

Power and Participation: An Examination of the Dynamics of Mental Health Service-User Involvement in Ireland

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ABSTRACT Discourse and rhetoric of service-user involvement are pervasive in all mental health services that see themselves as promoting a Recovery ethos. Yet, for the service-user movement internationally, 'Recovery' was articulated as an alternative discourse of overcoming and resisting an institutionalized and oppressive psychiatric model of care. Power is all pervasive within mental health services yet often overlooked in official discourse on user-involvement. Critical research is required to expose the unacknowledged structural and power constraints on participants. My research problematizes practices of user involvement in one mental health service area in Ireland.

Part I of this article examines the background context of policies and practices of user-involvement from the service-user perspective and explains developments in relation to service-user involvement in the case of Ireland. Participants in my study articulate their motivation for engagement with mental health service reform in terms of the right to participate in social justice terms, of wanting to improve services and humanise care. Power dynamics emerge as one of the primary obstacles to equitable involvement.

Part II of this article presents an explanatory framework of power, using a model developed in the field of development studies; Gaventa's (2006) 'power cube.' The three dimensions of the cube represent the forms, spaces and levels of power. The explanatory potential of this model to highlight how hidden and invisible power operates in mental health services is illustrated by selected comments from the same participants. The power cube is a useful tool to illuminate the dynamics occurring in service-user involvement spaces. Showing how different forms of power operate in the spaces and levels of mental health involvement can develop service-users' awareness of the hidden and invisible aspects of power. Through this awareness, they can strategize around their potential to influence decision-making in mental health services.

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ISSN: 1911-4788

Introduction

Service-user¹ involvement strategizes to challenge social injustices rooted in institutional practice, demonstrated to be endemic throughout mental health services in Ireland (Brennan, 2012; Hyde, Lohan, & McDonnell, 2004; Rafferty, 2011; Sapouna, 2006). Yet the underlying power dynamics operational in mental health services transfer into the spaces opened up by official policies of service-user involvement. Critical research is necessary to highlight the dynamics often overlooked in official discourses, in order to expose the social inequities and injustices experienced by mental health service-users. This article argues that service-user involvement must be problematized by highlighting hidden and invisible aspects of power operating within these spaces.

The argument is presented in two parts. Part I introduces the context for service-user involvement by tracing the links between Recovery and service-user involvement discourses as articulated by service-users. These discourses are grounded in ideas of social justice, particularly status recognition (Lewis, 2009) and participatory parity (Frazer, 2007). These concepts, and their importance to service-users, will be illustrated by comments from participants in my current empirical research on service-user involvement. Part I also explains the development of policies and practices of service-user involvement in the UK and the responses of the UK service-user movement. Finally I consider the Irish case, reviewing two published studies on the service-user movement and service-user involvement in Ireland. I discuss official policy and subsequent developments. One significant challenge for service-user involvement stands out from this review of the service-user experience to date: namely the complexities of power operating within the mental health system.

Part II presents a conceptual model of power, the ‘power cube’ developed by Gaventa (2006), as a useful framework for understanding power as it operates in the mental health services. The three dimensions of the cube represent the forms, spaces and levels of power. The power-cube has the potential to heighten service-users’ consciousness of how power/knowledge operates in relation to service-user involvement. Thus it could become a useful social movement tool for activists seeking to right some of the inherent injustices experienced in these spaces of unequal power. It is only through heightened awareness of the obstacles to be overcome that service-users can hope to achieve their aims of engagement.

The social justice concerns of user involvement and the explanatory potential of the power cube to expose the operations of power are illustrated by selected comments from interviews and ethnographic observation in my own study at a local mental health service over nine months in 2010/2011. This empirical study forms part of my current PhD research on mental health service-user involvement in Ireland. There are three sample groups in the overall study; eight service-users involved in various committees, mental health professionals, both at the local study site, and service-user movement

leaders with a national perspective. However, the article will be limited to the perspectives of the local service-users, three of whom were employed as peers-advocates, the other five as unpaid advisors. Feminist standpoint theory formed the basis of my epistemological approach and the resulting development of a survivor standpoint that underpinned my methodology (Beresford, 2003; Sweeney, 2009). My own standpoint is that of an Irish-born woman with experiences of different types of encounters with mental health services, and of being active in service-user-led research, advocacy and involvement spaces since 2000.

Part I: Recovery and Service-User Involvement

Recovery² was articulated by the service-user/survivor movement as a way of overcoming and resisting institutionalized and oppressive psychiatric care (Beresford & Wallcraft, 1997). From a service-user perspective, Recovery is a concept that focuses on attitudes of hope, coping strategies and supportive relationships which offer people a belief that it is possible to live a meaningful life with or without the presence of symptoms of emotional distress (Ralph, 2000). Recovery-oriented mental health services seek to redress the imbalance of traditional services' control over people's lives and to encourage people to recover autonomy, to re-integrate into their communities and to re-build a meaningful life (Repper & Perkins, 2003; Stickley & Wright, 2011). Turner-Crowson and Wallcraft (2002) discuss some of the concerns British service-users had about the importation of Recovery language into mental health service discourse, including issues regarding professionals defining Recovery in terms of service outcomes. This can result in services referring to people as not being 'compliant' with their Recovery plans. They highlighted the fears of service-users in relation to non-achievement of Recovery measures and outcomes, and the effect this might have on their social welfare provisions. Turner-Crowson and Wallcraft stress the importance, for the service-user movement and mental health service reformers, of continuing to focus on the "complementary themes" to Recovery, such as early intervention, suicide prevention, user involvement, practical measures for social inclusion, strategies for living, surviving and coping, and most importantly keeping hope alive (2002, p. 252).

