, equality and housing, transport and social exclusion. The first two principles of the *Review* (DHSSPS (NI), 2005a: 11) appear to reflect the importance placed on partnerships with service users. These were:

- partnership with users and carers in the planning, development, evaluation and monitoring of services;
- partnership with users in the individual assessment process and all therapeutic interventions of care and support.

An overall Steering Committee managed the *Review* and this was guided by inputs from 'expert working committees' allocated to ten specific areas, such as adult mental health, mental health promotion and social justice and citizenship. So who were these experts? At the outset, the *Review* was dominated by medical professionals, but subsequently the focus was expanded to reflect a much broader range of perspectives, including service users and a range of voluntary and community groups. Significantly, service users were not involved at the outset of the exercise and have expressed disquiet about being brought into the *Review* 'at a late stage to validate or to respond to agreements already in train' (DHSSPS (NI), 2005a: 207).

The evidence as to whether or not they made a difference to the outcomes is mixed. On the one hand, the emphasis on recovery, choice and self-control suggests they have been influential. The *Human Rights Report* produced by the *Review* (DHSSPS (NI), 2006b) stresses the centrality of a person-centred rights-based vision for service provision. On the other hand, as Wilson and Daly (2007) point out, the fact that service users' opinions are categorised in a separate 'experts by experience' appendix, rather than included in the main body of the consultative report, appears to highlight a power imbalance and suggests some uncertainty about their status. Their input was as experts, yet there was a clear differential between their contributions and those of 'other' experts, who were professionals. This administrative decision about the structure of the report can be seen as a rather telling reflection of the ambiguous nature of their role. This different but equal label can be seen as evidence of a clear hierarchy of experts which undermined the knowledge and views of service users. With regard to training, the service users expressed disappointment that both self-management training programmes and pro-active user development initiatives were completely overlooked. Consequently, there were genuine concerns about the value attached to their input in the *Review* and their role in the future development of a new vision for mental health. As they point out, this experience is painful but not new 'as mental health service users, we have become accustomed to and hence acutely aware of any denial of the expertise we have to offer' (DHSSPS (NI), 2005a: 219). These comments are not exactly a ringing endorsement of a process which claimed to be underpinned by a partnership with service users.

The *Review* presented a rather damning picture, identifying significant gaps and deficiencies in Northern Ireland's service provision for people with mental health needs. It stressed that a history of significant under-investment in this area had made prioritisation essential. A holistic and comprehensive approach to service provision and mental health practice was considered necessary to address the high prevalence and the wide spectrum of health, psychological and social needs of people with mental health problems. Despite a commitment to developing community-based approaches, mental health services were dominated by hospital services, including day-care within a hospital setting and acute psychiatric beds. Levels of institutionalism were significantly higher than in the rest of the UK. While 15 people per one million were in long-stay hospitals in England and Wales and 163 in Scotland, the figure for Northern Ireland was 222. Over 25 per cent of people with learning difficulties were in a nursing home compared to a 1997 figure of 7 per cent

for England and Wales (DHSSPS (NI), 2005b: 31). Service users and carers were described as poorly supported and insufficiently involved in the design and delivery of services.

The *Review of Public Administration*

In parallel with the *Bamford Review*, the *Review of Public Administration* (RPA) began in June 2002 to undertake a comprehensive examination of the arrangements for the administration and delivery of public services in Northern Ireland (RPA, 2006). The RPA reached a conclusion in March 2006 and the reforms it introduced represent a reduction in the number of existing organisations and some reconfiguration of the functions of existing structures and institutions. Under the existing system, the four area Boards were responsible for assessing the needs of their populations and commissioning services to meet those needs; the Health and Social Services Trusts were the main providers of services (Heenan and Birrell, 2006). Northern Ireland's health and social services were substantially reorganised as part of the RPA. The outcome was significantly fewer health and social service organisations, including:

- A reduction from 19 existing Health and Social Services Trusts to six Health and Social Care Trusts.
- The abolition of Health and Social Services Boards, replacing them with the establishment of a single Health and Social Services Authority with seven Local Commissioning Groups (LCGs) to replace the current 15 Local Health and Social Care Groups.
- The establishment of one Patient and Client Council to replace the existing four Health and Social Services Councils.

