Service-User Involvement in Irish Mental Health Services: A Sociological Analysis of Inherent Tensions for Service-Users, Service-Providers and Social Movement Actors.

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A thesis submitted for the Degree of Doctor of Philosophy
Submitted to the University of Limerick

Ph. D. 2013
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Abstract

Liz Brosnan

Title: Service-User Involvement in Irish Mental Health Services: A Sociological Analysis of Inherent Tensions for Service-Users, Service-Providers and Social Movement Actors.

There is very little critical analysis of the relatively new policy of Service User Involvement (SUI) in Irish mental-health services (MHS), in spite of lessons from decades of SUI practice internationally. SUI is endorsed by top MHS management as a reform strategy, while for service-users, it is linked to civil and human rights, originating from contestations of current practice in MHS, yet is often confined to a consideration of how better to implement existing services. No study of SUI in Ireland has contrasted and compared the service-user experiences with that of professionals in real world instances of SUI. The research question asks what are the understandings and experiences of service-users and service-providers who become involved in SUI?

The research adopts survivor standpoint epistemology in a case study of SUI occurring with a local multidisciplinary team. Eight local service-users and eleven service-providers were interviewed about their understandings of SUI and the practicalities of making this happen, the challenges and opportunities they have experienced. This local experience is triangulated by the perspectives of a top manager and twelve national user/survivor movement activists.

The overarching theme for service-user participants are the tensions inherent between their contestation of the current MHS, collaboration in the opportunities for reform presented by SUI and the risk of co-option given the power imbalances inherent in their positioning vis-à-vis the MHS. An additional tension for movement activists is the appropriateness of SUI as a movement strategy. The overarching theme among the service-provider participants is the inherent tension between their collaboration with service-users to change how service-users are positioned, with differing perspectives on the risks of co-option and tokenistic involvement. The key findings are further analysed using Gaventa’s (2006) conceptual model of the power cube which provides a useful social movement tool to conceptualise the complexities and dynamics of SUI.
Declaration

I ________________________ declare that the attached thesis is entirely my own work, in my own words, and that all sources used in researching it are fully acknowledged and all quotations properly identified.

ESSAYS, ASSIGNMENTS & PROJECTS WILL NOT BE ACCEPTED BY THE DEPARTMENT OF SOCIOLOGY WITHOUT A SIGNED SUBMISSION FORM.
Acknowledgments

I have so many people to thank for helping me over the process of completing this thesis.
Firstly and most importantly are my supervisors, Dr Orla McDonnell and Dr Elizabeth McKay. Both believed in me, and my ability to complete the work. Orla, in particular, encouraged me to believe I could apply for the scholarship that allowed me to study and research full-time. Their patience, support and constructive criticism of the many draft chapters submitted along the way were so important in crafting the final thesis. I also want to thank Dr Amanda Hynes, who was the third member of my Doctoral Studies Panel and was so generous with her time.
I also thank my external examiner Dr Mark Creswell, Durham University, UK and my internal examiner Dr Martin Power, for their positive engagement with the thesis and affirmation of my work. Also the viva was chaired in a very fair and professional fashion by Dr Helen Kelly Holmes. All three could not have been more helpful in ensuring the viva was a positive and stimulating intellectual experience.
I very grateful to the generous friends who gave me encouraging feedback on earlier drafts of my empirical and conclusion chapters; David Evans, Margaret Brehony and Mary Kay Ryan, and last but not least, Ann O’Dea who helped by proofreading the full draft. The work is my own but impossible alone.
For their practical and moral support I have so many others to be grateful to.
- My parents, who came up trumps when my scholarship ran out,
- My sisters for their constant belief I would stay with it to the end,
- Dr Odette Clark, a rock of moral support and practical help too.
There is one friend whose help made my life so much simpler, Padhraic O'Fathaigh, who took my patient, loyal companion, Miley, into his home on so many, many occasions when I had to travel away, either to college or for fieldwork.
I also had great technical support with my laptop from Thomas O’Shaughnessy in the Disability Support Services in the University of Limerick.
Lastly, but certainly not least, my research participants, who were all so incredibly generous with their time, and shared openly and honestly their experiences of doing service-user involvement. I hope you find this thesis, if you ever look at it, does the subject and your experiences, justice.
Without all of your help and support this work would not have been possible to complete. To all of you, heartfelt thanks

Go raibh míle, míle maith agaibh go léir
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 provided a doctoral scholarship for my research at the University Of Limerick.
With regard to Recovery I am minded of a lesson from history, from jazz music. Entwined as it was with the civil rights movement (that the recovery movement is associated with) the fifties and sixties were years of passion and fire, innovation and fighting, the seventies were years of consolidation. Then in the eighties, the sons and daughters of the early firebrands reached maturity and thanks to the activism of the parents they had jobs as professionals and professors. And the policing of the history came. As did Wynston Marsalis and jazz became coffee table banality. Of course this led to hip hop, but wait now, we have Fifty Cent and Jay Z (trying to sell T-shirts to Occupy protestors) coffee table hip hop. We get a sense of history repeating itself. First as tragedy, then as farce. These are processes in all movements. I think with some aspects of the recovery movement we're having a jazz eighties moment. … And I for one am waiting for the hip hop!

Alistair Kemp (2012),
(personal correspondence on Survivor History Group website 17/11/2012).
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<td>AI</td>
<td>Amnesty International, Ireland</td>
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<tr>
<td>DoHC</td>
<td>Department of Health and Children</td>
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<td>DON</td>
<td>Director of Nursing</td>
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<td>EHM</td>
<td>Embodied Health Movement</td>
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<td>HSE</td>
<td>Health Services Executive</td>
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<td>HSM</td>
<td>Health Social Movement</td>
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<td>IAN</td>
<td>Irish Advocacy Network</td>
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<td>IMG</td>
<td>Implementation Monitoring Group</td>
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<td>MDT</td>
<td>Multi-disciplinary team</td>
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<td>MHC</td>
<td>Mental Health Commission</td>
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<td>MHS</td>
<td>Mental Health Services</td>
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<td>NDA</td>
<td>National Disability Authority</td>
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<td>NGO</td>
<td>Non-Governmental Organisation</td>
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<td>NSUE</td>
<td>National Service User Executive</td>
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<td>SMO</td>
<td>Social Movement Organisation</td>
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<td>SUI</td>
<td>service-user involvement</td>
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Chapter One:

Introduction
Chapter One: Introduction

This thesis addresses the issue of service-user involvement (SUI) in public mental health services (MHS)\(^1\) in Ireland. It seeks to explore what is occurring in the practices of SUI in an Irish context by asking this research question: what do both service-users and service-providers understand by and how do they experience SUI in MHS. SUI is considered to be a necessary component of good practice internationally (Kemp 2010) and a feature of MHS planning and management in many countries, including the USA, Canada, Australia, New Zealand, Scandinavia (Chamberlin 2005; Cleary et al 2006; Elstad and Eide 2009; O’Hagan 2001; Restall and Strutt 2008). In the UK, it is necessary to demonstrate SUI in many aspects of health service governance, e.g. policy and service planning, staff recruitment and in professional training (Carey 2009; Kemp 2010).\(^2\) However Carpenter (2009, p.224), in a discussion of human rights and UK mental health policy developments states that: “paper policies are still a long way from becoming realities.” SUI is even less commonplace in Irish MHS, and there are few published studies of SUI in Ireland (McDaid 2009). This is the first research to approach the issue of SUI from the perspective of an Irish user-movement activist.

There are at least two directions for the impetus to include the voice of the service-user (Beresford 2002; 2010a; Forbes and Sashidharan 1997; Carey 2009). The first is a neo-liberal, managerialist, efficiency-focused push from top management committed to reforming MHS in Ireland, which operates under an out-of-date ethos originating from isolationist, asylum-era, bio-psychiatric orthodoxy and power. The second direction is the bottom-up impetus of the user-movement, inspired by civil and human rights movements, which claim the right to be included in shaping, planning and delivering MHS in order to improve the conditions of some of the most marginalised, stigmatised people in society, those experiencing psycho-social distress.\(^3\)

\(^1\)MHS refers to the plural rather than a specific service, to the system of bio-psychiatric dominated, statutory-based services.
\(^2\)All literature accessed has been published in English, which means that innovative and novel approaches to this topic not published in English would not have informed this study.
\(^3\) This term is used throughout instead of the terms ‘mental health problems’ or ‘mental illness’. See a note on terminology below.
The need for reform of the Irish MHS is almost universally accepted as necessary (Bracken 2012; Hyde et al 2004; Keogh 2009; MacGabhann et al 2010; Sapouna 2006; Share et al 2004; Walsh et al 2008). Some of the rhetoric about change is encapsulated in the term ‘Recovery’, originally a user-movement concept, which has become a poly-semantic conflation of all kinds of hopes and aspirations for transformation of a paternalistic, coercive, and institutionalised form of service provision, which does not meet the needs of people in psycho-social distress in the twenty-first century, nor indeed arguably the needs of those who work within the services. This thesis is not focusing on the concept of Recovery, but more specifically on the practices of SUI. However, there are clear links between the discourses of SUI and Recovery. Recovery was articulated by the user-movement as a way of overcoming and resisting institutionalised and oppressive psychiatric care (Beresford and Wallcraft 1997). It entered official Irish MHS and Health Service Executive (HSE) discourse with the publication of a discussion paper on Recovery-orientated practice by the Mental Health Commission (2005). In Irish government policy (A Vision for Change: Report of the Expert Group on Mental Health Policy, 2006) (hereafter referred to as Vision for Change) a Recovery ethos is evident within the document.

Recovery, as articulated by the user-movement, focuses on individuals’ journeys to regain a meaningful life with or without symptoms of emotional distress; it is a concept that focuses on attitudes of hope, coping strategies and supportive relationships, which offers people a belief that it is possible to regain control over one life (Ralph 2000). Mental health professionals have taken the concept of Recovery and redefined it in their own terms and so Recovery-orientated MHS seek to redress the imbalance of traditional services’ control over people’s lives and to encourage people to re-establish autonomy over their lives, to re-integrate into the community and to re-build a meaningful life (Repper and Perkins 2003; Slade 2009; Stickley and Wright 2011).

Turner-Crowson and Wallcraft (2002) discuss some of the concerns British service-users had about the importation of the Recovery language into MHS discourse in the UK, including the professional definition of Recovery in terms

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4 Recovery is capitalised throughout because it refers to a range of specific discourses and values.
of service outcomes, and how MHS regard people who are not ‘compliant’ with
their professionally defined Recovery plans. They stress the importance for the
user-movement and MHS reformers of focusing on the ‘complementary themes’
to Recovery, such as early intervention, suicide prevention, SUI, practical
measures for social inclusion, strategies for living, surviving and coping, and
most importantly keeping hope alive (Turner-Crowson and Wallcraft 2002,
p.252). SUI, from a user perspective, seeks to make MHS policies and practices
responsive to the realities of service-users’ lives by articulating their concerns of
how MHS impact on people.

A Note on Terminology

Language and how people are labeled is an important social justice issue,
given the widespread stigma and discrimination associated with psycho-social
distress. The terminology used in the area of mental health, to refer to both the
human distress, and the people, treated by the MHS, is contested and political
(Hyde et al 2004). What psychiatry and the MHS claim jurisdiction over is the
containment and administration of ‘mental illness’ (Rogers and Pilgrim 2005).
‘Mental illness’ itself is a contested construct with different causal explanations
(Boyle 2013). Psychiatry asserts a biological, chemical, neurological and/or
genetic aetiology; however the scientific evidence is so far unconvincing and the
biological determinism of psychiatry is contested by many oppositional positions
(Bracken 2012; Cresswell and Spandler 2009; Crossley 2004; Johnstone 2000;
Minkowitz 2007; Sapouna 2012). The term psycho-social distress is the term
used within the human rights inspired Convention on the Rights of Persons with
Disability (CRPD), (with active involvement of survivors in drafting the text
(Minkowitz 2007)) and is my preferred terminology.

The people who use, or have used, the MHS in Ireland and the UK are
generally referred to as service-users; older terms such as; ‘psychiatric patient’,
or ‘mental patient’, are no longer used due to resistance from those so designated
and labelled, and because of general recognition of the damaging, stigmatising
and exclusionary effects of prejudicial terms (Beresford 2010; Holland 2007).5

5 The only time the term patient is used in common parlance is to refer to someone detained
involuntarily under the Mental Health Act (2001), because that is how they are legally defined.
The term ‘service-user’ is a rejection of the associated neo-liberal term ‘consumer’ of MHS, which developed from notions of marketisation of health care, but which is in common usage in the rest of Anglophone world.

A more politicized term adopted by movement actors is that of ‘survivor’. Some survivors who adopt separatist, stridently oppositional positions to the MHS refer to themselves as survivors/thrivers (Maddock and Maddock 2006) or members of the mad community (McCarthy 2011). The concept of being a survivor of the MHS does not readily sit with the idea of engaging in participatory practices with the very system which is considered oppressive.

Some writers use c/s/x, to designate the more cumbersome term consumer/survivor/ex-patient, because there is so much debate about what term we chose to adopt (Holland 2007, p.897). A term sometimes tried on for size by service-users is that of ‘expert by experience’; this name is used for an advisory group of people with direct experience consulting with Amnesty International Ireland on their mental health campaign. Another term, ‘peer’, is often used to refer to people who have experienced psycho-social distress sharing their experience of what helped them with others. This term is frequently used to refer to people who are employed to work within the MHS or NGOs in a specialized role, e.g. peer-advocate and peer-support worker, providing support to other service-users.

Because the term service-user is the most widely used in an Irish context, it is the term I use most frequently. Following Beresford (2010a) I sometimes use the term service-user/survivor or user/survivor in relation to the participants, especially the more experienced and politicised participants, to indicate the tension over terminology. I use the term user-movement to refer to the broad health social movement of service-users and survivors. When the term survivor movement is used, it is to designate the more politicised spectrum of the movement.

I refer to the professional participants as service-providers, as that has become the accepted term, frequently used by participants to refer to themselves also, and by the service-user participants, possibly because it is logically paired with service-user. This term also has a distinctly commercial connotation which is uncomfortable to apply to health care, but is used for simplicity, as not all my
service-provider participants were technically ‘professionals’, and the term ‘staff’ within the context of the MHS is used generally as a euphemism to refer to nurses, who compromise the bulk of the employees.

**Irish policy on SUI**

The Department of Health and Children (DoHC)’s 2001 Health Strategy first introduced a policy of SUI in new discourse on a ‘people-centred service’; the *Community Participation Guidelines* (Health Boards Executive 2002) outlined protocols on how this was to be achieved. The Mental Health Commission (MHC) has advocated for SUI since it was established in 2001. In its standards framework, *Quality Framework for Mental Health Services in Ireland*, (MHC 2007) there is a focus on individual partnership with the services through provision of information, choice and peer advocacy in three standards (3.1, 3.2 and 3.3) while standard 3.4 requires that: “a clear accessible mechanism for participation in the delivery of mental health services is available to service users.”

Irish government policy on SUI in MHS 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 an expert group composed of diverse stakeholders, including psychiatrists and other mental health professionals, and one service-user (Sapouna 2006). Chapter Three contains statements about commitments to SUI, stating that 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.

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6 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 legalisation 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 2005). 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. The Mental Health Act 2001 also established the Mental Health Inspectorate team in 2001 under the remit of the Mental Health Commission. The Mental Health Commission has operated Mental Health Tribunals since 2006, following enactment of Part Two of the MH Act 2001. Mental Health Tribunals automatically review the detention of involuntary patients within 21 days, unless the patient is discharged before the tribunal, in which 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).
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. At the level of operational involvement, it recommends that service-users be included in the local catchment area management teams. In terms of involvement at the national level, *Vision for Change* (2006, p.27) recommends 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.” The chapter also includes principles that should guide SUI, developed by English service-users Devan & Reid ([n.d.] cited in Wallcraft et al 2003, pp.63-64). In light of the establishment of SUI as official policy, and its top-down implementation in some MHS areas, it is timely to ask, what are the experiences of those service-providers who are seeking to implement it at local level, and how service-users experience SUI? The Irish context for SUI is explained against the backdrop of efforts to reform the Irish MHS.

**Background Context- Irish MHS**

The mental health field internationally encapsulates wide and complex relationships between the MHS themselves, and the associated professional bodies and corporate interests of pharmaceutical companies, who invest heavily in the education of medical professionals, especially psychiatrists and mental health nurses (Crossley 2004; Hyde et al 2004; O’Donovan 2009; Rogers and Pilgrim 2005). In Ireland, the MHS are under the remit of the Health Service Executive (HSE), the national Irish health service structure within which the MHS operate. The MHS are established on a statutory basis and are structured to cover certain geographical areas based on population demographics such as deprivation indices, theorised to correlate with mental health needs of a population. *Vision for Change* (2006) recommended that mental health catchment areas (populations of 250,000-400,000) should be managed by
multidisciplinary Mental Health Catchment Area Management Teams. The ideal service would be community based (rather than based in old institutions), and provided by a multi-disciplinary team that is flexible and responsive to the emerging and changing needs of people in distress. These teams should include a full complement of professional expertise, including psychiatry, mental health nursing, occupational therapy, social work, psychology, social care workers, and ‘Recovery workers’. The inclusion of service-users is considered to be an important principle, with the term ‘partnership’ with service-users (and carers) appearing frequently. Teams were to be lead by the most appropriately qualified personnel, but like all areas of the Irish health service, clinical leadership has been reserved solely for consultant psychiatrists (Burke 2009; Hyde et al 2004).