Recovery entered official Irish discourse in 2005 with the publication of a discussion paper on Recovery by the Mental Health Commission³. In Irish government policy (*A Vision for Change: Report of the Expert Group on Mental Health Policy*, 2006)⁴, a Recovery ethos is evident within parts of this document. Service-users in my study had expectations about what Recovery-focused services would offer, and chief among these expectations was hope for a greater range of choices than the traditional service model. An important focus for the participants was at the individual level of involvement, peoples' therapeutic relationship, and allowing people opportunities to learn and develop by taking personal responsibility for their choices. At the most

fundamental level people wanted more treatment choices:

service-users have to be at the centre, . . . and they don't have the choices that they need. . . . it's no good saying we're a Recovery-focused service but all that we're offering you is a psychiatrist and drugs. It's about having a wider multidisciplinary team, service-user involvement in that . . . the service allowing the service-user to take responsibility, allowing them to make mistakes and starting again. (Female Peer-Advocate)

For this participant, Recovery and service-user involvement are inter-dependent, if a service is providing choices it will include meaningful service-user involvement, and not just at an individual level.

Service-user involvement does not occur in a vacuum. Service-users frequently experience care as coercive and controlling, without choices as to refusing care, what kinds of care may be considered, or over who provides this care. McGruder (2001) documents how seeking help results in the person losing autonomy, as the professionals take over. Lewis (2010, p. 3) observes how the experience of using mental health services and the constant threat of compulsory detention create a culture of fear and domination, a form of "affective power." Service-user involvement is understood by participants in my study as a way to contest this individual and systemic oppression. There is a sense of injustice evident in how the participants describe their own experiences of care as well as in their observations of the position and treatment of long-term residents.

A significant thread throughout one advocate's interview, and evident in many others, was the importance of empowering people to speak up for themselves, to know their rights and take control over their lives. She gave an example to illustrate how for years a long-time resident in services never felt he could visit his mother's grave. She was angry about how people can be left dependent because choice and volition is removed from their lives: "something is deadened inside." Providing opportunities for people to regain the agency to make choices was a major motivator for this woman in her work as a peer-advocate. She saw this as a fundamental human right. Another female peer-advocate claimed that using human rights discourses to advocate against injustices within the mental health system could be useful: "it's something that we can say, you know, I'm sorry but you can't do this because you're breaking human rights laws." A third peer-advocate described his motivation: "I've always believed in social justice and that people should be able to offer other people a helping hand." Two other participants also mentioned "injustices in the system" as motivation for becoming active in the unpaid advisory committee work that they were involved in. Clearly the opportunity to do something about their concerns, in relation to the way the mental health services interact with those receiving care, was a motivating factor for these participants. Having explained why service-user involvement is a matter of social justice to service-users, it may be instructive to examine what has influenced the policies and rhetoric around user-involvement.

Consumerist or Democratic Drivers for Service-User Involvement

Beresford (2002), with a particular interest in service-user involvement in research, traces the development of the rhetoric of user involvement/partnership/empowerment, and identifies two powerful driving forces, neo-liberalism and the rise of user movements. While both emphasize participation and user involvement, they result in two distinct models of participation, which he labels “consumerist” and “democratic.” The consumerist model of involvement, identified with a neo-liberalist agenda, is consultative by nature & primarily focuses on data collection methods of involvement. Pilgrim (2009, p. 87) points out that this is “analogous to the consumerist process of, say, hotels asking guests to fill in a satisfaction survey.” This understanding of involvement certainly fails to recognize the fact that many of the acute units are “unambiguous sites of coercive social control,” according to Rogers (as cited in Pilgrim, 2009, p. 88). Pilgrim (2005, p. 25) also points out that user-involvement is “in the gift” of services, in that it is discretionary as to whether service-users are invited to participate or under what conditions. Other developments in wider society which influenced the enthusiasm for service-user involvement have been identified, such as a trend towards more participative forms of governance, and the changing relationship between the public and the medical profession as trust in professionals declined following several well publicized medical and social care failures (Hyde, Lohan & McDonnell, 2004, p. 240; Kemp, 2010).

Beresford (2002) traces the democratic approach to participation emerging from civil rights movements, including the service-user movement, which prioritizes inclusion, autonomy, independence and self-advocacy. As an approach it is explicitly political, seeking to influence the power dynamics of participation. Beresford (2002) argues that the logic of the democratic approach is for “user-led” and “user-controlled” services, whereas the consumerist approach seeks to influence the provider-led approach to policy and services. Two British service-users have observed service-user involvement “is a ‘*must do*’ for the mental health system and ‘*an opportunity to do*’ for those using mental health services” (McKinley & Yiannoullou, 2012, p. 115).

The Service-User Movement and Service-User Involvement

Wallcraft, Read and Sweeney (2003) surveyed the English mental health service-user movement and found that, after self-help and social support at 79%, user involvement was the second most common activity with 72% of 318 local groups taking part in some form of consultation with mental health professionals and decision-makers. Service-user involvement work was often linked to implementation of the UK government policy for mental health services. There were variations in the forms and perception of influence of much involvement at local level. Wallcraft et al. (2003) clearly assert

that the service-user movement is more active than just being involved in decision-making bodies. While service-user involvement is an important part of the movement's activities, service-user/survivor groups exist for many other reasons and some decided not to do service-user involvement work. Importantly, the movement exists independently of its role in service-user involvement activities.

Rose, Fleischman and Schofield (2010) list eight different forms of service-user involvement. These can mean being consulted about staff recruitment, having a role in selection of candidates or being involved in staff performance evaluations. Service-users also can advise on local mental health services, and be involved in research. This is usually consultation but there is a growing body of user-led and controlled research. Service-users have been involved in training professionals; indeed it is often mandatory to demonstrate this. Increasingly in the UK, service-users are employed in services as peer-workers and there are growing numbers of user-led services. There is now a long established tradition of peer advocacy, and this is the most established aspect of service-user involvement in Ireland. And finally Rose, et al. (2010) identify campaigning and anti-stigma initiatives as another form of service-user involvement.