A key part of the government's agenda was the rationalisation and streamlining of service delivery with savings reallocated to front line services. Whilst it was widely agreed that Northern Ireland with its population of 1.5 million people was over-governed, changes following the RPA mean that Northern Ireland has moved to the other end of the spectrum. For example, the Belfast Health and Social Care Trust, in terms of population is one of the largest health public bodies in the UK (Birrell, 2008). This radical rationalisation and centralisation of service delivery may adversely affect the responsiveness of services. The interests of certain groups, such as those in dispersed communities or those suffering from mental health difficulties may not be well represented. It is also difficult to see how the proposed LCGs will actually be more local than the system they are replacing. The Northern Ireland Association for Mental Health has voiced concern that these LCGs could be service driven to the detriment of the strategic recommendations set out in the *Bamford Review* (NIAMH, 2008). Additionally, it has been suggested that the new structures and language used in the policy documents reflect the dominance of the medical model, for example a prerequisite to appointment to the LCGs has been clinical experience (NICVA, 2008).

Implementation of the *Review of Public Administration*

In relation to health and social care, there were two main phases of implementation of the RPA. The first phase, which took effect from April 2007, involved the establishment of the five new integrated Health and Social Care Trusts and the retention of the Ambulance Trust. The second phase involved establishing a new organisational structure to replace

the four Health and Social Services Boards, four Health and Social Services Councils and a number of agencies. This second phase was scheduled for completion in April 2008, but has been deferred until April 2009. The proposals for the second phase of Health and Social Care Reform, dealing largely with the planning and commissioning of care, went out for consultation in 2008 and included relatively little mention of mental health services. It was proposed that a single new Regional Health and Social Services Board would oversee the implementation of the recommendations of the *Bamford Review* 'which will ensure much needed improvement in mental health and learning disability' (DHSSPS (NI), 2008a: 16). Yet mental health and wellbeing are not described as top priority or even a priority area. User involvement appears to be limited to a complaints procedure and there is little obvious commitment to work with service users as partners in the design and delivery of health and social services. The consultation document does not reflect the crucial role played by the voluntary and community sectors in innovative service delivery, and advocacy for mental health service users.

The *Bamford Review* highlighted the difficulties faced by individuals when attempting to access mainstream health services. It illustrated the devastating impact on service users and their families when structures fail to respond appropriately to needs. The *Review* stressed the need for service users to be meaningfully involved in the development and delivery of services. The current move towards centralisation of health and social services means responsive, local services may prove problematic. It is difficult to see how mental health services will respond to the needs of small, dispersed, complex communities.

Under the proposed changes in Health and Social Care, the functions of the Mental Health Commission will be transferred to the independent body responsible for monitoring and inspecting the quality of health and social care services, the Regulation and Quality Improvement Authority (RQIA). It will no longer be a separate independent body, similar to those in the Republic of Ireland and Scotland, but will move to a model similar to that in England and Wales. This change comes about despite the fact that a Working Group of the *Bamford Review* determined that there was a very clear need for an independent watchdog body to monitor and regulate the services provided to people with a mental health and learning disability. There is clearly a risk that the interests of mental health service users will become marginalised in a larger body, where the acute hospital sector will take priority. Also, if the Mental Health Commission is subsumed in a larger organisation, the input of lay members from a range of backgrounds will be lost. Neither the Management Board nor the Mental Health and Learning Disability group of the RQIA has a nominated service user representative. In June 2008, the organisation produced a Draft Public Participation Strategy for consultation (RQIA, 2008), which was intended to help develop public involvement in the work of the organisation. The Draft Strategy notes that user-focused public participation is essential in taking forward the work of the organisation, interestingly though the steering group for this project has no service user representation.

Impact of the Review of Public Administration

Unsurprisingly, this overhaul of the entire system of public administration in Northern Ireland has impacted on the implementation of the recommendations of the *Bamford Review*. The reconfiguration of Trusts into much larger organisations means there is a

danger that mental health will be relegated to a secondary issue behind acute care, cancer services and children's services. The new structures contrast sharply to the situation in England, where focused mental health partnerships between Primary Care Trusts and Local Authority Social Services have been established. To allay fears that mental health issues could become buried in the new structures, the Minister for Health announced that the 'direction of travel would be very much in accordance with the recommendations of the *Bamford Review*' (NIA, 2008). In order to achieve this aspiration, he established a Mental Health and Learning Disability Board. The function of this new body was to advise him and be one of the driving forces in delivering the recommendations of the *Review*. He noted that 'most of the work of the Board will be long term that is why the membership is so wide ranging, drawing on the skills and expertise of people who have had real experience of current services' (DHSSPS (NI), 2007b). The membership of this six person Board is three professors and three people working in field of mental health. It is chaired by a consultant psychiatrist, and, incredibly, service users are not represented.