Annex 3 of Vision for Change (2006, pp.235-237) summarised quality of life issues for service-users reported to the expert group developing the policy. This easily overlooked appendix is a damning incitement of the experiences people reported within the MHS. The impact of polypharmacy is raised as a concern, with inadequate research on the interactions of these drugs leading to concerns over treatment efficacy and side-effects. Unpleasant and distressing side-effects of medication are discussed, as are the unsatisfactory nature of clinical reviews from service-users’ perspectives. The physical environment in many facilities was deemed inadequate and inappropriate on many occasions by the Inspector of Mental Hospitals. Families and service-users reported inadequate notice of discharge, which was conducted to suit the needs of the MHS for beds, rather than being in the service-users’ interests. Mixed-sex units were reported to lead to an environment which women experienced as male-dominated and aggressive. A failure to provide adequately for the needs of people with enduring ill health was acknowledged. These service-users have been ‘maintained’ rather than supported towards independent living. “Many people live in unsatisfactory physical environments […] and are often in ‘permanent training’ in sheltered employment” (2006, p.236). Other issues of concern were coercive and stigmatising processes around involuntary detention, lack of privacy and personal space in residential facilities, and the provision of respite beds (where these were available) for people in crisis in residential facilities where other service-users (not in crisis) lived. Finally, the lack of attention paid to service-
users’ physical health was acknowledged as a problem which would be addressed in the new ‘person-focused’ model proposed in *Vision for Change* (2006). There was a palpable air of optimism that a new era had begun when the new mental health policy outlined in *Vision for Change* was adopted by the Government in December 2005 and launched in January 2006 (Keogh 2009).

Six years later there was considerable disappointment about the level of progress in implementation (Independent Monitoring Group 2012) (IMG); the conditions outlined as obstacles to progress prior to the new policy remain in place (Amnesty International 2009; Hyde *et al* 2004; Keogh 2009; Sapouna 2006; 2012). Certainly there is no evidence of the emergence of peer-run MHS in Ireland. Indeed most of the reforms and recommendations have not been addressed yet, due to failures of leadership, restructuring of the general health service, professional resistance and a general culture of inertia (Keogh 2009). The National Mental Health Service Directorate which was supposed to have authority and control of resources to provide overall direction to implementing the recommendations and reform processes has not been established. There is no change from: “a largely medicalised and maintenance approach towards one based on recovery competencies” (IMG 2012, p.6). There is no “comprehensive, time lined and costed Implementation Plan” from the HSE, in fact resources allocated to implement *Vision for Change* policy have consistently been diverted to other areas of the health service (Indecon 2009). The money that was spent in the MHS has included capital expenditure to replace facilities long condemned as unfit for human habitation, and on employment of consultant psychiatrists to lead clinical teams. The current crisis situation for the public finances, including government policy to reduce numbers of public servants and a general moratorium on recruitment to public services have impacted more disproportionately on MHS than on other areas: “Existing community mental health teams are poorly populated with an estimated 1,500 vacant posts”, predominantly allied health professional posts (IMG 2012, p.5). Therefore the biomedical psychiatric model and philosophy informing service delivery and ethos remains unchanged. Sapouna (2012, p.614) summarises the issues that continue to concern the user-movement and their allies in the Critical Voices
Network as including: “the inhumane physical conditions in hospital units, over-reliance on and excessive use of medication, lack of meaningful community-based alternatives to hospitalization, involuntary treatment, abuse of professional power, and lack of information and choice in relation to ‘treatment’ options.” The situation within the MHS appears so resistant to change that Amnesty International Ireland adopted the position that specific legislation is required to drive reform (Amnesty International 2010).

In terms of MHS organisational structures, the reality on the ground is that structures are still in transition from the structures established by Planning for the Future (DoH 1984), which had multi-disciplinary teams working in areas based on county boundaries. Unlike the newer policy, which seeks to allocate resources based on more objective measures of population need, the old system was based on political patronage. A local MHS area is overseen by a management team of three, headed by a Clinical Director, (always a consultant psychiatrist leading one of the teams in the area), a Director of Nursing (DON) and an administrator. A MHS area comprises six to ten sector teams, each of which is headed up by a consultant psychiatrist, with junior psychiatrists in training, a team of nurses of various grades of management and specialities, and allied professionals assigned to the team. Service-users are assigned to a team based on their address, and have no choice about which team might suit their needs better. Each team is an independent entity, the ethos determined by the disposition of the consultant psychiatrist, and the other significant post holders (Sapouna 2006). The system remains hierarchical, dominated by consultant psychiatrists, a situation that has not changed from the previous policy environment.

SUI in Ireland

A literature review of SUI, commissioned by the DoHC, concluded that the: “history of SUI in health and social services, both in Ireland and internationally, is somewhat disappointing and has been weak due to its development in an ad-

7 The Critical Voices Network is new democratic, non-hierarchical space in the Irish mental health scene, described as a: “coalition of service users, carers, professionals, academics, national campaigning and advocacy groups, all looking for a mental health system not based on the traditional biomedical model” (Sapouna 2012, p.615).
hoc and isolated way” (McEvoy et al 2008, p.5). SUI was reported in three sectors of Irish healthcare, with Irish Travellers, mental health service-users and migrant and new communities (McEvoy et al 2008, pp.53-54). Consumer Panels emerged as a mechanism for SUI, following their proposal in the 2001 government health strategy: “to afford members of the community and staff an opportunity to work together to ensure that the [HSE] agencies/activities are responsible to the needs and concerns of the public” (DoHC 2002, p.11). The definition of service-user in these documents is wide and includes any potential future user of health and social care services.

Mental Health Consumer panels, comprised of service-users, carers and professionals working in mental health non-government organisations (NGOs), emerged to meet a more acutely perceived need for reform within the MHS, directed by a rationale that public participation can support management to address some of the structural and cultural obstacles to providing client-centred care (Carey 2009; Cowden and Singh 2007). There were initiatives to establish Consumer Panels in some local MHS throughout the 2000s following publication of the government strategy. Their existence and relationship with the MHS varies from place to place, but they generally have meetings with senior management of the local MHS to provide consumer feedback on services. There is also considerable variability as to the amount of support they receive, with some areas having a small account with funds provided from the MHS to cover members’ travel expenses, whereas other areas receive no such support.

The most established form of SUI nationally is peer-advocacy provided by the Irish Advocacy Network (IAN), all-island service-user run NGO established in 1999, which provides peer-advocacy on a contractual basis to MHS in all but one of the 26 counties of the Republic, and to several trusts in Northern Ireland. A more recent development is the National Service User Executive (NSUE), a body established in 2006 on a recommendation of Vision for Change (2006), to represent the service-user voice at a national level. Similar to Consumer Panels NSUE includes carers, but it does not include professionals.

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8 One county has advocacy services provided by a Northern Ireland based NGO, Steer, which includes carers as well as service-users.
It is within this context that SUI is occurring, albeit in a patchy ad hoc manner. Given this background context, the research question is timely and appropriate. It seeks to understand the experience of SUI in one local MHS and among national user/survivor movement activists. Given the dearth of policy in Ireland about how to implement SUI, this research seeks to inform the development of policy by drawing on the lessons from other jurisdictions, and from local initiatives to include service-users in service planning and evaluation.

**Motivation for this Research**

In addition to the context outlined above and the policy rational for this research, this research was motivated by my own personal experience as a survivor activist. This experience ranges from being involved in user-led research into users’ experiences of local MHS to sitting on high level national advisory committees, from seeking to establish local consumer panels to co-founding a user-led drop-in centre and being a member of the Board of Directors of the Irish Advocacy Network. This activism was informed by personal experience of the marginalised, disempowered positioning of mental health service-users both in society and vis-à-vis the mental health services. I have experienced denials of recognition and power imbalances associated with the status of being a service-user engaging in MHS committees. As a result of this experience, I am aware of the gap between rhetoric and practice between service-users’ experiences of involvement initiatives and those of well-intentioned professionals. I sought to understand and explain these disparities by researching how service-users, service-providers and survivor activists understood and experienced SUI practices. My experiences as a service-user and as an activist prompted me to seek to problematise SUI in relation to issues of power and social justice, concepts unacknowledged in official policy and overlooked by professional allies in the emerging initiatives to develop SUI in some local MHS. In the context of an emergent user/survivor movement in Ireland, there is a need to address how these concepts add to our understanding of the dynamics of SUI and to develop an accessible framework for activists to evaluate the effort they expend on SUI activities. Thus two sub-questions posed by this research seek to
illuminate the dynamics of how power imbalances and the politics of recognition manifest in the experiences of SUI.

**Theoretical Contribution of this Thesis**

This thesis makes a theoretical contribution to the international literature by adding further depth to our understanding of the dynamics of participation in SUI. Gaventa’s (2006) power cube is presented as a conceptual model to explain the forms, spaces and levels of power operating in a rigidly hierarchical, unequal field such as the MHS, especially in unpacking the hidden and invisible power of psychiatric hegemony. It also offers a theoretical account of recognition politics operating in relation to SUI, developing on the work of Fraser (2004) and Lewis (2009). In addition, it builds on the emerging body of work on survivor standpoint epistemology (Rose 2009; Sweeney *et al* 2009; Wallcraft *et al* 2009), by defending the proposition that those who experience both the effects of psychosocial distress and use of the MHS have a vital contribution to make to research on the MHS, and SUI in particular.

**Structure and Content of Thesis**

Chapters Two presents an overview of the international literature relevant to SUI, to explain the concepts associated with SUI in MHS, from both service-users’ perspectives and professional and/or academic authors. Research relevant to an Irish context is also reviewed in order to further contextualise the study. This review suggests a major gap in research on what is currently developing in an Irish context, as there is very little critical analysis or problematisation of the Irish policy of SUI, in spite of lessons from decades of SUI practice internationally. Also, no study of SUI in Ireland has contrasted and compared the service-user experiences with that of the service-providers working with them in real world instances of SUI.

Chapter Three presents two major theoretical concepts relevant to the practicalities of SUI: the social justice concept of participatory parity, and the dynamics of power. It introduces social movement theory, especially new scholarship on health social movements (Brown and Zavestoski 2004). Fraser’s (1997; 2004) theory of participatory parity has two dimensions of social justice, recognition and distribution, both of which are necessary to achieve parity of
participation. This theory and how it has been applied to mental health SUI by Lewis (2009) is outlined. It also discusses some of the many different understandings of power as it manifests in the MHS. Finally, I propose that a conceptual framework of power, Gaventa’s (2006) power cube, which has been developed in the area of citizen participation in the developing world, can be very usefully applied to mental health SUI.

Chapter Four outlines the methodology adopted in this qualitative study, including the epistemological and ontological standpoint of this research. This standpoint is informed by the situated knowledge of my own experience as a survivor movement academic in the sense referred to by Cresswell and Spandler (2012). Chapter Four also presents the practicalities and logistics of how I sought to answer my research question. The case study research design is outlined, and explains sampling methods and why I choose the participants. I describe the data collection and analysis processes, and ethical considerations are discussed. This chapter introduces the study site, and a summary of my ethnographic observations of meetings with SUI. I discuss my reflections on the research process, including the challenges and opportunities my insider status presented. I also outline here the strengths and limitations of this research.

There are three empirical chapters, which commence with profiles of the three different sample groups I interviewed. Chapter Five presents the perspectives of local involved service-users in relation to their experiences of SUI at the study site. The overarching theme which emerged is the tension inherent in SUI for participants between their contestation of, and their collaboration with, the MHS. Chapter Six presents findings on the research question from the service-providers’ perspectives, those of the local practitioners, and the national manager interviewed, all proponents of SUI. The overarching theme is the inherent tension between aligning with service-users to contest service-users’ positioning within the MHS and to reform institutionalised practice without access to the necessary resources and collaboration to change how service-users are treated, while being cognisant of the risk for service-users of co-option and tokenistic involvement. The chapter concludes with a synthesis of the findings from both sets of participants in Chapters Five and Six. Chapter Seven presents the profiles and findings from the national user/survivor sample.
The overarching theme emergent in this chapter is the inherent tensions among movement activists on the appropriateness of SUI as a movement strategy. This chapter concludes by tracing the points of convergence and difference between the key findings in all three empirical chapters.

Chapter Eight examines the main findings from the empirical chapters using Gaventa’s (2006) power cube as a theoretical lens. The power dynamics operating in collaborative spaces are explored under the different dimensions of power (forms, levels and spaces), which interact and shape participants’ experiences of collaboration in SUI processes.

Chapter Nine presents my concluding discussion. This includes a synthesis and discussion of the overarching themes within the empirical chapters. The tensions between contestations and collaboration, and the conditions and dynamics of participation are discussed in terms of their implications for SUI in Irish MHS. I outline the theoretical implications of the research findings, which include contributions to the growing literature on survivor epistemology, expanding the application of Fraser’s (1997) theory of social justice in participation politics to mental health SUI, and the novel application of Gaventa’s (2006) power cube framework to the mental health field. In terms of practical application, this thesis offers not just a conceptual model of power dynamics in SUI but has implications for policy and practice. I conclude with a summary of my core thesis about SUI in MHS in Ireland.
Chapter Two:

Literature Review
Chapter Two: Literature Review

Introduction

This literature review considers several themes in relation to contextualising the research question: What do both service-users and service-providers understand by, and how do they experience service-user involvement (SUI) in mental health services (MHS)? Therefore this chapter is not a systematic review of the literature; instead I have purposively sought to engage with theoretical and descriptive literature on SUI focusing on specific perspectives and themes, such as the experiences of SUI in other jurisdictions, and the observed risk of assimilation of service-users. The review places this study in an international context of research into SUI, and provides a rationale for this study by identifying gaps in the literature.

The chapter starts with an exploration of what is meant by SUI and the confusion that surrounds both the term service-user and the concept of SUI. It presents international literature from the growing body of user-movement academics and researchers on SUI, and critical academic commentators representing some of the different professional groups that work within MHS. It considers both theoretical and analytical papers, as well as empirical research on different aspects of SUI, such as involvement in research, professional education and training, and employment of service-users within the MHS internationally. Finally, literature that reviews the barriers to SUI is considered.

What is SUI?

There is widespread confusion within the literature about the meaning of SUI; even the term service-user refers to different groups in the literature. The first area requiring clarification is the definition of the term service-user. In much of the literature on SUI, the term refers to a wider group than just mental health service-users, e.g. Crawford et al’s (2002, p.1) review of SUI in UK health services includes: “patients, patient representatives, and wider public as potential patients.” This confusing variety is reflected in the use of the terms public and patient involvement (PPI) and service-user and carer participation (SUCP) in the
UK literature (Barnes and Cotterell 2012), suggesting the amalgamation of users and carers into the umbrella term service-user (Pilgrim 2009, p.86). Participation within the MHS has a distinctly different quality to other types of patient involvement as mental health service-users are subject to stigma, psychiatric disqualification, poverty, unemployment and poor housing as a result of social exclusion (Beresford 2010). Also mental health service-users are 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. I believe this is heightened in an Irish context because of the unique history of institutionalisation, of: ‘locking them up and throwing away the key’, a documented feature of Irish social history for those who did not conform to religious and social norms (Brennan 2012; Hyde et al 2004; Sapouna 2006).

The official Irish HSE understanding of the term service-user includes not only patients but also carers, parents and guardians, representative NGOs and communities, indeed: “anyone who is a potential user of health services and social care interventions” (DoHC and HSE 2008, p.6). Such a definition is problematic; leaving aside the question of inclusion of the entire population, many NGOs may have conflicting values and less than inclusive practices (Speed 2002). This definition is clearly linked to the consumerist view of SUI, discussed in theoretical literature below.

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 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 dilemmas about whether they are acting as an extension of the MHS, 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 the concerns of relatives are given higher credence than those of service-users when there are conflicting accounts of satisfaction with services (Rogers and Pilgrim 2005, p.219). For these reasons, a clear separation between both groups is preferred by many service-users.

The second aspect that requires clarification is the concept of service-user involvement. The interchanging use of terms such as involvement, partnership and consultation (Beresford 2010a; Rutter et al 2004) is widely noted in systematic reviews of SUI in service planning, research and professional education (Crawford et al 2002; Perry et al 2012; Repper and Breeze 2007). Staniszewska et al (2011, p.627) identify: “poor conceptualization, limited theorization, little attention given to the quantitative measurement of impact and poor reporting” of outcomes around SUI. They are concerned, as are other service-user researchers, to develop robust quantitative measures of the impact of SUI (Faulkner 2012; Morrow et al 2010). However, as this study focuses on a newly developing practice in the Irish MHS, qualitative methodology is more appropriate to contextualise the challenges experienced in operationalising SUI.

For the purposes of this study, SUI is defined primarily as the participation by mental health service-users, either individually or collectively, with the statutory MHS in service planning and evaluation, policy development, MHS research, education of professionals, and includes providing peer-advocacy support to, or on behalf of, other users. Other activities of the Irish user-movement such as protest, lobbying and aspirations towards direct service provision are also discussed as contestations and tensions arising from SUI.

One of the most widely cited typology of citizen participation is that of Arnstein’s (1971) ladder of participation, illustrated in Figure 1.
This model has appeared as recently as 2010 in the British Psychological Society’s guidelines on SUI but is critiqued by others as a linear, hierarchical model of involvement which fails to adequately represent the complex, dynamic nature of SUI (Titter and McCallum 2006 cited in McKinley and Yiannoulou 2012, p.116). SUI is occurring in practice along a continuum or spectrum, defined in different ways for different purposes. Gosling (2010) distinguishes between involvement defined by her UK based user-run organisation, Advocacy in Action, and SUI ‘hijacked’ by service-providers. According to Gosling (2010, pp.33-34), users understand involvement as collaboration, innovation, empowerment and redistribution, whereas it can also mean compliance, containment, coercion and incorporation if service-providers use involvement practices for their own ends.