Rose, et al. (2010) do not include the individual relationship of a service-user with service providers as a form of service-user involvement. However this is what many service-users and mental health practitioners in my study first mentioned when asked about their understanding of service-user-involvement. This is likely to be because, apart from peer advocacy, the other forms described by Rose, et al. (2010) are not established in Irish mental health services. Currently, there are one or two fledgling initiatives in Ireland to develop peer-support worker roles within mental health services.

There are growing critiques of what user involvement has achieved in terms of addressing the structural inequalities experienced by service-users in the UK. Campbell (2001) argued that when service-users do work together with service-providers, the discourses of partnership and collaboration can mask power imbalances and differing agendas. Service-users have articulated resistance to deal with the power and social inequities inherent in the position of service-users and the failure of many involvement initiatives to make any difference to users' lives (Campbell, 2005; Rose & Lucas, 2007; Wallcraft, 2008). Campbell (2001, p. 88) points out that service-user involvement has made no impact on the "clinical authority" of the mental health worker.

The policies and practices of user involvement are not without their academic and practitioner critics. Some of the more critical academic commentators (Carey, 2009; Forbes & Sashidharan, 1997; Pilgrim, 2005) argue that without addressing power imbalances service-user involvement may simply be a way for decision-makers to legitimize their decisions. These writers address the position service-users are in vis-à-vis the mental health services and highlight the coercive nature of many mental health service-users' encounters with services. Therefore participation within the mental health services has a distinctly different quality to other types of patient involvement. The power

imbalances are more acutely felt as every service-user is aware there is always a possibility they can be picked up and detained against their will (Pilgrim, 2009, pp. 115-118), without having committed any crime, a unique power under mental health legislation. Pilgrim notes two ways user involvement can be considered worthwhile from the user perspective, not only as a human right, but also as a “Trojan horse” (2009, p. 86). He refers to the way the service-user movement can regard user involvement as an opportunity to contest how they have been treated and present oppositional views to the coercive, bio-medical approach of mental health services. Pilgrim (2005) has also highlighted the co-option of the voice of protest into servicing the needs of the mental health establishment. He describes the tension between on the one hand the democratic impulses of the service-user movement⁵ to improve the care offered by mental health services, and on the other hand the agenda of the health care providers to co-opt the service-user voice in a corporatist, neo-liberal effort to achieve stated policy objectives and outcomes (Pilgrim, 2005). Research continues to raise concerns about quality of involvement, tokenism and the lack of resources for user involvement (McDaid, 2009). All of these obstacles to meaningful service-user involvement are issues of social injustice, stemming from processes of “misrecognition and maldistribution” described by Fraser (2007) and experienced by service-users both within the mental health services and in wider society. These issues are also evident in the Irish case.

Irish Experience of Service-User Involvement

Speed (2002) offers a critical discourse analysis of general literature by mental health social movement organizations (SMO) in Ireland plus detailed consideration of Department of Health documents as evidence of the development of a consumer ethos (Speed uses Crossley’s (1998) development of Bourdieu & Wacquant’s (1992) concept of habitus to explain this ethos). Both SMOs examined in his study (Schizophrenia Ireland, now known as Shine, and Aware, an SMO focused on Depression) demonstrated a consumerist rhetoric where the service-user was referred to as a “consumer” but the thinking was still influenced by the concept of “patient.” Families were included in the definition of consumer, but no guidelines offered as to their role. The four SMOs most active in the field were consumer organizations, comprising in one case of entirely seconded health service employees and another organization employing one or two service-users at lower levels (Speed, 2002, p. 77). The organizations by and large completely accepted the biomedical model. As such, these groups offered little in the way of active user involvement or dialogue. Speed (2002) argued that the Irish mental health field offered no challenge to psychiatric hegemony and this was a direct result of the lack of an organized user-led movement (p. 77). In fact he suggests that this consumer habitus was primarily driven by government policies, imposed from the top down, rather than emerging from service-users themselves.

Speed (2002) also observed that even though community care was the most self-evident and quantifiable transformation in the literature, there was a failure to legislate for it. This remains the case today. Achieving a legislative framework to progress the tardy implementation of the recommendations in *Vision for Change* (2006) is a core objective of an ongoing campaign by Amnesty International, Ireland (AI). The Irish branch of AI has focused on the Government's neglect of the mental health services as a failure to provide for the human rights of mental health service-users. There has been an active campaign by AI Ireland to lobby for improvements since 2003 (Amnesty 2003, 2006). An Expert by Experience Advisory group was established by AI in 2008 to inform and advise on the development and implementation of the current mental health campaign.

Since Speed's 2002 analysis, there is now an emergent service-user movement. The Irish Advocacy Network (IAN) has emerged as a strong presence in the field of mental health in Ireland. An island-wide NGO service-user run organization, it provides peer-advocacy services throughout the island of Ireland, with Health Service Executive (HSE) contracts to provide peer-advocacy services at approved centres (licensed centres to detain people under the Mental Health Act 2001) in all but one of the 26 counties. In the Northern Ireland (NI) jurisdiction, IAN provides peer-advocates in the community working independently alongside community mental health services. In addition, other more radical voices such as Mad Pride Ireland, Mind Freedom Ireland and Critical Voices Network have emerged over the past decade to create spaces of resistance to psychiatric hegemony.