Alongside these developments, DHSSPS are taking forward a programme to develop National Service Frameworks for Northern Ireland. These are long-term strategies for improving specific areas of care which set standards, identify key interventions and set out acceptable timescales for implementation. The Southern Health Board has been charged with taking forward the Mental Health Service Framework. They stress that it will provide standards of care that are underpinned by robust evidence, regional and national policies, findings of regional inquiries, the experience of service users and legislative requirements. It is claimed that this Framework is not simply a mechanism to address the range of mental health deficits identified by the *Bamford Review*, but should instead 'by necessity' be based on what can be 'realistically achieved' within the existing Health and Personal Social Services Framework. It will set out key standards and targets in respect to clinical outcomes, timeframes and settings. It is envisaged that this Framework will be agreed and in place by 2009. For all the emphasis on partnerships with service users, it is perhaps particularly revealing that the terms of reference for this project gives scant mention to their role (DHSSPS (NI), 2007c). Rather than being placed at the forefront of policy development and management they are last in a list of six possible groups of participants. Whilst the others, such as clinicians and senior management, are described as experts, the service users are referred to as representatives. Both the language and position afforded to them appear to suggest that full integration into the decision-making process was not as advanced as the rhetoric would suggest.

In June in 2008, the Health Minister announced a further consultation entitled 'Delivering the Bamford Vision' (DHSSPS (NI), 2008b). In the consultation document, the Government states that in order to make the Bamford vision a reality, the NI Executive will seek to provide person-centred, seamless community-based services, informed by the views of service users and their carers. It states that there must be a partnership approach where people with a mental health problem are not simply passive recipients of services, but must be empowered active participants. It does not, however, explain how this is going to happen, rather it is claimed that the proposed Regional Health and Social Care Board will 'help to ensure that mental services' are given priority within overall commissioning. In Northern Ireland there is no regional body with a specific mental health focus to oversee, co-ordinate and support the work of the four health boards who have developed individual strategies and initiatives.

Conclusions

Historically, mental health services in Northern Ireland have been under-resourced, over-stretched and reactive. The focus has been on crises management and fire-fighting with service user involvement viewed as additional to the core work of health care professionals. There is, therefore, some way to go to ensure effective participation and empowerment for mental health service users. While much has been said about the value of engagement, to date there have been very few tangible changes in the process of designing and delivering services. This is in contrast to the situation in the Republic of Ireland, where a major review of provision led to new legislation and the establishment of a National Service User Executive for mental heath services (HSE, 2007). This group ensures that service users are at the epicentre of developments, using their insights and knowledge to shape the direction of policy and practice.

Existing evidence (Barnes and Bowl, 2001; Hodge, 2005) suggests that creating effective interaction between users and staff is complex and challenging, but ultimately worthwhile as it can be the key to revolutionising services. Real change in this policy area will take time to achieve and it is essential that the devolved government pursue meaningful engagement and acknowledge tensions between greater user choice and service control. The reorganisation of services in Northern Ireland presents an ideal opportunity for new Trusts to develop environments that view users as equals and embed this ideology into their culture. The new agendas of human rights, social inclusion, respect and equality present an opportunity to develop more personalised and responsive health services. Significantly, in Northern Ireland mental health has moved out from the shadows, and stereotypes, prejudice and stigma are beginning to be acknowledged and addressed. However, ensuring that there is a move from care that is 'done to' service users towards a system of support built by the individual and their advocates will require something more radical than simply changing the law or developing another strategy. Affording mental health service users a meaningful and significant input into shaping the future development and direction of mental health services is an international policy issue. The WHO (2008) report notes that further work is required to determine the influence of service user groups on policy and practice both at national and local levels and to assess how this is related to other social, cultural and economic factors. In Northern Ireland, it appears that amongst policy makers there is still much resistance to sharing power with users and a system of professional protectionism prevails.

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