Often it can be difficult to distinguish between the level of user-control in empirical reports of SUI. Sweeney and Morgan (2009) explain levels of control in SUI in research as a continuum with token consultation at one end, ranging through various levels of contribution and collaboration to user-led or controlled research at the other end. The critical aspect of these processes is the level of
decision-making control service-users have. In relation to SUI more generally, Beresford (2010a) presented three different forms of SUI, consultative processes, deliberative structures and user-run organisations. These are further discussed below.

**Challenges for Service-User Representation**

There is also much debate within the literature about the diversity of experience, skills and the representativeness of individuals engaging in SUI activities within the MHS. Forbes and Sashidharan (1997) highlighted how the conflation of everyone who encounters social work or MHS under the term “service-user” fails to acknowledge how different individuals and groups experience services. They draw attention to a spectrum of experience from voluntary, supportive care to coercive, oppressive control. People whose experience is primarily at either end of the spectrum are not likely to understand the experience of people at the opposite end. Therefore it is important “to locate the position of users in relation to their power relationship with services” (Forbes and Sashidharan 1997, p.493).

Beresford has worked to build alliances among different groups of service-users across a wide cross-section of long-term health and social care users in the UK, including older, disabled, deaf people, mental health service-users, people living with HIV/AIDS, learning difficulties, chronic and life-limiting illnesses and conditions. He argues that such long-term service-recipients have perspectives that may not be the same as those of general public health service-users, because they occupy a marginalised and discredited position in society, and may well be dependent on the services seeking their involvement (Beresford 2010a). Such service-use is also different in quality because service-users may face particular limitations on their freedoms to use services, e.g. institutionalisation in the case of older people, or removal of their rights, as with mental health service-users.

Forbes and Sashidharan (1997) repeat the point made by Croft and Beresford (1993) that the usual forms of SUI mirror the exclusion of certain groups in society. Consequently certain groups will be more likely to be under and over-represented at each end of the care spectrum, depending on their positioning in
society. They point out how underlying assumptions of services about need and risk are also shaped by ideologies based on stereotypes around gender, age, race and ability. They argue that models of SUI that posit a functional relationship between users and services ignore the diversity of how people experience care. They suggest that the libratory struggles of feminist, disabled and black peoples movements offer more potential for an oppositional politics for the user-movement than the current emphasis on collaboration with a consumerist agenda of the MHS.

Cowden and Singh (2007) discussed the politics surrounding the professional-user employed by statutory bodies who present the user perspective acceptable to services, thereby maintaining control over who is involved and who is considered too difficult to engage. This issue has also been raised by Lakeman et al (2007), who note the tendency of some service-users to get comfortable in the celebrity role, thereby becoming distant from the needs of those at the bottom of what the authors refer to as the hierarchy of service-users, those who are homeless for instance. Beresford (2010a) pointed out a similar risk associated with traditional representational democracy where the structures of SUI can create group-think and disconnection from the experiences of the people they seek to represent.

However, levelling a charge of unrepresentativeness at those who become involved is also a tactic of power, which can be used to discredit both the speaker and their message (Beresford 2010a; Brandon 1995; Campbell 2001; Chamberlin 2005; Crepaz-Keay 1996; Lindow 1995; 1999a). In the context of the power dynamics of SUI, service-users perceive this as a challenge to their right to be involved in decisions about, or shaping the delivery of, the MHS. Recent research (Rose et al 2010) has demonstrated there is no discernible difference between activists’ and ordinary non-involved service-users’ perceptions about what SUI can achieve. In addition, as pointed out by Townend et al (2008), in a review of SUI in educating professionals, professionals are not expected to be representative of their entire profession, so why apply this double standard to service-users?
Activities classified as SUI

Another area of confusion are the various activities that are classified as SUI. Rose et al (2010, p.393) list eight different forms of SUI:

- Being consulted about staff recruitment, having a role in selection of candidates or being involved in staff performance evaluations,
- Advising on local MHS in committee work,
- Involvement in research. This is most usually consultation but there is a growing body of service-user-led and controlled research,
- User-led service delivery,
- Training of professionals,
- Employment in services as peer-workers,
- Peer-advocacy,
- Campaigning.

Rose et al (2010) do not include consultation on an individual’s own care in their list of forms of SUI. Neither is individual involvement included in Crawford et al’s (2003, p.410) summary of different methods of SUI reported in a survey of 18 London Trusts providing MHS in 2001. Comparison of Crawford et al’s (2003) data with Rose et al’s (2010) list indicates that engagement with healthcare agencies is the form of SUI which the MHS recognise, whereas for service-users it can include activities that occur in separate public spaces such as campaigning and political advocacy. Wallcraft et al (2003) also document that the user-movement is more active than just engaging with decision-making bodies. While SUI in MHS is an important part of the movement’s activities, these groups exist for many other reasons also and some decided not to do SUI work. The movement exists independently of its role in SUI. However, there are many accounts of MHS supporting the development of user groups in order to supply their need for users available for SUI (Beresford 2010a; Cleary et al 2006).

Individual Involvement

A fundamental demand of service-users seeking reform of how they experience MHS is to be involved in decisions about their own care, ideally to be
in control of their own care. This form of choice and control is highly significant for service-users, and can be considered as SUI at the individual level. Yet this level is often understood to represent SUI for professionals. McKinley and Yiannollou (2012, p.188) have observed that service-providers, in the process of developing a care plan, frequently ask people what services they want to access and refer to that process as SUI. They pointed out that it is easier for the MHS to involve service-users at a level where skills and corporate or technical knowledge are not essential for the process.

Rose (2003) has reported on service-user-led research on care planning within the UK, using User Focused Monitoring (UFM), developed by Rose and her colleagues. This social survey methodology examined people’s satisfaction with the NHS approved method of care planning used in the UK, Care Programme Approach\(^9\) (CPA). Rose argues that it is possible to deliver CPA without the service-user even being aware of the process at all. The approach taken by the staff in delivering CPA is very much informed by their attitude to users, whether they choose to involve people in their care or to draw on the strengths of service-users and treat them as partners. She asked what needs to be done to turn service-users into partners and stakeholders, and begin a process of empowerment. She concludes that: “coordination of care will only lead to better services when users themselves are, as a first step, aware of the processes of coordination and will only become meaningful when they are involved as stakeholders” (Rose 2003, p.61).

The surveys were carried out by user researchers, who prior to the study were themselves unaware of what CPA was. Indeed, they had never heard the term although many would have been receiving care from professionals under CPA. Spicker et al (1995 cited in Rose 2003, p.66) noted that: “users frequently don’t know what’s happening to them in formal mental health care and often feel bewildered,” which was consistent with Rose’s (2003) findings. Service-users reported that the process of CPA was too complicated and not explained to them. During a workshop, professionals said service-users were not interested in CPA and did not want to understand it. When they were asked to compare how long it

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\(^9\) The CPA program is a central plank in the UK mental health policy and is: “a means of coordinating the work of different professionals who work with a user” Rose (2003, p.60), similar to individual care plans advocated by the Irish Mental Health Commission.
took them to learn the system with how long they spent explaining it to service-users, the typical comparison was two days for staff and five minutes for service-users. She argued that the difficulty in making coordinated care more meaningful to service-users does not lie with increasing awareness of CPA among users but with “shift[ing] professional perceptions and practices”. One of the key findings was that where people were involved in their own care, with a focus on their strengths, they reported higher overall satisfaction with services.

The conclusion that Rose (2003) draws from this user-led study is that while partnership and SUI are high on policy and research agendas, this is not necessarily reflected in practice. In fact, her interpretation of the quantitative evidence strongly suggests that while partnership and coordination of care are strong policy concerns at a structural level in the UK, they do not result in SUI on the ground.

**SUI in Research**

Two of the most reported areas of strategic or operational SUI in the literature are in research and education of professionals, perhaps because of their links to academic activity. Two books on SUI in research were published recently by service-users (Sweeney et al 2009; Wallcraft et al 2009). Much of the work of Beresford (the most widely cited user-movement academic) has been in the field of SUI in research and has been very influential in developing the methodology for this thesis (discussed in Chapter Four). There are many aspects of SUI in research that carry over to SUI in general, one of them being the quality of SUI itself, and how meaningful it is for the service-users involved. A recent paper on SUI in health research (Morrow et al 2010) adds to the growing interest about how to work ethically with service-users (of all health services) as contributors to knowledge creation, and it is relevant to the spectrum of SUI activity.

Morrow et al’s (2010) paper proposes a quality assessment framework that could allow for greater reflexivity by researchers on the roles, expectations, and

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10 Strategic and operational SUI are forms of involvement which have a focus on influencing the MHS, rather than individual relationships with treating professionals. Operational SUI is concerned with oversight of how service is delivered, whereas strategic is focused on seeking changes to overall policy direction and future service development.
contributions of service-users to health research. They note the lack of clarity about what is understood by the term SUI in research, but assert that it is generally accepted to positively influence health research by improving the relevance of the questions asked, making the methods and tools more responsive to service-users concerns and informing appropriate choices in the data collection, analysis and interpretation (Morrow et al 2010, p.533). The authors argue that a focus on a quality assessment framework could help researchers and service-users reflect, negotiate and report on their positions, relationships and power disparities. They note the different value-bases from which quality assessment can start, considering structures, outcomes or processes. Morrow et al (2010) focus on the processes that can help ensure quality structures (equitable recruitment, better communication and ethical working practices) and outcomes.

The authors examined different aspects of the personal situation of service-users in the research context: such as the resources available to them in terms of funding, their goals for becoming involved, and whether they feel they can make a contribution. They argue that all aspects of service-users’ roles and identities need to be acknowledged and discussed within the research team. The authors also discuss research relationships, how the research is conducted and the research structures. They refer to Bachrach and Baratz’s (1962) concept of ‘non-decision making’ where concerns are not even discussed because decisions about the research are so fixed by the professional researchers that service-users’ considerations are not listened to or even acknowledged. Service-users therefore may not believe they can raise issues because they expect these to be ignored, opposed or dismissed as not being a realistic option. The authors conclude by suggesting that paying attention to how power operates at covert levels within the research process will contribute to better quality SUI in health research. Morrow et al (2010) present a set of questions that could be usefully employed in all settings to ensure that SUI efforts by professionals, allies especially, address some of the more obvious power dynamics.
SUI in Professional Education

There is significant policy\textsuperscript{11} emphasis on SUI in planning, providing and evaluating education and training in the UK (Campbell and Lindow 1997; Chase \textit{et al} 2005; Grant 2006; Lindow 1992; Reynolds and Read 1999; Sayce 1993 cited in Townend \textit{et al} 2007, p.68). Such involvement: “can enable workers to understand more about the implications for users of their actions, their treatments and their approaches” (Reynolds and Read 1999 cited in Townend \textit{et al} 2007, p.69). According to Happell and Roper (2009), SUI in professional education provides students an opportunity to consider how their duty of care means they have to act in ways that would otherwise be unconscionable, e.g. treating someone against their will (2009, p.577). The service-user perspective presents this dilemma to student nurses as a reality they must learn to hold: the dual awareness of the damage they are doing while operating their duty of care mandate. Happell and Roper (2009) report that students’ evaluation of the role of the consumer\textsuperscript{12} academic in their training suggests this was challenging, but it also heightened their awareness of the human rights issues in their practice as nurses. Townend \textit{et al} (2007 citing Livingson and Cooper 2004; Simpson and House 2002), suggest the reason occupational courses, such as psychiatry, mental health nursing, social work, occupational therapy and psychology, have increasingly begun to incorporate SUI in their training is because the power and coercion associated with their roles (psychiatry and nursing especially) made these professional educational systems a focus of user lobbying for inclusion. These authors also argue that the emphasis on evidence-based practice denigrates the standpoint and experiential knowledge of service-users and show how the developing knowledge base of service-users is challenging both professional orthodoxies and their power bases.

Repper and Breeze (2007) reviewed 38 studies that reported findings on SUI in education, half of which included mental health service-users. The benefits reported by service-user participants included cathartic experiences, gaining more knowledge, increasing their confidence and self worth and a feeling of


\textsuperscript{12} Happell and Roper are Australian based, hence the term consumer is retained in this context.
empowerment. The studies that focused on mental health service-users’ views on content or skills revealed a consistent emphasis on the humanistic and interpersonal components of caring rather than the professional and technical. Two studies indicated that the biggest difference between students exposed or not to SUI was their ability to demonstrate empathic understanding, an individual approach, and an appreciation of good communication skills. The two most common concerns for user-trainers were remuneration and preparation, and Repper and Breeze (2007) conclude that educational organisations need to develop systems of training for educators as well as service-users, which include support and payment structures.

They also reported that imbalances of power and control in favour of the professional or organisation were evident throughout the studies. For instance; students rated teacher-led sessions as being more credible than user-led sessions, the rules, regulations, or traditions of the academic institution were privileged above how they impacted on service-users. They reported a desire to ensure ‘academic balance’ to service-users’ accounts and a bias in favour of evidence of the professional. Some teachers/academics were not convinced about the benefits of SUI, and felt threatened in their role as educators. Some expressed ethical concerns about accountability (i.e. the service-users could advocate something that would compromise professional accountability) or that service-users would have to revisit a painful experience. However, service-users did not have the same concerns; they felt it could be cathartic. These differences suggest the need for debate between service-user groups and teachers/academics in order to advance SUI in professional education.

Repper and Breeze (2007) discussed the need for a system-wide approach in academic institutions rather than the current situation where individuals instigate SUI on their courses. They noted that patronising attitudes which prevail in professional education can only change with systematic efforts to include service-users across the entire system, in the selection of students and staff, the development of portfolios of courses, the planning of curricula and the delivery and assessment of teaching. Happell and Roper (2009) report on the establishment of a ‘consumer academic’ within a mental health nursing department in Australia. They note that the success of the position depended on
the following critical factors: partnership and commitment between different agents most particularly the school of nursing and a local consumer group who worked closely together to provide the second critical factor, support. The scope and autonomy provided to the incumbent in the position was also of critical importance to ensure it was not a tokenistic role.

**Benefits of SUI in Education**

Repper and Breeze (2007) noted in their review that students reported that hearing real life experiences from user educators enhanced their understanding. This finding surprised them, given that they consider this opportunity exists in routine practice. However the difference is that SUI in education may erode students’ expectations that they must assume the role of experts when in practice; once they are able to conceive of service-users and carers as experts in their own experiences, they may be better able to listen to the accounts they hear in practice. Perry *et al* (2012) carried out a systematic review of mental health SUI in education, specifically focusing on improving interpersonal communication skills of mental health students. They found this type of teaching made students more reflexive about how they communicate. In addition, (Townend *et al* 2007, p.69) found SUI in education of psychotherapists lead to: “improved service outcomes and individually focussed care.”

**Employment in MHS as peer-support workers**

Another common form of SUI (internationally) is the employment of service-users in MHS as Recovery-support or peer-support workers. Solomon (2004) described the wide range of peer-support programmes provided in the USA, defining peer-support as social, emotional, and sometimes instrumental support offered by someone who has experienced mental health difficulties to another who is in need of support. Solomon (2004) reviewed the research into consumer provided services in the USA which may include consumer-run services, or consumers employed within MHS. The evidence suggests that everyone benefits from having consumers employed in the MHS in sufficient numbers so that consumers are not isolated and can offer each other support. It

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13 Mental health students in Perry *et al*’s (2012) review are students from a range of mental health professions including: nursing, medical, occupational therapy, social work and clinical psychology.
benefits professionals in that they see service-users as competent workers, which reduces stigmatising attitudes among professionals. It benefits services in that users are more likely to identify with the peer-workers and be more willing to engage, especially with traditionally ‘hard to reach’ groups (Solomon 2004). There has been a great expansion of these positions within UK MHS in the past decade (Repper and Carter 2011). Repper and Carter’s (2011) review of literature on peer-support workers internationally concluded that contact with peer-support workers can result in many positive outcomes for those they work with, including increased hope and belief in the possibility of Recovery, empowerment and increased self-esteem, self-efficacy and self-management of difficulties and social inclusion, engagement and increased social networks. Chamberlin (1977; 2005) claims that service-users best understand the support other service-users need because they have been through the depersonalisation and psychiatric mystification of the mainstream MHS, a claim supported by other service-user writers (Brandon 1995; Faulkner 2002; Jenkinson 1999; Lindow 1999a; Rose 2003). There are currently pilot projects in different MHS in Ireland which have begun to employ peer-support workers but no further information about these is available at time of writing.

Peer-run MHS

The user/survivor movement, especially in the USA, has been actively involved in establishing a different way of providing care to people in psycho-social distress (Campbell 2009). According to Goldstrom et al (2006) services run by and for people and their families more than double the number of mainstream services. There are some accounts of user-run (and carer-run) alternatives and crisis houses in the UK (Faulkner 2002; Jenkinson 1999; King 1996; Lindow 1999a; Wallcraft 1996). A report on eight crisis service projects by Faulkner (2002), two of which were service-user run, reported high user satisfaction with user-led crisis services. Stastny and Lehmann (2007) provide many international accounts of user-run models of crisis and support programmes. Doughty and Tse (2011) systematically review 29 controlled studies comparing peer-run services with mainstream MHS and concluded that the peer-run services were equally as effective as mainstream services, especially
in areas such as employment, living arrangements and reduced hospital readmissions. Underfunding remains one of the biggest barriers such services face.