Irish policy on mental health service-user involvement appears in Chapter Three of *Vision for Change* (2006) under the title of "Partnerships in Care: Service Users and Carers." The overall policy was developed by diverse stakeholders, including psychiatrists and other mental health professionals, yet it contains relatively strong statements about commitments to service-user involvement. It asserts that service-user involvement is more than simply consulting; service-users and carers must be at the centre of decision-making, from the level of decisions about their own care through to the strategic development of local services and national policy. Some attention is given to the role of peer-advocacy, with a clear recommendation that advocacy should be provided as a right in all parts of the country. Peer-run services are discussed, with evidence about the benefits to service-users generally, the peer providers, and the savings to the services in terms of improved outcomes for service-users. To date, six years on, there is no evidence of the emergence of peer-run mental health services. At the level of operational involvement, it is recommended that service-users need to be included on the local catchment area management teams. In terms of involvement at the national level, *Vision for Change* recommended the establishment of a National Service User Executive (NSUE) with the brief of informing national planning and regulatory bodies on "issues relating to user involvement in planning, delivering, evaluating and monitoring services, including models of best practice and to develop and implement best practice guidelines between

the user and provider interface.” (2006, p. 27). The chapter also includes principles that should guide service-user involvement. These are based on those published by UK service-users Devan & Reid, (as cited in Wallcraft, et al., 2003, pp. 63-4). These principles include assertions that service-user involvement is a right, and should be incorporated into how professionals work. They maintain support should be provided to service-user organizations: that imbalances of power need to be acknowledged and addressed; that service-users be allowed to decide what they want to do rather than having to adapt to others’ plans for them; that the existing experience, knowledge and skills of service-users be valued even though these may challenge those of some professionals, and that service-users should be reimbursed for out-of-pocket expenses at the same rates as health professionals.⁶ The principles conclude by noting that service-users and carers are not interchangeable: service-users can often be made to feel disempowered by well-meaning carers, and in some instances may be in direct conflict with carers. Users and carers should not be considered a homogenous group.

The understanding of the term service-user is very broad in the official discourse of public and patient participation. The official Irish HSE understanding of the term “service-user” is so broad that it could become meaningless. It includes not only “patients”; but also carers, parents and guardians; representative NGOs and “communities” and “anyone who is a potential user of health services and social care interventions” (DoHC & HSE, 2008, p. 6). Such a definition is problematic; leaving aside the question of inclusion of the entire population, the inclusion of NGOs and ‘communities’ as representative of mental health service-users raises many issues about representative justice (Fraser, 2007; Lewis, 2009). As noted above, many NGOs may have conflicting values and less than inclusive practices. Of particular note in these principles is that the interests of service-users and carers are not interchangeable. Pilgrim discusses the managerial “amalgam discourse” (2009, p. 86) of conflating service-users and carers as problematic for mental health service-users especially. There are points on which the agendas of both can differ significantly. Service-users can often be made to feel disempowered by well-meaning carers, and in some instances may be in direct conflict with carers. For instance, Pilgrim (2009, p. 91) explains how improved communication by service providers with carers about risk assessment and prediction of relapse, can embroil family and friends in role tension. This includes dilemmas about whether they are acting as an extension of the mental health services, or if their first loyalty is to their loved one. Also, while carers often have common cause with service-users in seeking improved mental health care, sometimes there are differences in how they define better care. Many relatives of service-users are dominant in the NGOs active in the field, (Sane and Rethink in the UK, the National Alliance for the Mentally Ill in the USA, Shine in Ireland). They are more likely to be supporters of a bio-medical model (Speed, 2002), and to place greater emphasis on inpatient care and the coercive control of madness (Pilgrim, 2009, p. 91). It is generally recognized that service-users and carers have different identities and concerns, and that the concerns of relatives are given

higher credence when there are conflicting accounts of satisfaction with services (Rogers & Pilgrim, 2005, p. 219). There is an increasing recognition of the social justice issues involved in the caring role played by relatives across the wide range of health and social care fields, including concerns about the feminization of care and the non-recognition of the value of caring in society generally (Barnes & Cotterell, 2012, p. 228; Lynch & Walsh, 2009). Notwithstanding these concerns, a clear separation between both groups is preferred by many service-users because of the different identities and the possibilities of conflicting agendas.

During the process of the establishment of the NSUE in Ireland in 2007, it was decided that this representative body would include carers as well as service-users in a ratio of three service-users to one carer. People are elected onto the NSUE from a body of voters consisting of self-selected members. Service-users and carers have separate ballots and panels. People are elected onto the NSUE to represent the four regions of the HSE, on a four year rotation, with one election to take place every year. Therefore, there should in theory be a constant turnover of service-users and carers on the NSUE. It is a challenging task to become elected onto the NSUE, as there is little available in terms of resources to support potential candidates. There is no local presence in the regions, and members of NSUE have to meet their own travel and other costs. Establishing a proportional representational electoral system for a fledgling, tentative user movement may not have been the wisest move in terms of supporting “participatory parity” (Fraser, 2007, p. 27) or the development of a strong grassroots movement given the marginalization of service-users (National Economic and Social Forum, 2007) generally in society. The process of representational democracy can foster a culture of powerful elites, compared to participatory democracy which values each voice equally (Beresford, 2010; Chambers, 1997; Kirby & Murphy, 2009; Young, 2000).