**SUI in Partnership Models of Crisis Care**

Johnson *et al* (2007) review the literature on community based alternatives to in-patient crisis treatment and classify the programmes they reviewed into three types: placement in family homes, crisis houses, and hybrid services, which include crisis beds attached to other MHS, such as day centres. They find most of the examples of crisis houses were disparate projects with differing values and approaches, set up by local professional champions and which often disappeared on change of personnel. They report that the clinical outcomes for people attending a community based crisis house were comparable to those of people admitted to traditional inpatient units, while the service-users reported far higher satisfaction, especially in a women only project, Drayton House in Islington, UK. They also discuss the Soteria Project (1972 to 1983) in the USA and replica models in Germany and Switzerland, which are currently operational (Ciompi *et al* 1992, cited in Johnson *et al* 2007). They highlight the transitory nature of alternatives to traditional care, and suggest possible explanations of why this may be the case: funding arrangements are likely to favour the established forms of care which are considered a necessity, and to regard crisis houses as a luxury. There is likely to be intense scepticism among clinicians to treating people in crisis outside hospital settings, and established projects are vulnerable to key champions moving away (Johnson *et al* 2007, p.263).

‘Open dialogue’ is a Finnish example of another MHS-led alternative to inpatient admission (Seikkula and Olson 2003), an approach presented by Whitaker in his Irish tour (Whitaker 2010b). The focus of ‘Open dialogue’ is on treating the individual in their family setting, intervening without psychotropic mediation, or at least significantly delaying commencement until all other possibilities have been exhausted, and supporting them to find their ‘route into adulthood’ in a holistic, family-focused, dialogic process (Seikkula and Olson 2003). This approach has reported significant reductions in the rate of diagnosis of schizophrenia in that region, but more particularly, no new admissions of people into long-stay wards with ‘chronic’ conditions (Seikkula and Olson 2003,
p.415). To return the focus to what is currently feasible in an Irish context, this chapter continues to review SUI within mainstream MHS.

**Service-User Perspectives on SUI**

Campbell (2001; 2005) discusses the considerable energy the user/survivor movement in the UK has invested in efforts to reform the MHS. After 20 years of activism in the user-movement in the UK, he recalls how in the mid 1980s service-users would spend time defending their right to be at the table. Now the presence of service-users is accepted as a right, driven by government policy. He refers to user activities, including consultation in planning, managing and monitoring of the MHS, as: “the government approved features of involvement” (Campbell 2001, p.87). He suggests the changes resulting from this level of involvement have been more about influence than control; including people in the process of making choices is not the same as providing meaningful choices. In terms of assessing the impact of other forms of SUI, Campbell (2001) noted the growing acceptance of service-user feedback about service use, which is required by statute in the UK. However, frequent references to the ‘representativeness’ of those involved and the ‘professional user’ indicate that this practice is still contested. Although SUI has impacted to some variable extent on the status of the service-user within the UK MHS according to Campbell (2001), it has failed to affect change in their status in society. He also notes that SUI has made no impact on the ‘clinical authority’ of the mental health worker and argues that the language of partnership and collaboration can mask the power imbalance and different agendas of service-users and service-providers.

Beresford (2010a) presents some of the features of successful partnerships from the perspective of wider groups of marginalised service-users (people with different disabilities, including mental health service-users and older people) involved with the state and related bodies. These necessary features range from listening, valuing and respecting service-users, to recognising the need for training for professionals to work on equal terms with service-users, allowing them to co-lead and develop appropriate skills. Principles for equal partnership must be agreed, which include safe space and opportunities for negotiating and
reaching joint decisions. The final feature of successful partnerships is the provision of adequate and reliable funding and other support for service-users’ organizations (Beresford et al 2007, cited in Beresford 2010a, p.499).

McKinley and Yiannoullou (2012, pp.116-117) present work by Faulkner (2009) to develop a monitoring framework for SUI that aids service-users in determining if SUI is meeting their needs. This is the Purpose, Presence, Process, Impact (PPPI) approach, which outlines factors that can help assess whether SUI is a meaningful activity for the service-users and carers, who become involved. Purpose requires a clear statement of the reason for SUI, which can help provide clarity about the roles people are expected to take up and can help to avoid tokenism and involvement just for its own sake. Presence relates to the numbers and characteristics of the service-users and carers involved (e.g. age, gender, ethnicity, specific experience, etc). Process refers to roles, how people experience the process, the supports made available and whether good practice guidelines are followed. Impact considers what impact SUI is achieving on the work stream or programme, and what impact the SUI is having on the service-users or carers.

McKinley and Yiannoullou (2012) state that SUI should have a positive impact on how the MHS is used, perceived and experienced by the involved service-users, and should enhance their well-being. The impact of SUI is dependent on the purpose, presence and process stages being adequately addressed. However, they note that measuring the impact of involvement and the well-being of involved service-users is complex and not generally undertaken. Service-user researchers have begun to seek ways to address the need to assess both the quality of SUI and quantitative impact measures in SUI practices in the UK (Faulkner 2012; Morrow et al 2010; Staniszewska et al 2011). The experience of those engaged in such initiatives needs to be highlighted and qualitative research is best placed to describe the context and experience of a new development in Irish MHS.

Disappointment over the progress achieved given the energy expended has been articulated by many individuals within the UK user-movement (Campbell 2001; 2005; Wallcraft 2008), a theme elaborated on by others (McDaid 2009; Pilgrim 2005). Pilgrim (2005) described the tension between the democratic
impulses of the service-user movement to improve, or indeed in many cases to resist, even reject altogether, the care offered by the MHS, and 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. Elsewhere, he notes two ways SUI can be considered worthwhile from the user perspective, not only as a human right, but also as a “Trojan horse” (2009, p.86), in that SUI provides an opportunity for the service-user movement, once at the table, to contest how they have been treated and present oppositional views to the coercive, bio-medical approach of the MHS. McDaid (2009) questioned whether the user-movement would see more results from developing collective power and political strategies to highlight the unjust conditions of poverty, exclusion and disempowerment that service-users experience in wider society.

**Theoretical Commentary on SUI**

Beresford (2002), writing about SUI in research, traces the development of the rhetoric of SUI/partnership, identifying two powerful driving forces, neo-liberalism and the rise of user-movements. These two ideologies suggest distinct models of participation, which he labels ‘consumerist’ and ‘democratic’. The consumerist model of involvement, identified with the neo-liberalist agenda, is consultative by nature focuses on data collection, for example, patient satisfaction surveys and is initiated by management to improve the experiences of care. It is now an international health policy (Bennetts *et al* 2011; Beresford 2010a; Elstad and Eide 2009; Howley 2011; Restall and Strutt 2008). The democratic approach to participation, emergent from the service-user movement, prioritises inclusion, autonomy, independence, self-advocacy and civil/human rights. As an approach it is explicitly political, seeking to influence the power dynamics of participation. Beresford 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.

Forbes and Sashidharan (1997), a social worker and psychiatrist respectively, robustly critique the rhetoric around SUI in the UK. They argue that: “incorporation and moderation of an oppositional position” serves the system service-users seek to change (1997, p.496). They draw attention to several
uncontested concepts associated with SUI that are uncomfortable for professionals to address, such as the power imbalances in everyday interactions between service-users and the MHS. They discuss power imbalances documented by service-users which are not examined in consumerist ideas about SUI. They present Lindow’s (1994) argument that self-advocacy is about liberation politics, in much the same way that Gay Pride highlighted gay rights (cited in Forbes and Sashidharan 1997, p.485). Referring to Croft and Beresford’s (1990) explanation of the different drivers for SUI, they argue that the consumerist model of inviting involvement in service planning marginalises what service-users want and limits possible responses to what is available within the service, thus such a model cannot alter the social conditions of service-users lives. Forbes and Sashidharan also highlight the tensions between forms of SUI, such as self-advocacy and user-controlled services, and the coercive model of care operating in the MHS. Forbes and Sashidharan (1997, pp.486-487) discuss survivor writers (Lindow 1994; Zinman 1987; O’Hagan 1993) who point out the liberatory impulse of the survivor movement and the risk of co-option in struggles to be free from the oppressive forces of psychiatric systems.

Cowden and Singh (2007, p.6) take issue with ‘the supermarketised version’ of SUI underpinning New Labour reforms of the NHS and MHS, where power is reduced to an issue of choice. Drawing on the theories of Friere (1968) and Franz Fannon [n.d.], they argue that corporatist models of SUI do not encourage users to understand their subjugation or to envision ways to break free from oppression. They explain how difficult it is for people from marginalised communities to challenge the conditions which underpin their circumstances; thus consumerist ideas of SUI empower those with the most expectations, while marginalising those with the least.

Cowden and Singh (2007) argue that SUI is bound up with a neo-liberal New Left hegemony that aligns progressive social movement ideals with market forces. Cowden and Singh refer to Althusser’s (1971) concept of ideology to explain the uncritical adoption of SUI. Althusser argues that ideologies represent more than false ideas; they are the stories we tell ourselves about our world and the social conditions in our world. Cowden and Singh (2007) describe the story of SUI; in the past, users were simply subjects acted upon by psychiatry, whereas
with SUI they are actively involved in making decisions and therefore have more control over their lives. This, however, is not the reality; it is the professionals and bureaucracy which determine how and when users become involved. Cowden and Singh (2007) maintain that SUI has become a new means of obscuring the reality of the surveillance and governmentality of the state, by making public servants more accountable for the state’s spending through oversight by the public. They contend that SUI can be subverted into an ideology for neo-liberals’ own managerialist ends, to control workers by decoupling practice from analysis. For this reason, front-line workers should resist empty managerialist rhetoric about SUI, which does not analyse power and the powerlessness experienced by service-users. They should instead engage with the important issues to be fought for in the users’ agenda, such as power and powerlessness, critiques of a coercive MHS, or welfare responses to poverty and stigma.

Carey (2009) uses Gramsci’s (1971) concept of hegemony to develop his explanation of the close link between service-user and carer participation (SUCP) in social work and the marketisation of social services. Eagleton (2007 cited by Carey 2009, p.181) explains hegemony as the mechanism by which governing bodies gain control over those who consent to be governed, by subtle and enticing processes. It: “aspires to engage and interact” (Carey 2009, p.181) (italics in original) with the population while fostering empathy with the needs of the ruling classes. Therefore it is: “an interactive and symbotic form of ideology” which takes many forms, cultural, social and political. It is most often expressed and replicated in linguistic form (textbooks, newspapers, policy, speeches, etc.) which allow for dynamic, persuasive claims which appear transformative, seductive and enticing. However such claims are illusions which hide other agendas.

Carey (2009) points to the promises contained in SUCP to reform services by greater public participation, making them more accountable, improving service provision, while the reality is contraction and rationalisation. This reveals another feature of hegemony (pointed out by Jones 2005 cited by Carey 2009, p.182), the ability to adopt counter-hegemonic discourses, and appear in sympathy with user-movement objectives. Carey (2009) uses the example of how
the language of service-users’ demands is incorporated into the rhetoric of SUCP by appropriating terms such as social exclusion, empowerment, globalisation and SUCP to further a neo-liberal agenda, to privatise public services. What makes these ideas vulnerable to appropriation, according to Carey (2009, p.182), is an inherent: “ambivalence that is easy to exploit, ontologically hijack and use for very different political ends.” Carey provides two examples of how SUCP fulfils hegemonic roles. Firstly, it sits well with consumerism, given the appearance of participation, choice, and improved service delivery. Secondly, it addresses another New Labour ideology of social inclusion by bringing in from the margins people who might otherwise be considered the disenfranchised, morally unsound, potentially troublesome burdens on the taxpayer, and getting them into socially productive enterprises.

Carey summarises many practical and ethical criticisms of SUCP from different sources (Croft and Beresford 1995; Carr 2004; Warren 2007, pp.52–6; Humphries 2008, p.67 cited in Carey 2009, p.184). These include observations about SUI being a means to reduce operations and maintenance costs by government agencies, or to enhance an organisation’s profile. Carey lists many structural and cultural obstacles to meaningful participation: limited resources; inadequate legal and policy related support; complex, confusing organizational procedures and rituals; discrimination and stigma generated by professionals; feelings of powerlessness, low self-esteem, scepticism or apathy towards SUCP amongst many service-users and carers. He also reports a tendency of professionals to advocate greater SUCP to extend personal autonomy and power, and academics to rely upon ‘abstracted discussion’ and subsequently obfuscate SUCP within paradigms such as social policy and social work (Carey 2009, p.184).

Stickley (2006), a mental health nursing educator, reviewed SUI in the UK from a critical realist perspective, and argued that many instances of SUI in the UK amounted to little more than: “reinforcing the power position of the dominant discourse” (Stickley 2006, p.571). He argued that much of SUI work was carried out in the name of ‘empowerment’, a popular buzzword in the UK MHS in the 1990s, yet this process retained power with the service-provider who ‘empowered’ the service-users under their own terms and within MHS
frameworks. He observed that under the current model of SUI some service-users might ascend the ‘power ladder’, unsettling some of those in power along the way, but ultimately the power of psychiatry and the MHS remains intact (2006, p.575). Indeed drawing on Foucault’s (1988) argument about identifying the structures of power which perpetuate its domination, Stickley (2006) contends that practices which appear democratic (such as SUI) reinforce the very structures they appear to reform. Stickley (2006) proposed that the concept of emancipation might be better achieved by user-led groups contracting services to the MHS to assist them in fulfilling their requirements for SUI under the consumerist/managerialist policies of the UK government. He cited examples of service-user controlled initiatives14 that are emancipatory and offer more hope for change than initiatives around SUI established within the system. Stickley (2006) went on to note how important allies are to secure funding and resources for projects under service-user control. Indeed he pointed out that those who seek change within the MHS must recognise that external user-controlled, independently operated, ‘emancipatory’ projects are the best way to secure such change (Stickley 2013).

This is a position taken up and discussed by Beresford (2010a), who highlights how much of the wide-spread discussion about public participation and partnership in the UK and internationally occurs without the actual participation of service-users themselves, whose contributions are often at best reported by others as research findings. He claims that as a result of disillusionment with partnerships, service-user organisations are more likely to prefer the concept of alliances. Alliances offer the possibility: “that there may be cooperation and collaboration where there is an overlap of interests, aims, objectives and values and these can be negotiated and agreed democratically and on as equal terms as possible” (Beresford 2010a, p.497).

14 Service User Research Enterprise (SURE), at the Institute for Psychiatry (Rose 2003); projects at the Sainsbury Centre for Mental Health, such as User Focused Monitoring (SCMH 1998; Rose 1998); Strategies for Living research at the Mental Health Foundation (Faulkner 2000) and other user-led initiatives like Shaping Our Lives.
Different Approaches to SUI

Beresford (2010a) notes that consultative involvement is the dominant form of SUI, whereby service-users and their organisations are invited onto committees and other arrangements with state services, in the context of policy, planning, research and evaluation activities. He observes that the main function of consultative involvement: “is to elicit information, views and intelligence for the initiating (state) agencies, for them to draw upon to inform judgements and decisions that they will take” (Beresford 2010a, p.497). Yet there is ‘consultation fatigue’ amongst service-users, with terms such as ‘all consulted out’, ‘over-consulted’ and ‘tick box activities’ in common parlance within service-user groups involved in these type of arrangements. This negative response arises from a lack of results or positive change given the effort service-users invest in consultation exercises: “energy, time and resources, all of which may be in short supply and which might better be used in other ways” (Beresford 2010a, p.497).

Deliberative structures for involvement, structures like parliaments, panels, partners’ councils and citizen juries are increasing within the UK Public and Patient Involvement (PPI) landscape. They differ from consultative involvement in that they exist over time and thereby provide the possibility for shared discussion among members, thus potentially developing a more deliberated response than once-off events. These deliberations can feed into decision-making processes. Beresford (2010a, pp.497-498, citing Davies et al 2006) however, highlights that over time such structures develop a culture of their own, in which they become socialised into the norms and language of their host bodies, regardless of how ‘representative’ members were when they joined, or how often new members are brought in, over time they adopt the ideas and identity of the collective group. Therefore, such structures are likely to reproduce: “existing exclusions, prejudices and unequal power relationships” (Beresford 2010a, p.497). As service-users develop the skills to operate in such mainstream structures the risk increases that they become removed from the understandings, experience and viewpoints of those they were recruited to represent.

Beresford (2010a) traces the modern development of social and health care recipients’ movements in the UK from the 1970s, when groups of disabled people began to distinguish between organisations and services that were run for
them rather than run by them. The Independent Living movement developed from such awareness, as did the movement slogan ‘nothing about us, without us’, and the paradigm altering theory of the social model of disability. Since then organisations of people with learning difficulties, older people, mental health service-users, young people in state care, people living with HIV/AIDS and other groups have emerged to demand their rights to control their own lives and represent their eclipsed experiences. User-controlled organisations are more likely to be reflective of the concerns of their members, and thus form a credible basis for developing broad based alliances with statutory bodies.

Beresford (2010a) discusses additional issues such as whether SUI is initiated by the state bodies which preset the opportunities for participation and terms of discussion, in other words top-down initiatives to which service-user organisations respond. When service-users themselves create opportunities for involvement with state and related bodies, they can come from a: “position of greater individual awareness and understanding and increased collective strength and solidarity” (Beresford 2010a, p.498). However, formal care services have challenged this form of self-organisation as unrepresentative and have sought to widen the discussion to others who may not be as developed in their critique of the dominant discourses.

A second issue is that of autonomous service-user movement structures versus a partnership model. Beresford looks at the way the disabled peoples’ movement has developed more autonomy, i.e. centres for independent living, whereas the survivor movement, focused on seeking to reform the psychiatric/mental health system, has operated more in ‘partnership’ models, responding to initiatives for SUI from the state and related bodies rather than setting their own agendas. Consequently, most of the funded activity of the user-movement has occurred within or been administered by non-user-controlled organisations (Beresford 2010a). He highlights the consequences of these conflicting ideologies: the former approach means that users often experience tokenistic involvement, whereas autonomous user-organisations often adopt campaigning and pressure approaches as well as engaging in partnership approaches. Thus they may be as likely to engage in conflict as collaboration with state services.
Nevertheless, many service-users working as peer-educators or consumer consultants believe that their contribution does make a difference, as discussed above in relation to SUI in education. For example, research conducted with managers in Australia working with ‘consumer consultant’ employees found that this form of SUI did change the dynamics of decision-making, but more importantly managers learnt to understand the service-user perspective from contact with consumer employees (Bennetts et al 2011). Power was identified as a major theme in their research; a theme I shall take up in the next chapter.

**Barriers to SUI**

Beresford (2010a) reported the reservations about partnership of a collective of disparate forms of service-users in the UK. They highlight the gap between rhetoric about partnership and practice, including the meaninglessness of top-level decisions that services be delivered in partnership but which do not translate into practice by frontline staff. For instance, bullying and disrespectful behaviour from staff towards users make partnership talk hollow indeed. Service-users need to feel valued and respected and their access needs routinely met in order to make partnership real (Beresford 2010a, p.496). Beresford also suggests a starting point is for service-users to examine the powerlessness and discriminations they themselves experience in relation, not just to services, but a society which excludes them.

McMillan et al (2006) describe barriers to meaningful SUI which were reported by a group of service-users and carers in Belfast, Northern Ireland. These included having decisions made without them, being made to feel stupid at meetings, the chair always filled by someone on the statutory side, having to constantly repeat their stories, and no real information presented about obstacles to implementing their suggestions. Top down consultative processes are often criticised as failing to provide genuine opportunities for participation (Beresford 2002; 2010a; Carey 2009; Chamberlin 2005; Church 1996; Church and Reville 1988; Repper and Breeze 2007). In contrast projects developed in real partnership with groups from the ground up, e.g. building capacity in local groups through human rights based approaches (e.g. McMillan et al 2006), and
supporting them in developing their own user-led benchmarks and indicators can be the beginnings of meaningful participation for service-users.

Structural barriers to SUI include a culture within the MHS which is resistant to change (Hyde *et al* 2004; Rogers and Pilgrim 2005; Sapouna 2006; Sayce 2000; Townend *et al* 2008). Johnstone (2000, pp.201-218) a psychologist, argues that the culture within the MHS is supported by a range of vested interests. These include the benefits accruing to a society that wants to pass responsibility for distressed people to psychiatry rather than provide supports in their communities, and the training of staff inculcating the medical model, which is to the advantage of the psychiatric profession and the powerful drug companies. The political system itself has a vested interest in a biological cause for distress, rather than admitting that a myriad of social problems can lead to psycho-social distress. Similar analyses have been made from a sociological perspective by Busfield (2001) and Rogers and Pilgrim (2005) among others.

Some of the other issues are staff attitudes towards service-users in SUI forums (Bennetts *et al* 2011; Barnes and Bowl 2001; Bowl 1996; Crawford *et al* 2003; Lewis 2009; McDaid 2009; Rutter *et al* 2004). Staff training in preparation for SUI is identified as a need by some (including Croft and Beresford 1995; Eastman 1995; McDaid 2009; Rose 2003) but with far less frequency than those identifying the need for user training. McDaid (2009, p.463) asserted that obstacles to SUI are more fundamental than a perceived need for improved ‘capacity and competency’ of the service-user and a requirement for better communication between professionals and users; an important obstacle is that professionals have been demonstrated to: “lack not just an understanding of service-users’ views but a willingness to listen.” Cowden and Singh (2007) used the metaphor of the ‘pause button’ being pressed as service-users speak at meetings, until the serious business of the meeting is resumed. Weinstein (2010, p.139) writing with a group of service-users, Southwark MIND council members, on their experiences of three different cases of local SUI, observed that even though they believed the local Trust was one of the more ‘progressive’ Trusts in terms of supporting SUI: “there remain significant cultural, financial and political barriers to be overcome before service-users feel they can really make a difference on the important decisions.”
Bowl (1996) documented clearly, in a wide ranging survey of SUI activities throughout the UK in the early 1990s, the obstacles encountered by service-users and staff to meaningful involvement. Training and preparation, including opportunities for users to see what other groups had achieved, were determined as being very important to inform and inspire service-users. In one example, outside trainers were brought in to facilitate staff and users separately to identify their key issues around involvement. Staff concerns were about power-sharing and the conflicting expectations of controlling service-users and empowering them. Users identified the need for training, self-advocacy, group development, assertiveness and committee skills. The support of service management was critical, but also the attitudes and actions of staff. Staff could be genuinely helpful, or controlling and restrictive of the agendas of user groups, albeit unwittingly at times. Preparation was determined as critical to allow for adequate involvement at meetings. This meant key support and dedicated time from an identified staff member who would go through the agenda and previous minutes, explaining the role of the committee and expectations for the service-user role. Time and support was also needed to allow the service-users consult with their peers, and to debrief after meetings.

One of the cultural barriers to participation is the lack of attention paid to the ‘affective dimension’ (Barnes 2008; Church 1996; Church and Reville 1988; McDaid 2009). Church (1996) asserted that consumer participation is never unemotional and is about the re-distribution of power. She described how bureaucratic procedures were unsettled by the presence of survivors, who insisted in having the lived experiences of service-users heard by bureaucrats writing legislation. The officials found this difficult and referred to the style of engagement by survivors as ‘bad manners’. This discursive labelling, Church (1996) demonstrated, was a response to disruption of dry, officious, unemotional processes of business-as-usual by the officials.

One of the first areas of contention was over payment of expenses to the survivors; which was a fraught experience for the officials, because of the inflexibility of the bureaucratic system, and also having to deal with the anger of the survivors at what they experienced as exclusionary processes. However, the more emotional and affective dimension to the officials’ work occurred when
they listened to the stories of service-users at the public consultations. Serviceproviders spoke of decentralisation, local authority, mandates, funding mechanisms, professional autonomy. Service-users talked:

about hate, prejudice, poverty; about self-help, capacity and power; about loss, suffering, struggle. They asked to be included. They paid tribute to each other. Some of them cried or were openly angry about the quality of their lives. (Church 1996, pp.33-34).

The official report on the hearings concluded that people experienced a double trauma; that of the illness and the subsequent treatment by services. The survivor participants found the professional committee members: “too system-focused, too protective of the system” (Church 1996, p.38). For the officials, the process of SUI: “engendered conflict. It was confusing, unexpected, perhaps frightening.” She argued that “emotion was the deep-structure of power” (Church 1996, p.38). Church (1996) observed that most of the respondents, the bureaucrats especially, had nowhere to go with their unresolved feelings about the process, because of the privileging of a code of professional etiquette which defines emotional expression as irrational. Church cited Lyman (1981) as she constructed a code of implicit etiquette for service-users around SUI: “Don’t give offence. Don’t be unpleasant or adversarial. Don’t complain or fight. Be nice. Be reasonable. Be considerate. Be cooperative” (Church 1996, p.38). When SUI did not operate according to these unspoken rules, officials or professionals became uncomfortable, upset and/or angry. Breaches of these codes were deemed ‘bad manners’. On the contrary, for survivors, ‘bad manners’ manifested in the professional attempts to deny the reality of the lived experiences of people’s lives and circumstances, and an attempt to marshal their realities into the confines of the terms of references established for the committee. Church (1996) concluded, like other researchers (Barnes 2008; Lewis 2010; McDaid 2009; Wadsworth and Epstein 1998) by observing the need for SUI processes to allow space for emotional expression, to reflect the highly charged feelings that can surround the double trauma of using MHS, which motivate many service-users to engage with SUI. I would argue that SUI itself can be experienced as a third trauma, under the current conditions of participation. I will return to this argument.
Access to resources is arguably one of the most tangible and material barriers to SUI. Many writers (Beresford 2010a; Chamberlin 2005; Church 1996; McDaid 2009; Stickley 2006) highlight the precarious nature of funding for service-user-led SMOs, and for SUI in research (Beresford 2000; 2005; Sweeney et al 2009; Wallcraft et al 2009). There are differing views as to whether SUI should be rewarded financially, as some service-users do not want or demand payment (Lebia 2010; Delman and Lincoln 2009), especially as it is likely to be tokenistic in the absence of official structures for reimbursement. For many, a sense of ‘giving something back’ is sufficient (Lebia 2010). Also, payment of a gratuity could affect social welfare payments (McDaid 2009). However, for the service-user movement generally, payment is considered to be a matter of principle (Chamberlin 2005; Wallcraft et al 2003; Sweeney et al 2009; Read 1996).

Ryan and Brambler (2002) report on a survey of policy and practices of paying service-users and carers for participation throughout one NHS region in the UK. Some of the practical issues that emerged include: varying, ad hoc local policies causing different expectations, and indeed embarrassment over payment on part of participants and service-providers; bureaucratic and budgetary obstacles, not least a fear by some managers that agreeing on certain minimum rates of recompense without budget allocations would make SUI ‘too expensive’ therefore reduce SUI. There were few written guidelines on payment for expenses or time in the organisations surveyed, even though SUI had been in vogue since the 1980s. Unwritten custom and practice had a tendency to sometimes create misunderstandings, discrepancies and conflict between those making payments and those expecting them. This can send out negative messages, devaluing to those participating. The authors conclude that, although this is a complex area, service-users are likely to be ambivalent about SUI in the absence of clear agreements about how their expenses and time are recompensed.

**Irish Experience of SUI**

Speed (2002) conducted a critical discourse analysis of general literature by mental health social movement organizations (SMOs) in Ireland, plus detailed
consideration of Department of Health documents\(^\text{15}\) (1984; 1994; 1998). He argues that the Irish mental health field offered no challenge to psychiatric hegemony, resulting from the lack of an organized user-led movement (Speed 2002, p.77). He also observes 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), which regards the Government’s neglect of the MHS as a failure to provide for the human rights of mental health service-users. There has been an active campaign by AI to lobby for improvements since 2003 (Amnesty 2003; 2006a).\(^\text{16}\)

McDaid (2009) conducted participatory action research on SUI within the context of an Irish mental health NGO, and interviewed 20 Irish service-users and movement activists. She applies the Equality of Condition framework (Baker *et al* 2004), as a mechanism to identify the full range of structural obstacles faced by service-users engaged in decision-making. This framework prioritises creating more equal power relations in society, identifying four different dimensions of inequality: power; respect and recognition; resources; and ‘love care and solidarity’ (Baker *et al* 2004). 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 in detail in the following chapter.

**Irish Service-User SMOs**

Since Speed’s (2002) analysis, there is now an emergent service-user movement in Ireland. The Irish Advocacy Network (IAN) has emerged as a strong presence in the field of mental health in Ireland. It is an island-wide


\(^{16}\) Amnesty campaign focused on three main objectives: To review the Mental Health Act 2001 against human rights principles; to lobby for legislation to drive reform of MHS and to promote greater cross departmental working at government level on issues of concern for users lives. See [http://www.amnesty.ie/mentalhealth](http://www.amnesty.ie/mentalhealth) for more information.
service-user-run SMO formed in 1999, contracted by the HSE 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 of the Republic. In Northern Ireland, IAN provides peer-advocates in the community working independently alongside community MHS. In addition, other more radical voices such as Mad Pride Ireland, Mind Freedom Ireland (small in numbers but very active with significant links with their international counterparts) and Critical Voices Network have emerged over the past decade to create spaces of resistance to psychiatric hegemony (Sapouna 2012). There has also been the establishment of an ‘official voice’ for service-users and carers - the National Service User Executive. It is described in more detail because it is not solely user-run and occupies an ambivalent position within the user-movement as it is a deliberative structure, as described by Beresford (2010a).

**National Service User Executive**

The National Service User Executive (NSUE) was claimed as one of the earliest achievements of Vision for Change (2006). Service-users and carers, in a ratio of three to one, 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. 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 2010a; Chambers 1997; Kirby and Murphy 2009, pp.143-4; Young 2000). The amalgamation of the service-user and carer voice has not helped.

Heenan (2009, p.459) claimed that the establishment of the NSUE was a move forward in terms of developing the service-user perspective on the MHS, by ensuring that service-users are “at the epicentre of developments, using their insights and knowledge to shape the direction of policy and practice”. However, 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 imposed representative body (Lakeman et al 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’ (National Service User Executive 2010; 2011; 2012). The last survey has incorporated some more nuanced qualitative accounts of satisfaction, and lack of same, with the MHS. On the basis of these surveys the NSUE has established annual awards for the best performing MHS.

**Summary**

This chapter has reviewed both theoretical and empirical literature on the definition of service-user and of SUI. Engagement with healthcare agencies is the form of SUI which the MHS recognise whereas for service-users it includes activities that occur in separate public spaces such as campaigning and political advocacy. SUI was defined for this study as the participation by mental health service-users, either individually or collectively, with the statutory MHS in service planning and evaluation, policy development, MHS research, education of professionals, and providing advocacy support to other users. It includes the individual service-user having control over their own care and treatment decisions.

The theoretical literature I reviewed considers the differing ideologies influencing SUI. One imperative is a top-down, policy-led, neoliberal ‘consumerist’ approach which determines how and when and which service-users become involved. The other driver of SUI is a bottom-up, civil rights inspired, democratic approach which favours ‘user-led’ and ‘user-controlled’ services (Beresford 2002; 2003). SUI in the literature is presented as a continuum between consultation, contribution, collaboration and control, where the critical aspect is control over decision-making (Sweeney and Morgan 2009). Examples of these different approaches appear in the literature on SUI in education of professionals and in research. Literature on the benefits and drawbacks of different forms of SUI is reviewed. Several unproblematised concepts associated with SUI are presented which are sources of pivotal struggle for service-users:
the power imbalances between service-users and service-providers, hegemony as a means of subtle and invisible power, the appropriation of the dissenting voice, and whether emotions and personal experience are acceptable forms of knowledge. Structural barriers to SUI were found to include a culture within the MHS which is resistant to change, obstructive and/or patronising staff attitudes, a significant gap between rhetoric and practice, lack of resources to support SUI and a culture which does not allow for emotional expression.

Finally, the chapter concludes with a brief review of Irish studies of SUI (McDaid 2009; Speed 2002) and a brief description of Irish user-controlled SMOs. All of the literature reviewed indicates that the official Irish MHS rationale for SUI must be problematised and underlying assumptions about power and conditions of participation must be addressed before meaningful SUI is possible. This chapter highlights the necessity to critically examine what is developing around SUI in an Irish context.
Chapter Three:

Power and Recognition

Dynamics
Chapter Three: Power and Recognition Dynamics

Given the tensions around the process and agenda of SUI that emerged in the literature review in the previous chapter, power dynamics are a significant component of SUI. Power dynamics are ubiquitous throughout the MHS, in the construction of knowledge, hierarchical structures, inter-professional status and relationships between service-users and service-providers. This chapter explores various theoretical accounts of how power manifests within the MHS, and impacts on SUI, and outlines a theoretical framework, Gaventa’s (2006) power cube, which informs my analysis of the power dynamics occurring within the practices of SUI. This conceptual model is adapted for mental health SUI and presented as a potential social movement tool to unpack the dynamics of participation.

Fraser’s (1997; 2000; 2004; 2007) social justice concept of the politics of recognition, and Lewis’ (2009; 2010) adaption of this theory to SUI, is presented as a subsidiary explanatory framework. The chapter review will start with an overview of literature on health social movements, then discuss conditions for parity of participation and conclude on the topic of power.

Health Social Movements

There is a body of academic literature which describes the history of the US and UK user-movements in terms of new social movement theory (Crossley 2006; Rogers and Pilgrim 1991; Tomes 2006). A recent development in this scholarship, relevant to my thesis, is the emergence of health social movement (HSM) literature. Brown and Zavetoski (2004, p.679) define HSMs as: “collective challenges to medical policy, public health policy and politics, belief systems, research and practice, which include an array of formal and informal organisations, supporters, networks of cooperation and media.” This challenge is categorised under three broad domains; access to health care, the illness experience, including illness contestation, and health inequalities.

Health access movements seek equitable access and improved provision of health care services (Brown and Zavetoski 2004, p.685). Constituency-based
HSMs address health inequities based on race, ethnicity, gender, class, sexuality differences and address disproportionate outcomes and oversight by the scientific community and/or weak science (Brown and Zavetoski 2004, p.686). The third type of HSMs, embodied health movements, (EHMs) are of particular interest in conceptualising the survivor/user-movement. These address disease, disability or illness experience by challenging science on aetiology, diagnosis, treatment and prevention. EHMs include ‘contested illnesses’ that are either unexplained by current medical knowledge or have environmental explanations that are often disputed (Brown and Zavetoski 2004, p.685). EHMs have three unique features: 1) they introduce the biological body to social movements, especially with regard to the embodied experience of people with the condition or disease; 2) they typically challenge and/or reject existing medical/scientific knowledge and practice; and 3) they often involve activists collaborating with scientists and health professionals in pursuing treatment, prevention, research and expanded funding (Brown et al 2004, p.50). Brown et al (2004) characterise radical elements of the ‘psychiatric survivors’ movement as an EMH because: “they resist traditional psychiatry, eschew reform approaches and oppose the very idea that they have (or have had) mental illness” (Brown et al 2004, p.53).