Heenan (2009, p. 459) claims that the establishment of the NSUE is a move forward in terms of developing the service-user perspective on mental health services, by ensuring that service-users are “at the epicentre of developments, using their insights and knowledge to shape the direction of policy and practice.” She is focused on the challenges of implementing service-user involvement in Northern Ireland (NI) where there has also been lack of action in relation to the promises of the policy review of mental health services in that jurisdiction. The NI review held out promise of greater service-user involvement, but like the policy for mental health services set out in *Vision for Change* (2006), a structural reconfiguration of mental health services in relation to the general health service has meant that many of the finer aspirations about more Recovery-focused mental health services which include the service-user in planning, evaluation and monitoring of services have not materialized (Keogh, 2009). The amalgamation of the service-user and carer voice has not helped. In addition there is emerging disquiet within the service-user movement in Ireland that the relatively well-funded NSUE is not sufficiently accessible to local service-users who are removed from the

operations of their designated representative body (Lakeman, McGowan, & Walsh, 2007). It has to date produced three reports on a survey of its members, reporting that the majority are “happy with their local mental health service,” and feel their local services “promote Recovery” (NSUE, 2010, 2011, 2012). The last survey has incorporated some more nuanced qualitative accounts of satisfaction, and lack of same, with mental health services. On the basis of these surveys the NSUE has established annual awards for the best performing services. It would appear that the NSUE, which may have been a good idea as initially proposed, has lost credibility as a critical force for change. Thus a potential opportunity to develop a participative democratic base for the user movement in Ireland has not materialized and obstacles to user involvement on the ground remain entrenched. Research by McDaid (2009) highlights these obstacles.

McDaid (2009) conducted interviews with 20 Irish mental health service-users from an egalitarian perspective. She applied the Equality of Condition framework, (Baker, Lynch, Cantillon, & Walsh, 2004) as a mechanism to identify the full range of structural obstacles faced by service-users engaged in strategic decision-making. The Equality of Condition framework prioritizes creating more equal power relations in society, identifying four different dimensions of inequality which include; power, respect and recognition, resources, and “love care and solidarity.” The power dimension refers to both “power over” and to empowerment. Power over covers coercion, disciplinary power, the power of authority and power/knowledge. Respect refers to acceptance of both individual and social diversity, and recognition refers to the social esteem held by members of different groups. Resources include all that is needed by an individual in order to participate in strategic decision-making, including economic resources but also time, cultural resources such as context specific knowledge, physical and mental resources. The final category refers to the affective domain and the ways relationships and affiliations with peers and allies impact on inequality. Solidarity allows space for the emotional content of public participation, a domain particularly relevant for service-users as emotional expression delegitimizes mental health service-users. McDaid (2009) demonstrates empirically how each of these domains of inequality were present, thereby illustrating the range of structural inequalities service-users face, which affects their opportunity for equal participation. One of the most intractable structural inequalities is the power domain, which will be examined now in Part II.

Part II: A Strategic Model of Power for Service-User Involvement

Power imbalances are a dominant feature of the environment in which service-users engage with mental health services. Gaventa and colleagues have examined issues of power within the field of development work. Gaventa (2006) suggests a three dimensional model of power based on the rubix cube: the power cube (see Figure 1 below). Using this model, he

explores how power interacts with marginalized or subaltern groups who participate in initiatives to include their voice, and the spaces for participation. He suggests that the discourse of participation by powerful players in the development field such as the World Bank and the International Monetary Fund obscures the power dynamics that underlie the reality of participation for marginalized communities. The same dynamics are at play within the mental health field and in the adoption of the discourses about Recovery and service-user involvement by the mental health services (Campbell, 2005). The lessons learnt from the experiences of participation by marginalized or disadvantaged groups around the world can inform service-users engaging in participatory forums of mental health services. The topics of concern for the participants may be different but the processes of involvement are similar. Hence it is worth examining this work as it can problematize issues of power and participation experienced by mental health service-users. The power cube in all its different layers is presented first and then applied to mental health services, with illustrations from participants' voices from my study.

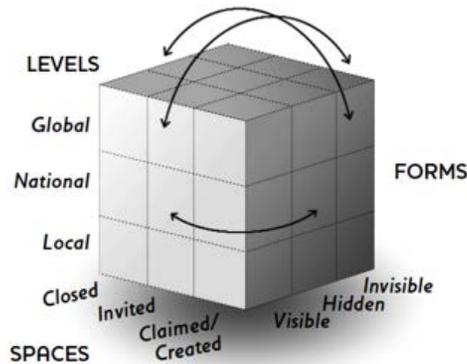


Figure 1: the power cube: levels, spaces and forms of power (Gaventa, 2006, p. 25 and <http://www.powercube.net>)

Gaventa (2006) presents the power cube as it relates to levels of development work, which includes governments and international agencies, so this dimension of his model needs modification before it might be applicable to the field of mental health service-user involvement. However, the concepts of forms of power and spaces for participation are useful conceptual tools readily applicable to service-user involvement. Gaventa (2006) proposes three forms of power, based on Lukes' (1974, 2005) influential ideas. Power can have three forms: visible, hidden and invisible. Visible power determines the agenda for participation including the way decision-making forums operate, the rules and procedures adopted. This level concerns the political processes of policy making; the who, what and how of decision-making. However, the next levels are often over-looked when considering how power influences opportunities to become involved. Hidden power is that held by those powerful actors who can influence what is or is not allowed onto the

agenda, what knowledge is valid for consideration, but more importantly who is not allowed to the decision-making table. The final form of power is the invisible:

shaping of the psychological and ideological boundaries of participation. Significant problems and issues are not only kept from the decision-making table, but also from the minds and consciousness of the different players involved, even those directly affected by the problem. (as cited in Gaventa, 2006, p. 29)