The embodied nature of EHMs develops from a personal awareness and understanding of an ‘illness experience’ which represents: “the intersection of social constructions of illness and the personal illness experience” (Brown et al 2004, p.55). Drawing on the work of Poletta and Jasper (2001) and Charmaz (1991), Brown et al (2004, p.60) describe a collective illness identity as a “cognitive, moral, and emotional connection” with a community of people experiencing the same illness, which may result in, for instance, peer-support groups. The ‘politicised collective illness identity’ develops through switching the focus to a wider social analysis that considers structural inequalities and the uneven distribution of social power as responsible for the causes and/or triggers of ill-health, transforming health issues from a personal trouble into a social problem (Brown et al 2004, p.61).

Brown et al (2004) explain the diversity within movements in terms of the goals and strategies social movement organisations (SMOs) pursue. They propose a strategy and agenda continuum. At one end of the continuum are
advocacy-oriented SMOs, i.e. groups that work within the existing system and biomedical model, use tactics other than direct, disruptive action (e.g. education), and tend not to push for lay knowledge to be inserted into expert knowledge systems. They position activist-oriented groups at the other end of the continuum who engage in direct action, challenge current scientific and medical paradigms, and pursue democratic participation in scientific or policy knowledge production by working largely outside the system (Brown et al 2004, p.51).

HSMs leverage medical science and public health to marshal resources, conduct research, and produce their own scientific knowledge, in order to influence policy direction and research agendas (Brown and Zavetoski 2004). Hess (2004; 2004a) has described the epistemic politics that play out in the contestation of research agendas and knowledge development in health fields such as environmental activism and cancer in the USA. The new knowledge acquired by HSM activists challenges the medical scientific community, who respond to alternative agendas by one of three defence mechanisms: denying the scientific credibility of alternative framing of traditional areas of concern, attacking the credentials of those scientists researching new or competing ideas or incorporating new areas of concern into traditional research agendas.

The cooperation of movement activists has consequences within the HSMs, because as activists acquire expertise or develop negotiated common concerns with scientific elites, movements can divide between an insider, compromise-oriented wing and an outsider wing that proposes more radical solutions (Hess 2004a, pp.424-425). These are some of the epistemological politics and social movement tensions operating in SUI. The next conceptual framework examines the politics of recognition occurring within SUI practices.

Parity of Participation

Fraser (1990; 1997; 2000; 2004; 2007), a feminist moral philosopher, has long argued for a dual approach to social justice, incorporating cultural justice (which includes recognition and equal respect for marginalised groups) and re-distributive justice (which moves beyond formal theories of justice). She explains the lack of recognition of marginalised groups as cultural injustice, symbolic in character: “rooted in social patterns of representation, interpretation
and communication” (Fraser 1997, pp.13-14). She describes how cultural domination subjects disadvantaged and minority groups to patterns of interpretation and communication of another culture which is hostile to one’s own. Non-recognition is shown to be a means of making a marginalised culture invisible by authoritative representation or interpretation by the dominant culture. She explains disrespect as a form of routine disparagement in stereotypical images and/or everyday interactions (Fraser 1997).

The hegemonic understanding of bio-psychiatry is an example of cultural domination in the area of service-user/survivor oppositional discourses, as the paradigm of bio-psychiatry denies recognition of the experiential knowledge of survivors, and the significance of the many social determinants of psychosocial health. Non-recognition in relation to SUI occurs through discounting the credibility of service-users, termed ‘psychiatric disqualification’ by Lindow (1995). Disrespect flows from the stereotyping associated with the status of being a service-user. The guiding principle of social justice, Fraser argues, must be parity of participation, which allows all participants: “to interact with one another as peers” (italics in original, Fraser 2004, p.127). Two conditions, at least, are necessary for this to occur. Firstly, addressing the social and economic structures that: “institutionalize deprivation, exploitation, and gross disparities in wealth, income, and leisure time, which prevent some people from participating as full partners in social interaction”. Secondly, addressing the: “institutionalized value patterns that systematically depreciate some categories of people and the qualities associated with them” (Fraser 2004, pp.127-128). Both forms of injustice must be addressed to achieve participatory parity. If people are constituted as peers, then their interactions are those of “reciprocal recognition and status equality” (2004, p.129 italics in original).

17 Kemper and Collins (1990) and Rossel and Collins (2001) explain interaction rituals in micro-level conflict theory. Power and status are two dimensions within rituals, which explain the resources that can emerge from interactions. Power rituals are defined as ‘interactions in which one person can make another person display a certain kind of behaviour’, while status rituals are ‘characterised by voluntary recognition and sympathy, thus by a formally egalitarian relationship between two people’ (Rossel and Collins 2001, p.519). However, micro-level conflict theory’s focus on interaction rituals within commercial markets, networks and organisations renders it less appealing than the social justice focus on recognition and redistribution of Fraser’s framework employed in this thesis. Gaventa’s (2006) power cube shifts the focus from personal characteristics and individual levels of power-over towards structural power imbalances operating in hidden and invisible forms of power.
“Parity-impeding values” (Fraser 2000, p.114) manifest in different ways: misrecognition may be institutionalised; in legalisation (anti-gay laws for instance), through government policies (e.g. failure to ensure equal access for people with disabilities), administrative codes or professional practice (e.g. non-family friendly work hours), or operate informally through social networks, customs or habitual social practices of civil society. These processes of misrecognition have echoes with Bourdieuian mechanisms of capitals which privilege those who already have recognition and social status. Mal-distribution also impedes participation because injustices here stem from: “economic structures, property regimes or labour markets [which] deprive actors of the resources needed for full participation” (Fraser 2000, p.117). Therefore a cycle of subordination maintains the exclusion. Discussion of Fraser’s theoretical remedies for mal-distribution injustices, which hinder equal participation, is beyond the scope of this review, but essentially take two ideal forms, redistributive and transformative. Transformative remedies for mal-distribution would involve socialist-type interventions on an economic level, and for misrecognition would include deconstruction of the conditions which devalue some identities and privilege others, work that is fundamental to the recognition of service-users engaged in SUI. She has discussed the relationships and complexities of such restorative dimensions at length and ultimately adopts a pragmatic resolution, “nonreformist reform” (Fraser 2004, p.136) that is, working with what is possible under re-distributive paradigms, while always keeping the transformative potential of such work to the fore. Fraser’s work has drawn much critical and philosophical debate (see Fraser and Honneth 2003; Fraser and Naples 2004; Yar 2001; Young 1997). Of particular interest to this thesis is how Fraser’s theory of social justice based on parity of participation and recognition has been applied to SUI by Lewis (2009).

Lewis (2009) explored the outcomes of SUI in Scotland, based on interviews with members of three service-user groups, employing a feminist critical discourse analysis of the interview data. She applied recognition theory as a key conceptual component in understanding the politics of SUI. In spite of official policies which espouse the value of participation and democratisation of service relations, service-users participating in her study experienced a failure of
recognition. Lewis (2009, p.258 citing Fraser 2000; Lister 2004; 2007) defined a politics of recognition as aiming to see and value: “individuals, groups, identities, experiences, knowledges and expertise, (potential) contributions, humanity and personhood; upholding citizenship rights and affording people dignity and respect.” She developed Fraser’s (1997) three forms of misrecognition. Non-recognition refers to the invisibility of people who do not conform to dominant cultural norms; mis-recognition occurs when people are regarded as lacking value and inferior; disrespect occurs as people are maligned or disparaged in everyday interactions or representations.

Two dimensions to failures of recognition became the focus of symbolic struggle for service-users in her study: status subordination and psychiatric disqualification. The discourse and practices of SUI have competing and contradictory effects since they simultaneously undermine the status of users, while opening up spaces where hierarchical social relations are played out. Lewis (2009, p.264 citing Bourdieu 1992) examined how the: “injustice of misrecognition and internalised oppression” has consequences for status and self-esteem and results in symbolic violence.¹⁸ She highlighted how participants symbolically challenge and resist their ascribed status, and ‘psychiatric disqualification’ which denies social recognition for users. The MHS, Lewis (2009) argues, must both address status and identity issues in order to challenge hierarchical relations central to institutionalised power and inequality, and recognise the informative and educational capacities and role of service-user

¹⁸ Bourdieu (1986) described how the educational system replicates privilege. Some groups in society are privileged not just by economic resources but by additional advantages (cultural capital) which accrue to them by virtue of their education and social position, for example forms of knowledge, style of dress, speech or physical appearance. Forms of cultural capital determine social status and mark out those who do not possess them. For Bourdieu (1977, p.178) capital acts as a social relation within a system of exchange. Different forms of capital can be converted into symbolic capital, whereby they legitimate high status and authority. When those with high cultural and symbolic capitals engage with others with less cultural advantages, for instance when the law misrecognises the realities of those of lower status, the interactions can be experienced as symbolic violence, a form of cultural domination. Several writers (Crossley 2004; Lewis 2009; Speed 2002) have applied Bourdieu’s theory to the mental health field and to some extent I draw on this body of work. However, my research question focused on the politics of recognition and dynamics of participation in order to make the deep rooted structures of power available for examination by movement activists, which Gaventa’s (2006) power cube renders accessible. Bourdieu’s work draws heavily on the inter-relationship between capitals, habitus and field. In order to use his work effectively I would have needed to approach the mental health system as a specific field of action, whereas I took a case study approach to examine a specific instance of SUI implementation.
groups to effect changes in policy and practice. Institutionalised power is one of the core obstacles to parity of participation for service-users and will now be explored in detail in relation to both the hegemony of psychiatry and the dynamics of SUI.

**Power/Knowledge and SUI**

Gaventa and Cornwall (2008), in the context of participatory action research, utilise Lukes’ (1974; 2005) and Foucault’s theories of how power operates and knowledge is constructed to explain the exclusion of marginalised groups’ ways of knowing, explaining how simplistic dichotomies around power (them and us) fail to appreciate the mechanisms of power. These ideas are useful to examine psychiatric hegemony and the power dynamics of SUI.

Lukes (2005) proposed that power has three ‘faces’. The first face of power is ‘overt’:

[a] product of conflicts between actors to determine who wins and who loses on key, clearly recognised issues, in a relatively open system in which there are established decision-making arenas. … Little attention is paid in this view to whose voices or whose knowledge is represented in the decision-making process, nor on how forms of power affect the ways in which certain problems come to be framed (Gaventa and Cornwall 2008, p.173).

This continues to be a very prevalent, pluralist understanding of how power affects policy: that we live in an open society, where competing interests engage in informed debate to develop policy. However, Bachrach and Barritz (1970 cited in Lukes 2005 pp.6-7,20-25) describe a second face of power which is not about who wins and loses on key issues, but rather who and what is kept out of the discussion altogether. For instance, as Gaventa and Cornwall (2008) argue, scientific rules establish some knowledge as more valid than others and these rules are used to prioritise some perspectives and discredit the legitimacy of others. Thus, Gaventa and Cornwall (2008, p.174) argue that from the second dimension of power, empowerment through knowledge means not only: “challenging expertise with expertise but expanding who participates in the knowledge production process in the first place.”

Lukes (2005) pointed out that in addition to covert power over decision-making, the powerful also work to prevent conflict through influencing
consciousness and awareness of those who might have a grievance. Accordingly, control of knowledge is vital to the exercise of power. Gaventa and Cornwall (2008, p.174) refer to Entwistle’s (1979) argument that power can be described in ways that begin to resemble Gramscian notions of ‘hegemony’, and Freire’s (1981) ideas on the ways knowledge is internalised, to develop a ‘culture of silence’ among the oppressed. This latent power is Lukes’ (2005) third face of power. “Knowledge mechanisms such as socialisation, education, media, secrecy, information control and the shaping of political beliefs and ideologies all become important to the understanding of power and how it operates” (Gaventa and Cornwall 2008, p.174). Turning to Foucault’s idea of power as inherent in all social relations, as existing only through action, but pervasive through all spheres of life, Gaventa and Cornwall (2008) discuss how knowledge and power operate to create subjects. For Foucault, power works through discourses, institutions and practices that are productive of power effects, framing the bounds of possibility that govern action. Knowledge is power:

\[
\text{power and knowledge directly imply one another...there is no power relation without the correlative constitution of the field of knowledge, nor any knowledge that does not presuppose and constitution at the same time power relations (Foucault 1977 cited in Gaventa and Cornwell 2008, p.175).}
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They refer to the influence of Foucault’s description of architecture of institutions, (the Panopticon), the construction and reproduction of social mores as discourses, and the disciplining of the body itself in the creation of subjects. Gaventa and Cornwell (2008) also discuss work by Chambers (1997) who focused on domination in personal and interpersonal terms. Chambers outlines two categories or positions of power held by people: ‘uppers’ who occupy dominant positions and ‘lowers’ who have subordinate or weaker positions. For Chambers, power is fluid, fixed not in the person so much as the position held. He argued that the professions produce and reproduce hierarchies of knowledge and power. Thereby the professions become the agents of who knows best and who are best placed to make decisions. Thus the knowledge and realities of ‘uppers’ displaces and discredits the knowledge of ‘lowers’. Gaventa and Cornwell (2008) point out how this echoes Foucault’s description of ‘regimes of truth’ maintained through discourses, institutions and practices. Certainly the role
played by the psychiatric profession manifests ‘power-over’ in the mental health field, an issue returned to below.

Control of the agenda (hidden power) and what can and cannot be discussed during citizen participation forums has consequences for addressing structural inequalities. Gaventa and Cornwell (2008) explain that the process can be subtle, shaping certain understandings and voices into the policy process while excluding others. In such situations participation risks legitimating the status quo by: “reinforcing structural inequalities with a more participatory face” (Brock et al 2004 cited in Gaventa and Cornwell 2008, p.185). The need to be effective at the decision-making table also means that citizen activists quickly learn the language and idioms of the experts themselves, sometimes at the expense of having their social and political energy drawn away from mobilisation in their own spaces through protests or building movements of the constituencies (Mahmud 2005 cited in Gaventa and Cornwell 2008, p.185).

Gaventa and Cornwell (2008) conclude that knowledge is an important power resource both within and outside formal decision-making processes. They end with a plea for ‘cognitive justice’, which affirms the right of different systems of knowledge to exist as part of the dialogue with power (Gaventa and Cornwell 2008, p.186).

**Power and the Mental Health System**

Foucault (1971) traced the development of psychiatry through societies’ responses to madness, from the ‘great confinement’ in the asylums of the Nineteenth and Twentieth Centuries, which provided a site for medical practice to observe and categorise states of madness, and thereby outline a scientific basis for the approach of contemporary psychiatry, which has a predominantly biological basis to its understanding of mental distress. Thus psychiatry developed a strong power base in the area of social control of unreason and irrationality, becoming an arm of the state in governing people.

Foucault’s understanding of power is summarised by McDonnell et al (2009, p.98). They explain that he understood power not as the property of individuals, social groups (such as a dominant social class or institution) or the state. It is not held but exercised, and it is exercised not from a central point (e.g. the state) but
through a myriad of power relations that are networked in a capillary-like fashion throughout society. Power serves multiple social functions and its effects are not uniform. Nevertheless, power is all encompassing: while power relations shift, power is a force field from which we cannot escape or transcend. Finally, power is not simply repressive, either in the functions that it performs or its effects; power is also productive in terms of its practical effects in producing new objects of knowledge, new discourses, new practices and new modes of subjectivities (McDonnell et al 2009, p.98).

One important component of Foucault’s understanding of power is ‘disciplinary power’. McDonnell et al (2009, p.93) explain this as techniques used for: “controlling, regulating and managing bodies - in other words, a form of knowledge that is bound up with the production of knowledge and operationalised through the mechanism of surveillance”. Another important Foucauldian concept is that of ‘governmentality’. McDonnell et al (2009, p.96) define this as: “a specific form of modern regulatory power or a rationality of government, which conjoins ‘technologies of power’” (e.g. technologies of the surveillance associated with disciplinary power) and ‘technologies of the self’ (self-regulatory practices).

Foucault’s theories of power can offer an explanation for the operation of power at Lukes’ third dimension, latent power, according to Masterson and Owen (2006). They review how Foucault’s concept of a power/knowledge nexus explains the relationship between knowledge, ‘truth’ and power, which work together to control people within modern society by influencing how they think and conceptualise the world. Foucault considered all knowledge to be the effect of a specific regime of power where forms of knowledge constitute the social reality they describe and analyse. How disciplines construct and interpret reality becomes accepted as self-evident by the general population. This can clearly be traced through the development of bio-psychiatry, which according to many writers (Boyle 1996; 1999; 2013; Busfield 2001; McGowan et al 2009; Rogers and Pilgrim 2003; Walsh et al 2008) has such control over the discourses around mental illness that its theoretical assumptions are largely unquestioned. Whether one considers the diagnostic classifications themselves (Frances 2012; McLaren 2009; Read et al 2004), neuro-scientific hypotheses (Bracken 2012; Breggin
1993; Lynch 2001; McLaren 2007), or the reliance on psychotropic drugs as the only treatment for psychosocial distress (Busfield 2006; Moncrieff 2003; O’Donovan 2009; Whitaker 2010) the power of psychiatry means that its explanations and theoretical assumptions are considered to be the only legitimate, credible explanation. Thus, the authority of a psychiatrist yields great power. Foucault did not consider power as an interpersonal force, or indeed a coercive force, and so other theories are used to explain the interpersonal interactions between mental health practitioners and service-users. Power-over and power-to are recurring concepts used in explaining power in interpersonal relations.

**Power-over and Power-to**

Breeze and Repper (1998) provide a summary overview of literature on power in order to discuss their findings on how nurses and service-users experience struggles over control of the ‘difficult patient’ in MHS settings. They noted the confusion over different understandings of power. The first distinction they draw is between power-over and power-to. Drawing on Hokanson Hawks (1991), the authors define ‘power-over’ as the capacity to exert control, and ‘power-to’ as effectiveness (the ability to act effectively). They suggest that power-to can be understood in relation to nurses’ ability to provide care and skilful interventions and to give some control back to the patient, as distinct from imposing control over the ‘difficult’ patient (power-over).

Referring to Wrong (1995), Breeze and Repper (1998) point out the disagreements over whether social power is intentional or structural or both. Intentional power sees power as individual agency expressed behaviourally, whereas structural power is defined as: “an ongoing set of reproduced relations between different social groups” (Layder 1985 cited by Breeze and Repper 1998, p.1367). These social processes overlay and structure individual agency. Breeze and Repper discuss Lukes’ (1974) theory as an approach which can resolve some of the contradictions between agency versus structure in considering power-over dynamics. They outline Lukes’ three faces of power; overt, covert and latent, and go on to suggest that the so called ‘difficult patient’ might resist the latent power inscribed in defining her as mentally ill. In other words, a ‘difficult patient’ is
less likely to be controlled by latent power, because she resists the hegemony of mental illness (Breeze and Repper 1998, p.1309).

Empirical work in Sweden with staff treating suicidal patients also discusses professional relationships with service-users in terms of power-over and power-to (Talseth et al. 2004). Using Fromm’s (1973) theory, they explain power-to in terms of being able to accomplish things, which can translate in mental health work as the ability to be present with the person, to meet their pain and deal with it in a real connection. Power-over, a negative controlling response, is a response to not having a sense of power to help and so the service-provider responds by exercising power-over to protect their self-esteem. They point out that by relying on power-over in care situations, the professional: “is in danger of becoming dehumanised, which means the absence of any kindness or friendliness to any human being.” (Talseth et al. 2004, p.278). They go on to refer to Marcel’s (1963) observation that to become dehumanised is associated with losing the ability to be reflective, with the consequent risk of becoming enslaved to routines and not able to relate to others as unique human beings requiring dignity and respect. This suggests that service-providers who can move from interacting with service-users in overly controlling, power-over relationships to more humane power-to interactions also gain personally (Talseth et al. 2004).

Tew (2005) approaches power from a different vantage point, to explain the links between power and powerlessness, and how structural oppressions, such as racism or gendered trauma, impact on people and contribute to mental distress. Tew links Weber’s (1968, p.1111) definition: “the capacity of an individual to realise his will” to ‘power-to’, and argues that power-to relates more to privileged groups in society, such as white, upper-middle class males. Tew (2005, p.73 citing Dominelli 2002) points out how people in dominant positions in society can set up ‘them-us’ distinctions and “label ‘others’ as inferior and legitimate the exercise of power over them” (italics in original). Such power-over can be a “form of systematic oppression, exploitation or exclusion from dominant modes of social participation” (Tew 2005, p.73). Tew explains that resistance to such power-over is possible through networks of mutual support and co-operation, which he referred to as ‘power together’ (italics in original). He also distinguishes between power as limiting or productive, referring to
Foucault’s concept of power as positive, as capable of producing new possibilities. From these concepts he develops a matrix (reproduced below) to conceptualise how these different aspects can interact with each other.

Tew (2005) discusses the sociological idea of deviance as oppressive power, where the imposition of a label such as: “nutter, mentally ill or schizophrenic” can define the whole person in both lay and professional discourses, and lead to disparagement and likely exclusion or withdrawal from society. He argues that these and other oppressive structural realities are one of the core mechanisms of the way oppressive power manifests in modern societies. This can lead to processes where people designated as ‘other’ are rejected and denied the opportunity to join the exclusive club. Such exclusionary processes may be overt or covert, employing social codes or markers to define who is in or out of the group. These processes can be justified or rationalised by: “constructing collusive ways of seeing which shift responsibility onto those who are victimised – defining inequalities as somehow natural or inevitable, resulting from the inherent inadequacies or wayward natures of those defined as ‘other’” (Tew 2005, p.77). On the other hand, when power operates in a progressive manner, power-over can be used to ‘shield’ people from potential abuse, exploitation or exclusion. Tew emphasises that protective power can guard against generating dependence by giving people space to develop their capacities (Tew 2005, p.79).

He discusses research by Barnes et al (2000) where a minority of people detained said it felt protective to be detained under mental health legislation. He concludes that any attempt by the MHS to operate this form of power-over must be reviewed in terms of all possible alternatives, including reforming legislation and providing other supports. He asserts that peoples’ wishes and preferences must be consulted in order to operate protective power.

In contrast, people can work together in forms of power-together. Cooperative power results from people coming together to resist the oppressive forces they may experience. Tew (2005) observes that this form of power underlies the success of social movements such as trade unionism, feminism, eco-warriors or Mad Pride. He suggests that a matrix of power, (reproduced in Table 1 below), can be useful to understand the processes involved in Recovery. Such a process would involve people moving from experiencing the limiting
forms of power associated with mental distress, both internalised self-stigmatising attitudes and/or manifesting in social and professional relationships, to experiencing nurturing and facilitative forms of protective power. This may then lead to opportunities to develop co-operative power relations with others. Tew does not naïvely suggest this is simple transition from positions of powerlessness and oppression. Rather it may be a gradual process of challenging limiting factors, involving both internal and external social structures (Tew 2005, p.86).

Table 1: Reproduced from Tew (2005, p.74)

<table>
<thead>
<tr>
<th>Productive modes of power</th>
<th>Power-Over</th>
<th>Power-together</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protective power</td>
<td>Deploying power in order to safeguard vulnerable people and their possibilities for advancement</td>
<td>Collective action, sharing, mutual support and challenge- through valuing commonality and difference</td>
</tr>
<tr>
<td>Co-operative power</td>
<td>Collective action, sharing, mutual support and challenge- through valuing commonality and difference</td>
<td>Banding together to exclude or suppress “otherness” whether internal or external</td>
</tr>
</tbody>
</table>

**Power-Over and Psychiatry**

One significant aspect of the powers attached to the profession of psychiatry is the invisible power to define the reality of psycho-social distress and the scope of their jurisdiction over controlling it (Bracken 2012; Masterson and Owen 2006; Walsh et al 2008). Psychiatric hegemony has critics external to the profession, but there are also internal debates and conflicts about the nature of madness and misery, and their origins in particular, details of which are beyond the scope of this thesis.¹⁹ In brief, whatever ground bio-psychosocial explanations had gained by the mid 20th century was lost completely in the turn towards biological determinism since the 1970s, propelled by the advent of neuroleptic drugs and the fruitless search for biological markers for mental

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¹⁹ Within the psychiatric profession itself there are a number of writers arguing for dismantling some of the power associated with psychiatry in terms of defining the understandings of mental distress (Bracken 2012; Bracken and Thomas 2005; Cohen and Timimi 2008; Double 2001; Frances 2012; McLaren 2010) and outlining the harms of the over-reliance on medication (Breggin 1993; Healy 2012; Moncrieff 2008).
illness. Rogers and Pilgrim (2005, p.144) examine the tension between psychiatry’s aspirations to be a respected medical speciality pronouncing valid claims to knowledge in its declared subject area, and the actual credibility of its claims, with both other medical colleagues and the growing social movement of disaffected service-users. There is no other branch of medicine that has such a strong oppositional movement (Lindow 1995). And yet, or in spite of this, the field of academic psychiatry is stronger than ever in its pronouncements of professional certainty. It claims the moral and legal authority to control madness and distress.

Rogers and Pilgrim (2003) outlined four consequences for service-users of psychiatric hegemony: “The power imbalance created by professional knowledge; medical dominance and ‘individualism’; normative knowledge and social control; and knowledge and status differentials” (Rogers and Pilgrim 2003, p.173). Knowledge and status differentials have been discussed in my earlier review of recognition theory and the power/knowledge nexus and will not be considered again.

People engaging with mental health professionals enter into an unequal relationship because of the knowledge differential. This is more pronounced in MHS than in other medical fields because in mental health it is a totalising effect. It is not a broken leg that the doctor is fixing, but the whole person is affected (Rogers and Pilgrim 2003, p.173). This is why receiving a psychiatric diagnosis is particularly disempowering, the whole person is declared under the remit of care. Even though there have been debates within psychiatry about the nature and epistemology of madness and distress, lay accounts are not welcome or incorporated into the explanations in the literature. On the rare occasions where subjective accounts are incorporated, they are overlaid and interpreted through the theoretical frameworks of the psychiatric approach. Even the most person-centred approach, that of Carl Rogers, entails the professional having a world view that the client is unknowingly shaped by (Rogers and Pilgrim 2003, p.174).

Medical explanations of madness and distress have predominantly focused on individual pathology. Rather than locating explanations in the social circumstances of individuals, such as poverty, poor housing, lack of social, educational, occupational opportunities, violence, racism, war etc, mental
distress is unquestioningly located in faulty brain functioning (Beresford 2009; 2010). Even though there is no scientific basis or backup in academic biology to these claims, they are repeatedly pronounced by leading academic psychiatrists and readily taken up by entrants to the profession who learn bio-determinism “by assumption”, as questioning and critical thinking is not generally encouraged in medical students, junior psychiatrists in particular (Rogers and Pilgrim 2003, p.176). This emphasis on the aetiology of mental distress completely disempowers the individual who will not be listened to about the stresses they experience in their social world. Rogers and Pilgrim (2003) note the resultant overwhelming preponderance of medical treatment by drugs in public mental health services in the UK, and the lack of availability of psychotherapy in everyday clinical practice, a concern frequently expressed by any commentary on the system in Ireland too (Amnesty 2003; Burke 2009; Hyde et al 2004; O’Donovan 2009; Quin and Redmond 2005).

The MHS police social deviancy, and produce conformity though an overt acceptance of the ‘sick role’ and treatments prescribed, and secondarily through the covert power invested by the state in the detention of the seriously disordered offenders, and the power to legally detain temporarily ‘insane’ people, and treat them against their will (Johnstone 2000; Pilgrim 2009). Professional interests, models and practices are privileged in MHS over and above lay knowledge. Although this may be sought out in evaluations of services and in managerial policies to incorporate the ‘user voice’, in practice lay knowledge is not highly valued, and has little real influence in shaping the direction of services, particularly in the face of overt or covert resistance from the dominant profession.

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, Masterson and Owen (2006) suggest such a discussion might be considered an equal
exercise of power at a covert level. The psychiatrist’s use of covert power limits the agenda to a ‘choice’ of different drugs rather than any consideration of alternatives to medication. Masterson and Owen (2006) link latent power to a Foucauldian understanding of power to shape the discourse within the MHS, to de-legitimise any possible understanding of psychosocial distress other than bio-psychiatric hegemony. The power to create the boundaries of acceptable understandings of psychosocial 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 with a psychiatric interpretation of their needs. Pilgrim (2005, p.25) pointed out that service-users engaging in SUI do so from the basis of acceptance that MHS 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 MHS are the most appropriate place for psycho-social distress to be treated or controlled. The taken-for-grantedness of MHS within society is another manifestation of invisible power.

**A Strategic Model of Power for SUI**

Gaventa (2006) suggests a three dimensional model of power based on the Rubik cube: the ‘power cube’ (Figure 2 below). Using this model, he explores how power interacts with marginalized or subaltern groups who participate in initiatives to include their voices. 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 SUI by the MHS (Campbell 2005). The lessons learnt from the experiences of participation by marginalized groups around the world can inform service-users engaging in participatory forums of the MHS; 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 problematise issues of power and participation experienced by service-users. There are three domains in the power cube: forms, spaces and levels of power. These are presented first and then applied to the MHS.
Gaventa (2006) proposes three forms of power, (visible, hidden and invisible) based on Lukes’ (1974, 2005) faces of power (overt, covert and latent). Visible power determines the agenda for participation, including the way decision-making forums operate, the rules and procedures adopted. It is concerned with 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 omitted from decision-making. 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. (VeneKlasen and Miller 2002 cited in Gaventa 2006, p.29).

The forms of power and their consequences for citizen participation, and SUI, were outlined in the theoretical discussion of power and knowledge earlier.
Moving to the next domain, Gaventa (2006) presents Cornwall’s (2002) ideas about the spaces that people occupy in relation to participation. She noted that metaphors for participation tended to be spacial: “opening-up, widening, broadening opportunities and deepening democratic processes for citizen participation” (Cornwall 2002, p.52). 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: “decisions are made by a set of actors behind closed doors, without any pretence of broadening the boundaries for inclusion” (Gaventa 2006, p.26). Invited spaces as: “those into which people (as users, citizens or beneficiaries) are invited to participate by various kinds of authorities” (Cornwall 2002 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 that citizens create to hold the powerful to account using various methodologies including human rights based approaches (McMillian 2009). Such spaces develop 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 discuss and strategise before or after formal

20 The public sphere is a core component of Habermas’ (1962) theory which he first outlined in a historical sociological account of the brief flourishing of bourgeois public spheres in Eighteenth Century Europe. These public spheres created a space for public deliberation in which rational discursive debate among enlightened citizens shaped political discourse. However, Fraser (1990) points out that Habermas’ public sphere did not admit marginalised groups, and so is exclusive in furthering the interests of privileged elites. Indeed, Fraser argues that Habermas’ historical public sphere describes a privileged male hegemonic space that valorised rational discourse. Moreover, she argues that Habermas’s theory of the public sphere continued to ‘bracket out’ the significance of gender and social class in terms of how the public sphere is structured and excludes. Fraser argues such inequalities require theorising. She suggests that marginalised groups establish “subaltern counterpublics” as “parallel discursive arenas where members of subordinated social groups invent and circulate counter-discourses to formulate oppositional interpretations of their identities, interests, and needs” (Fraser 1990, p. 67). Fraser (2013), while acknowledging the central importance of Habermas’ theoretical framework, continues to critique his theory as andocentric in failing to recognise the gender subtext of how women, primarily marginalised low income and single mothers, are constructed as ‘clients’ in welfare-state capitalism. ‘Welfare bureaucracies and therapeutocracies compound the disempowerment of [feminised] clients by pre-empting their capacities to interpret their own needs, experiences, and life-problems’ (Fraser 2013, p.44). Service-users are a marginalised group who also argue for the right to interpret their own experiences. Another fundamental constraint in Habermas’ applicability as a theorist in this thesis is his privileging of rational discourse (Habermas 1990, pp.43-115) which can be understood as a mechanism of control and power in the context of SUI within MHS (Church 1998).
participation with authorities. Soja (1996) has referred to these as ‘third spaces’ where people gather to reject hegemonic space (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 who normally operate 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 that 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. Originally Gaventa analysed power at global, national and local levels. I have adapted his framework to suit SUI by replacing these with strategic, operational and local levels of SUI. Baggott (2005, p.535) defines patient and public involvement in the NHS as being concerned with “decision-making domains”. These he classified, using the previous work of Charles and DeMaio (1993), into three different levels: macro-level policy planning, decisions about service planning and resources, and matters relating to individual treatment. McKinley and Yiannoullou (2012) refer to decision-making SUI occurring at individual, service and strategic levels. 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 SUI nationally (or internationally) in attempting to shape future development of MHS: shaping legislation, and national policies, staff recruitment and delivering training to professionals. It also includes the development of peer-support worker roles or peer-run services such as crisis houses. The next level of SUI is consultation about operational and functional
concerns: how the service is delivered. This may involve attending committees that are concerned with operational issues, and 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 MHS research on local services. At the individual level of involvement, service-users have concerns about decision-making in relation to their own care (Walsh et al 2008).

A model for power relating to SUI, based on Gaventa’s (2006) power cube would look like Figure 3 below. It is a model that is intuitively easy to understand but allows for the incredibly complex, messy processes of the real world of MHS and SUI. It may seem simple but as anyone knows who tried to re-align a disturbed Rubik 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 3: The power cube: adapted from Gaventa (2006, p.25) for SUI.**

![Power Cube Diagram](image)

**Summary**

This chapter considers three theoretical areas which have direct relevance to understanding social relations of power as they operate in SUI. I commenced with an overview of health social movement theory, as the user-movement can be characterised as an embodied health movement (EHM) (Brown et al 2004).
EHM processes include the development of a politicised, collective ‘illness’\textsuperscript{21} identity and epistemological politics, emergent features of SUI. The chapter then continued by outlining how both the politics of recognition (Fraser 1997) and the dynamics of power play out in participatory processes. Fraser’s (1997) work on social justice, about parity of participation, is especially relevant given the marginalised status of mental health service-users and the unequal spaces that they enter into in SUI initiatives, and is an important supplementary theory in the following empirical chapters. Power, in many guises, is a major factor in SUI spaces and so different understandings of power were examined, both theoretical and as applied to MHS. Finally a conceptual model, Gaventa’s (2006) power cube, was adapted and proposed as an analytical lens to examine participants’ understandings and experiences of SUI. These three theoretical areas are synthesised to explain the dynamics unfolding within the following empirical chapters. The next chapter explains how I set out to research SUI in an Irish context.