Gaventa (2006) presents Cornwall's (2002) ideas about the spaces that people occupy in relation to participation. She noted that metaphors for participation include terms like "opening-up, widening, broadening opportunities and deepening democratic processes for citizen participation" (Cornwall, 2002, p. 52). She observed that decision-making occurs in different spaces, which can be characterized as closed, invited or claimed spaces. Closed spaces are those where decision-making is not accessible to any outside the small circle of privileged elected officials, professionals and bureaucrats. Gaventa defined closed decision-making spaces as places where "decisions are made by a set of actors behind closed doors, without any pretence of broadening the boundaries for inclusion" (2006, p. 26). Cornwall describes invited spaces as "those into which people (as users, citizens or beneficiaries) are invited to participate by various kinds of authorities" (as cited in Gaventa, 2006, p. 26). Claimed/created spaces are those that people create for themselves: examples include informal gatherings or citizen juries, or other events citizens create to hold the powerful to account, using methodologies including human rights based approaches. These are 'organic' spaces which emerge out of common concerns or identities as a result of popular mobilization. They may result from the activities of social movements, or more simply be the places where people meet to gather, discuss and strategize before or after formal participation with authorities. Soja has referred to these as 'third spaces' where people can gather to reject hegemonic space (as cited in Gaventa, 2006, p. 26).

In terms of power within these spaces, Gaventa (2006) points out that those who create these different spaces are most likely those who hold power within them. Also, there are dynamic relationships between these spaces, and there remains potential for transformation within and between them. For instance, those in closed spaces may seek to increase their legitimacy by creating invited spaces for people to participate in some aspects of their decision-making. Equally, invited spaces can be created by those in independent social movements, who initiate consultation and participation opportunities with more powerful decision-makers in closed spaces. Power gained in one space, through increasing capacity skills and knowledge, can be used to gain entry into other spaces. Gaventa (2006) cautions there is always a risk of 'capture' by the more powerful state agencies unless claimed/created spaces are maintained where countervailing forces can challenge the hegemony of powerful discourses.

The final dimension of Gaventa's power cube is that of levels of involvement.

As he refers to local, national and global levels where civil society may seek to engage with decision-makers around development issues, this dimension requires adaption to make it applicable to service-user involvement. Baggott (2005) defines patient and public involvement in the NHS as being concerned with “decision-making domains” (p. 535). These he classified, using the previous work of Charles and DeMaio, into three different levels: macro-level policy planning, decisions about service planning and resources, and matters relating to individual treatment. These classifications correspond with the terms used here: strategic, operational and individual, to refer to decision-making domains in which service-users engage. The top level is strategic, where there may be service-user involvement nationally (or internationally) in shaping the future development of mental health services: shaping legislation, staff recruitment, delivering training to professionals and developing peer-support worker roles or peer-run services such as crisis houses. The next level of service-user involvement is consultation about operational and functional concerns: how the service is delivered. This may involve attending committees that are concerned with operational issues, developing local policies and practices that are more responsive to service-users’ needs. It may also involve monitoring and evaluation of services, and user involvement in research on local services. At the individual level of involvement, service-users have concerns about decision-making in relation to their own care, the choices they can exercise about treatments, about their individual care plans.

A model for power relating to service-user involvement, based on Gaventa’s (2006) power cube, would look like this (see Figure 2). It is a model that is intuitively easy to understand but allows for the incredibly, complex, messy processes of the real world of mental health services and service-user involvement initiatives. It may seem simple but as anyone knows who tried to re-align a disturbed rubix cube, it is a very tricky, challenging task, and seems appropriate as a representation of the complexity of power dynamics in user-involvement processes.

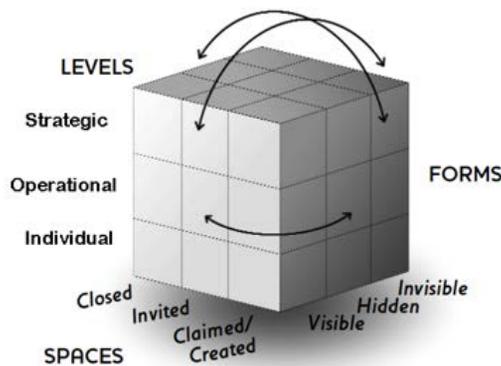


Figure 2: The power cube, levels, spaces, and forms of power operational in mental health service-user involvement, (adapted from Gaventa, 2006, p. 25)

The power cube and Mental Health Service-User Involvement

Masterson and Owen (2006) apply Lukes' theory of power to the mental health field, and illustrate it using the example of decision-making around medication. The traditional Weberian understanding of power is apparent at the first face of power: here the authority of a psychiatrist is very visible. In addition though, covert use of power controls the agenda of what can be discussed. If both the psychiatrist and the service-user were to discuss the relative merits of different drugs, with the final decision resting with the service-user, this can be considered an equal exercise of power at the level of covert (hidden) power. What is more common, however, is that the discussion might preclude the use of expensive medications, or that the service-user could cope without medication. These issues are not on the agenda for discussion, as the psychiatrist sets the agenda and uses covert power to preempt the decision-making process. Masterson and Owen (2006) link the final face of latent power to a Foucauldian understanding of power to shape the discourse within the mental health field, to de-legitimize any other alternative explanations than the psychiatric orthodoxy of a biochemical explanation for mental distress. This positive power to create the boundaries of acceptable understandings of mental distress means that considerations of issues such as treatment options for people are predetermined as a priori facts, and so people remain acquiescent and compliant to a psychiatric interpretation of their needs. Pilgrim (2005, p. 25) points out that service-users engaging in user involvement do so from the basis of acceptance that mental health services exist and will continue to do so. Therefore any changes will be modifications to pre-existing service configurations. What is never at issue is the a priori assumption that mental health services are the most appropriate place for mental distress to be treated or controlled. The taken-for-grantedness of mental health services within society is another manifestation of invisible power.

Returning to Gaventa's power cube, the analyses of power within the mental health system by Masterson and Owen (2006) and Pilgrim (2005, 2009) demonstrate how the dimension of the three forms of power can be useful to explain the mental health field. There was ample evidence from participants in my study about the visible forms of power at meetings, illustrated by this comment by a female peer-advocate: "*I've been to meetings where the consultant psychiatrists and nurses have completely ignored me, I mean you would not be there for them.*" Denials of recognition in general are an issue of social justice, (Lewis, 2009; McDaid, 2009;), and a prominent feature of user-involvement dynamics also evident in my participants' accounts.

Hidden power defines the boundaries of what can and cannot be discussed, as another participant points out. He had given a lot of consideration to the power dynamics operating within the mental health services. He explicitly refers to the dimensions of power:

If you've ever studied power, the dimensions of power, you have certain people who are gatekeepers. You can actually use procedures to prevent something

being discussed that you don't want discussed. So there are very many covert ways that certain things can be manipulated, I'm not even saying this happened consciously but I'm very well aware that certain people, ... can manipulate situations where the service-users do not become involved. (Male peer-advocate)

Here, the peer advocate highlights the ability of “*gate-keeping*” professionals to prevent service-user involvement by blocking discussion of the need to consult service-users about initiatives being established. He is met by silence when questioning if service-users were consulted about an initiative. He also referred to the power of psychiatry and other powerful agents to determine what can and cannot even be discussed, which undermines the perspective of service-users.

The same participant gives another example of power, this time of the invisible power of the cultural mindset. He observed the influence of the “professional knows best” attitude: “their opinion because it's an expert opinion is worth more than the service user's perspective ... for some people that's so set, it's such an integral part of their mindset that it's virtually impossible to change.” Thus, the service-user perspective is always on the defensive, given the taken-for-grantedness of the dominant psychiatric professional perspective.

Gaventa's (2006) power cube suggests different decision-making spaces exist. Closed spaces abound; committees at the highest level nationally where decisions about budget allocations are taken; organizations for mental health professions (closed in the sense that membership requires long years of study and significant resources) and Mental Health Tribunals. All are examples of closed spaces where service-users have no say in decision-making.

There was also ample evidence of how power plays out in the invited spaces of involvement, those within the ‘gift’ of the mental health services. These included formal operational meetings in various mental health settings. One participant referred to how she felt “belittled and it bloody well hurt” after meetings in her early days, before she developed strong defences against hurtful power dynamics. Another participant spoke about the exclusion she experienced in some meetings:

I have felt excluded . . . my self-esteem would get lower and lower, I'd be powerless, I wouldn't have a voice so would be sitting in a big blob of fear not able to talk. And very often I would have really, really good stuff in my head ... but I'd be too frightened to say it and then low and behold somebody else at the table would say it and I would realise what I was going to bring to the meeting was very valuable but I would lose it because I would feel this sense of isolation around the table. (Female peer-advocate)

This participant is very explicit about her experience of exclusion. There was also, however, evidence of support and solidarity created by de-briefing sessions after meetings such as these. Participants discussed the challenges of participating in difficult meetings with the more experienced service-users and professional allies, thereby forming solidarity bonds as a strategy of resistance in the created/claimed spaces.

Created/claimed spaces were evident through social activities that occurred outside the formal meetings and training courses. Part of what occurred in claimed spaces was a gain in 'power within.' Gaventa (2006, p. 24) defines power within as gaining a sense of self-identity, confidence and agency that presupposes political action. Solidarity increased participants' resilience, enabling them to persevere and also acted as a countervailing response to the feelings of powerlessness generated at meetings. Positive support from each other allowed the participants to develop their own power within as individuals. 'Power with' describes a form of collective group strength people develop as a result of the opportunity claimed spaces can create.

Gaventa (2006, p. 24) defines this form of collective power with as a synergy which can emerge through partnerships and collaboration with others, or through processes of collective action and alliance building. There was evidence of participants developing power within and power with in the created/claimed spaces, as illustrated by this participant:

I think the more the service-user is empowered the more changes will happen . . . the more I'm empowered, I'm not going to go in and let somebody tell me what he or she thinks I should be doing, so there's a change. Sometimes they're very small changes that are happening but they will ripple out, a bit like Armstrong on the moon, one small step for man. (Female Peer-advocate)

The participants provided evidence in relation to power operating at the second two levels of involvement, operational and individual. Participants reported positive experiences in the operational committees of the team in the study, of feeling listened to and respected. However dismissive attitudes were also reported, which can be effective in reducing any sense of agency a service-user can feel: "There is still an element of, well some [professionals], they make their disdain pretty obvious." Participants were clear about the importance of the therapeutic relationship: "I think the understanding of how important that therapeutic relationship is also feeds back into how important it is for the service user's voice to be heard, you can't have one without the other." One female participant expressed a common fear of the consequences of speaking out: "It could affect my treatment you know and they might stop listening." Clearly power dynamics were experienced as obstacles by the participants at the operational and individual levels.

Before I conclude my discussion of the power-cube as a useful tool for problematizing user involvement, I present a final illustrative anecdote related by a participant:

I went with an advocate to a meeting where we presented bullet points of what service-users thought was good in the services and what they think needs attention. And a really nice kind of involving service provider clapped the advocate on the shoulder, "oh well done, well done." I mean if we would do that to a consultant who just gave a presentation, go up to the consultant, tap his shoulder and [say] "oh well done, oh didn't you do great there, well done, well done, how did it feel, how did it feel?" I don't think that would be appreciated. (Female peer-advocate)

This comment is an example of the positive force of power which is significant from the participants' perspective. This forms a countervailing force to the power-over experienced at a personal human level from too many psychiatrists. Yet the power imbalance in their respective positions renders the supportive gesture and verbal congratulations far more loaded than intended. Once the power imbalance is pointed out in a graphic reversal of the gesture, the incongruousness of a subordinate service-user clapping a psychiatrist on the shoulder is illustrative of the power dynamics at play. As a particular incident of power we can place it onto the power cube along all three power dimensions. The power is visible in that the consultant psychiatrist has the visible power of his position as team director to invite the service-users to present to the professionals. He has set the agenda (hidden power), in this case to give some space to service-users to present their perspective. This is an opportunity for them to contest their positioning (invisible power) within the power structures by naming practices that position them in devalued disempowered positions. The other two dimensions are 'operational' involvement, then on the 'invited' spaces dimension. This example illustrates the explanatory potential of the model to critique the different elements interacting between powerful and subordinate actors.

Conclusion

This paper sketched out some of the history of service-user involvement within the UK, our nearest neighbour, and closest model for developments in Irish mental health services. The lessons learnt by the service-user movement elsewhere are applicable to current trends influencing mental health services in Ireland. Service-user involvement is a new development in the Irish context, resisted fiercely by some interests, and welcomed as a potential source of reform by others. Like Recovery, it is being incorporated into the official discourses without sufficient attention being paid to the complexities of the social justice issues inherent in the user-perspective and failing to problematize the power dynamics service-users must engage with if they choose to enter the new spaces into which they are being invited.

Gaventa and Cornwall (2008) describe the interplay between knowledge and power in situations where the knowledge and experience of subaltern groups is sought out by professionals in participatory forums. There is a real risk that the presence of service-users at the table legitimizes the practices of the establishment, providing a more democratic face by appearing to include service-users. Without addressing the underlying power dynamics one must ask to what extent the energy and radical potential of the service-user movement is being hijacked by illusionary inclusion.

The power cube (Gaventa, 2006) was presented as a conceptual tool to frame some of the power dynamics service-users encounter if they accept the invitation into these participatory spaces. In order to avoid becoming pawns for legitimizing establishment decision-making, service-users must become

aware of the hidden and invisible forms of power and learn to assess their potential influence on decision-making. Awareness of the power dynamics operating in user involvement forums can be heightened by strategic adoption of the power cube as a social movement tool to illuminate power inequities. Participants in my research had many years of experience between them, and were optimistic about the spaces being created by one mental health team, but aware also of how difficult it is to influence a system steeped in long institutionalized ways of working. They believe service-user involvement can change the way services deliver care. Time will tell.

Acknowledgements

I want to thank the editors of this special issue, Jijian Voronka and Alison Howell and the two anonymous peer reviewers for their helpful comments on an earlier draft of this article. I also want to acknowledge the generous contribution of Dr. Odette Clarke, and Anne O’Dea in editing the current version and Dr. Mary Keys who advised on the statutory aspects of the Mental Health Act 2001. I would also like to thank my colleagues: Jim Walsh, Louie Maguire and Stephan Gharbaoui for their comments on the current service-user movement in Ireland. Finally I wish to thank my PhD supervisors, Dr. Orla McDonnell, University of Limerick, and Dr. Elizabeth McKay, Brunel University, for their constant support.

I also wish to acknowledge the support of the Irish Social Sciences Platform (ISSP) funded by the Higher Education Authority under the Programme for Research in Third-Level Institutions, Cycle 4, which is providing a doctoral scholarship for my research at the University Of Limerick.

Notes

- ¹ The term service-user is used here to refer to people with experience of mental ill-health and/or of past or current use of mental health services. This is the commonly used terminology in Ireland and the UK. Language and how people are labeled is an important social justice issue, given the widespread stigma and discrimination associated with mental health issues. Service-user is a slightly less contentious term than the other usage in the Anglophone world, that of consumer of services. The use of the term service-user is a rejection of the associated neo-liberal meaning which developed from notions of marketization of health care. A more politicized term is that of survivor. However the concept of being a survivor of mental health services does not readily sit with the idea of engaging in participatory practices with the very system which is considered oppressive. A term gaining in acceptance by the service-user movement is that of “Expert-by experience.”
- ² Recovery is written with a capital R throughout as it refers to a particular form of discourse within Mental Health services.
- ³ The Mental Health Commission, a statutory body, was established following the enactment of the Mental Health Act 2001. This act replaced the old legislation dating back to 1945. It was enacted as breakthrough legalization in response to pending criticism from the European Court of Human Rights for failure by the Irish Government to protect the human rights of people detained in psychiatric institutions (Keys, 2002; O’Neill, 2008). The Mental Health Commission has statutory powers to oversee the operation and licensing of Approved Mental Health Centres and to publish standards and guidelines to promote best practice. It established the Mental Health Inspectorate team in 2001 and operates Mental Health Tribunals since 2006, following enactment of Part Two of the MH Act 2001. Mental Health Tribunals review the detention of involuntary patients within 21 days, unless the patient is discharged before the MH tribunal. In that case, a patient has the right to request a tribunal. For a recent review of

the effectiveness of the Mental Health Commission in protecting the rights of service-users see (Murray, 2011).

- 4 Irish Government policy on mental health services was updated from the previous policy, *The Psychiatric Services - Planning for the Future*, which dated from 1984, in the long awaited publication of *A Vision for Change: Report of the Expert Group on Mental Health Policy* (2006).
- 5 It is important to point out the diversity of the service-user movement. There are many strands within the movement who resist, even reject altogether, the care offered by mental health services. Groups such as Mad Pride, Mind Freedom, and Hearing Voices Network are alternative spaces of resistance. (See Chamberlin, 2004, for a discussion of user-run alternatives to traditional services).
- 6 Recently published policy guidelines for payment of expenses to service-users attending approved meetings with health officials fall far below these rates. There is no reference to payment for time. (HSE 2011)

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