\textsuperscript{21}The fact that ‘mental illness’ is contested (and ultimately rejected) by many in the user-survivor movement does not negate its drawing power as the core identity around which collective experiences coalesce, which can subsequently become politicised. It is the experience of rejection of the condition that constitutes the user-movement as an embodied health movement (Brown \textit{et al} 2004).
Chapter Four:

Methodology
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Introduction

O'Hagan's (1996, p.46) notes from her diary and her medical file have been used by several authors (Bracken and Thomas 2008; Reaper and Perkins 2003) to illustrate the epistemological gap between the experience of service-users and people who work with them (Read and Reynolds 2003). A record from her diary reads:

Today I wanted to die. Everything was hurting. My body was screaming.
I saw the doctor. I said nothing. Now I feel terrible. Nothing seems
good and nothing good seems possible.

I'm stuck in this twilight mood
Where I go down
Like the setting sun
Into a lonely black hole
Where there is room for only one.

On the same day her hospital file recorded:

Flat. Lacking in motivation, and appetite good. Discussed aetiology.
Cont. LiCarb 250 mg qid. Levels next time.

This, and other personal accounts (various in Read and Reynolds 1996; Stastny and Lehmann 2007) demonstrate the epistemological gulf between traditional psychiatric interpretations of mental distress and that of the person experiencing the condition. We see traditional psychiatric discourse, the “orthodox biology of mental distress” (Johnstone 2000, p.211) juxtaposed with an eloquently poetic account of depression, an account that is far more evocative of the reality experienced by the person than the medical record. I believe standpoint theory is an appropriate approach to attempting to understand and theorise on the perspective of people who experience mental health problems. It is an epistemology that is sensitive to the position of the knower while questioning who determines what is knowledge.

This chapter outlines the theoretical approach underpinning this study, by positioning the research paradigm, the epistemology, ontology, and methodology employed in researching the question: how do service-users and service-
providers experience and understand service-user involvement (SUI), including the politics of recognition and power dynamics operating in SUI? It seeks to address the nature and scope of human knowledge as it applies to research and the research process, considering what kinds of knowledge are possible, the criteria for judging the adequacy of knowledge, and for distinguishing between scientific and non-scientific knowledge (Blaikie 2007, p.4).

Following the theoretical discussion, the practicalities of how this research was conducted are outlined. I explain the objectives of the study and how the research design addressed these. The sampling, data collection and analysis strategies employed are then discussed, followed by an account of the ethical issues raised by the research and how these were addressed. Finally, I clarify my position as a researcher with insider experience and describe and reflect on my fieldwork.

**Methodology**

Methodologies articulate philosophical assumptions, principles and stances on how to do research, which have processes that may be; empirical, systematic, theoretical, public, self-reflective and open-ended (Newman 2003). Letherby explains that:

> methodological thinking involves describing and analysing the methods used, evaluating their value, detailing the dilemmas their usage causes and exploring the relationship between the methods we use and how we use them, and the production and presentation of our data – our ‘findings’ (Letherby 2003, p.5).

She defines a method as a technique, a tool for doing research, for gathering evidence, for collecting data (Letherby 2003, p.5). Qualitative inquiry aims to understand the meaning of human activity as distinct from understanding the prevalence of the activity (Schwandt 2007). Denzin and Lincoln define qualitative research as:

> …a situated activity that locates the observer in the world. … This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them (Denzin and Lincoln 2005, p.3).

Qualitative methodologies are particularly appropriate to explain the context and experience of an issue such as SUI, which occurs in a context of highly
inequitable conditions of power, resources and recognition politics. One of the primary considerations in qualitative research is therefore to explain the nature of the social world being studied and how it is the researcher approaches understanding this world, the epistemological theory underpinning research. This research is guided by Feminist Standpoint Epistemology and the application of this theory to develop survivor standpoint epistemology. My methodological approach also derives from Feminist Standpoint Theory (FST) because, as Harding (2004, p.1) points out, FST is not just an explanatory theory but also offers a prescriptive theory of method to guide research. FST, among other critical theories, has influenced an emerging area of new research, which this study aims to contribute to, that of survivor research (Sweeny et al 2009, Wallcraft et al 2009).

**Standpoint Epistemology**

Stanley and Wise describe epistemology as a:

> framework or theory for specifying the constitution and generation of knowledge about the social world; that is, it concerns how to understand the nature of ‘reality’. A given epistemological framework specifies not only what ‘knowledge’ is and how to recognize it, but who are ‘knowers’ and by what means someone becomes one (Stanley and Wise 1993, p.188).

Letherby (2003, p.5) explains that: “thinking epistemologically involves a consideration of the relationship between the knower and the known, and the issues of epistemology relate to issues of ontology (being/the nature of things/that which is knowable).” Letherby (2003, pp.5-6 citing Kelly et al 1994), argues that research has been presented as: “orderly, coherent and clean: as hygienic” yet it is manifestly ideological, as no-one can separate themselves from their values and opinions and the influences which have shaped their experience and knowledge. Feminist research is not only open and transparent about the relationship of the researcher with the research but celebrates it. FST’s epistemology is based on the knowledge available from the knower’s experience and perspective.
Feminist Standpoint Epistemology

Feminist standpoint theory evolved as a feminist critical theory in the 1970s and 1980s from the work of Karl Marx who developed the proletariat’s perspective, using the Hegelian concept of master and slave to explain the condition of the working classes (Harding 2004). Hartstock (2004 cited in Harding 2004, p.2) argues that feminist researchers could use a Marxist approach by expanding it to include all human activity, not just the production of material goods. Standpoint epistemology begins with the assumption there is no universal, Archimedean vantage point from which to observe the world. Haraway (1988) critiques the claims of science to truth, exposing a doctrine of objectivity which promises transcendence, the “god’s eye view” (Haraway 1988, pp.86-89). She asks who is this see-er and where is this knower placed? This disembodied observer, who does not interact or engage with the world being studied, cannot exist; all beings are situated, and all knowledge is situated. Thus, standpoint epistemology is a situated knowledge. According to Haraway, situated knowledges are honest, embodied ways of knowing, offering embodied objectivity. This is the objectivity offered by the: “joining of partial views and halting voices into a collective subject position that promises a vision of the means of ongoing finite embodiment, of living within limits and contradictions, of views from somewhere” (Haraway 1988, p.90). For Haraway, knowledge is produced through a: “power-charged social relation of ‘conversation’” and found through: “situated conversation at every level of its articulation” (Haraway 1988, p.96). The god-trick Haraway describes, a detached, disembodied ‘relativism’: “a way of being nowhere while claiming to be everywhere” (Haraway 1988, p.89), permeates the field of psychiatry and its relation to psycho-social distress, in particular, its emphasis on ‘scientific’ diagnostic criteria which categorise mental distress into discrete illnesses (Frances 2012; McLaren 2010a; Walsh et al 2008).

Empirical observations and theoretical reflections can reveal the standpoint of any particular group, which Harding defines as an: “objective position in social relations as articulated through one or another theory or discourse” (Harding 2008, p.333). Harding (2008) highlights several important themes in standpoint approaches. Firstly, she points out that the activities of those at the top of social relations both organise and set limits on what the dominant or
privileged can understand about themselves and the world about them. But exploring the activities of those exploited by social hierarchies can provide starting points for research and scholarship that reveal otherwise hidden relations between social groups. The efforts of dominant groups to limit, avoid, devalue and silence critical questions are revealed in attempts to expose them (Harding 2008, p.334). Each group’s social situation enables and sets limits on what it can know. Standpoint epistemology puts the relationship between knowledge and politics to the centre as it attempts to explain the effects different kinds of political arrangements have on the production of knowledge. It claims all knowledge is socially situated and some social locations are better than others as starting points for knowledge. Therefore FST challenges some of the assumptions of the scientific worldview of how knowledge should be produced (Harding 2008, p.335).

Feminist epistemologies commonly challenge the orthodoxies of traditional research: objectivity, distance, hierarchies amongst knowers, androcentrism in research language, assumptions of universality, and uniqueness (Humphries et al 2000). FST is a: “critical theory about relations between the production of knowledge and practices of power” (Harding 2004, p.2). It offers a radically different starting point which challenges an approach to science that:

certifies as value-neutral, normal, and not political at all the existing scientific policies and practices through which powerful groups can gain the information and explanations they need to advance their priorities (Harding 1991, pp.568-569).

FST provides a remedy for inadequate, masculine science, exposing: “patriarchal institutions and ideologies as perverse inversions of more humane social relations” (Hartstock 2004, p.36). These orthodoxies are more likely to create advantages for dominant groups, such as privileged white males. Such positioning is: “scientifically and epistemologically disadvantaged…for generating knowledge” according to Harding (1991, p.43). Feminist standpoint theorists argue that women are an oppressed group and thereby have an epistemic privilege of having insight into the world of the oppressor, because they live in it, as well as experience being oppressed by it, which offers a valuable double advantage for different ways of understanding social relations. Mental health service-users are also an oppressed group (Croft and Beresford
and can use this privileged double perspective to uncover: “partial and distorted conceptual frameworks” (Harding 2008, p.333).

Harding (2008) makes the point that one cannot assume that knowledge emerges automatically from the marginalised perspective. The dominant discourses limit what everyone can see and can distort consciousness. “Marginalised experiences and what marginalised peoples say are crucial guides to the new questions that can be asked about … social relations” (Harding 2008, p.337). These questions arise out of the gap between marginalised experiences and the dominant conceptual schemes that organise social relations. The availability of competing discourses allows for people in dominant positions to adopt feminist standpoints; i.e. men can think as feminists, even if they are unable to avoid the privilege of being men, and people without the direct experience of using the MHS can conduct standpoint epistemologically informed research about the experiences of those who use services if they seek to listen and truly understand. Standpoint epistemology, therefore, is an ‘achievement’ rather than a natural ‘property’ of researchers (Harding 2008, p.337).

Standpoint epistemology has been accused of being an identity politics based on being a woman or black, an essentialist theory which reduces the differences between individuals’ experiences and circumstances. However, Harding (2004) asserts feminist standpoint epistemology is much bigger than an identity politics based on questions of where one comes from, but it may ask who one wants to be. It is bigger than being a member of an oppressed group, which in itself could be construed as an essentialist position. There is a wide church of opinion within the mental health service-user/survivor movement (Beresford 2010; Pilgrim 2009; Survivors History Group 2012), as in all social movements. But a common identity of having experienced the effects of a disempowering, de-personalising and excessively medically-orientated MHS is a unifying stance (Beresford 2010) which provides for the possibility of adopting a strategic essentialism (Spivak 1988).

22 This temporary tactic of essentialising and reducing the complexity of experiences and identities of people who have used/survived the MHS, while problematic, is used in the manner suggested by Spivak, as a means to understand the social structures against which individuals with common experience might unite (Kobayashi 1994).
By openly adopting a survivor standpoint, I position myself within the field as informed by this perspective, and thus seek the objectivity of this situated knowledge. The challenge in this research is to weave the perspectives of service-users and service-providers on SUI into an account that illuminates both perspectives, and creates an enriched understanding of SUI, informed by survivor epistemology.

**Survivor Epistemologies.**

Beresford and Wallcraft (1997) described the context in which survivor research was occurring in the UK. They identify factors such as unequal power relations with psychiatry, medicalisation of distress, a hostile political, media and social climate, and a lack of a coherent and agreed philosophy for the survivor movement.

Undertaking emancipatory research has been part of the survivor movement's project of survivors speaking and acting for themselves; improving their lives and liberating themselves from an oppressive psychiatric system; of changing and equalising relationships between research and research subjects, and developing survivors' own knowledge collectively. (Beresford and Wallcraft 1997, p.10)

Survivor research has challenged the medical paradigm in several ways: offering different explanations of distress, rejecting the concept of mental illness and psychiatric labels, offering social or spiritual models instead, naming some medical practices as abuse, or even torture. Survivor researchers address what it is that their research can articulate about knowledge, and how it is produced. Sweeney (2009, pp.32-33) reviews the perspective of three writers in particular: Rose (2004), Armes (2009) and Beresford (2003), identifying common themes and divergent approaches. The common principle they put forward is the experiential base of service-user knowledge of experiencing psychosocial distress or failures of the MHS, thereby challenging 'mainstream' knowledge (Sweeney 2009). All three writers explain this in terms of the relationship between power and knowledge. As the dominant paradigm, psychiatry privileges positivistic science which: “has the power to define the best methods to generate knowledge and thus define truth, whilst the knowledge of those with experience is dismissed as unscientific” and as such is devalued (Sweeney 2009, p.32). Rose (2009) uses feminist standpoint epistemology to argue that service-users
produce different knowledge from that of ‘mainstream’ researchers; having access to both professional and user discourses, they have more complete knowledge. Armes presents a social constructionist framework, arguing that perspectives are framed by discourses such as the medical model, so power belongs to psychiatry to assert their model as reality, rejecting service-user discourses (Armes 2009, pp.140-146). Beresford (2003) argues that people with experience need to re-claim and re-explore the value of firsthand experience as it is likely to be the most authentic knowledge, a position he continues to advocate (Beresford 2013). Other survivor researchers have built a substantial body of academic work articulating the contribution of survivor research (Campbell 2009; Faulkner 2004; Holland 2007; Lindow 2001; Staddon 2012; Wallcraft 2013) to name but a few.

**Ontology**

Scott and Marshall (2005) describe ontology as a way of understanding the world or any part of it including the implicit or explicit assumptions made about the nature and condition of beings in that world. Social worlds are: “interpretative nets woven by individuals and groups” (Scott and Marshall 2005, p.607). Constructivism is a broad ontology which generally agrees that human beings do not find or discover knowledge so much as construct or make it, inventing concepts, models and schemes to make sense of experience (Schwandt 2007, p.38). Social constructivism privileges: “the actor’s definition of the situation and seeks to understand how social actors recognize, produce, and reproduce social actions and how they come to share an intersubjective understanding of specific life circumstances” (Schwandt 2007, p.39). Thus, Schwandt (2007, p.40) points out that a social constructivist approach can explain how circumstances such as disability, mental illness, domestic violence, gender, family etc are: “culturally produced or can be unmasked as an ideology,” yet still be a real experience. Stanley and Wise (1993, p.222) assert that the ontologies of oppressed groups are forbidden and subversive, as these ontologies construct a narrative of everyday life that defines, explains and constructs group members whilst also attesting to internal differences.
My role in constructing and presenting the reality communicated to me by participants, and the choices I made in interpreting the data, are part of the power dynamics of research. The decisions I made were reviewed in a reflexive process of engagement through journaling and discussion with my supervisors and peer-mentors and made transparent to the reader. My standpoint as a survivor researcher informs my epistemology and ontology, and the problematizing of psychiatric hegemony and certainties, especially in relation to SUI. Thus, I use survivor standpoint epistemology to inform my methodological approach to this research.

The research design section explains how the study was designed. It includes an explanation of the case study methodology followed, the data collection and sampling considerations.

**Research Design**

My research question aims to explore some of the complex dynamics around power and the politics of participation occurring in the spaces of involvement, from the perspectives of both service-users and service-providers at a local site, and nationally. The aim is to provide insight into experiences of SUI and to advance understanding by studying an instance of SUI. Stake (2005) argues for the intrinsic value of studying cases for their own sake, rather than a step in theory building, so in this instance I approached the issue of SUI as it was occurring within one local MHS as a topic worthy of study in its own right. Following this stage of observation and in-depth interviews with local service-users and service-providers at the case study site, I triangulated these understandings and experiences by interviewing a national policy manager and activists within the wider Irish user/survivor-movement.

**Case Study Methodology: Site and Sample Selection**

Yin (2003, p.13) defines a case study as an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident. Yin maintains case studies are suitable for studying one or several individuals, as well as decisions, programmes, organisations, an implementation process, an industry or policy. Case studies have several distinct features, most notable of
which is consideration of a bounded system. There are several bounding constraints in the study, time (nine month period of data collection), geography (one local MHS) and meetings with SUI within the MHS itself. The problem under consideration, SUI and the context within which it is occurring, the wider MHS in Ireland, is outlined in Chapter One.

Creswell (2007, p.75) requires case selection to show “purposeful maximal sampling”. He suggests this means including cases to illustrate different perspectives of the problem to be studied. Opportunity to learn from the case is the most important criteria in selecting what to study. This criteria is more important than representativeness of the case, and so while the extent to which SUI is happening within the local MHS is not representative of the national picture, nevertheless it offers significant opportunities for learning from good practice.

**Service-User Sample: Local**

Due to my previous role in research and development with service-user groups in this region, I had established strong working relationships with many involved service-users/survivors. At the local research site people were approached directly as activists in their own right, rather than through HSE gatekeepers. Purposive sampling of involved service-users and peer-advocates with IAN in the area, and the training that was occurring when I entered the field led to snowball sampling which allowed me identify additional participants not already known to me.

**Service-Provider Sample**

The local MDT at the study site was purposively sampled because of their significant experience of implementing SUI initiatives. Permission was sought to engage in observation of the multi-disciplinary team (MDT) meetings not concerned with individual case management, which service-users (and carers) attended. All members of the MDT that I met through participant observation at meetings were requested to consider providing me with an interview. A manager in the national policy implementation office was approached as a key informant on overall national policy and practice in relation in SUI, and this interview was
included in the professional sample to triangulate with local practice perspectives.

**Service-User Sample: National**

My intended population, as with the local service-users, was those who use or have used the MHS and as a result have become activists and representatives of their peers. They are individuals who choose to engage in work, usually voluntary and often unrecognised and unrewarded, to improve conditions for all those who use MHS. The criteria for inclusion in the national sample were those who came through the user-movement as activists to take up the positions they now hold. Those who hold paid positions in SMOs but were not formerly involved as movement activists were excluded, as the ethos of survivor activism is a social change movement, not one influenced by professional culture. Therefore my peers in the user-movement involved with all of the user-led SMOs in the mental health field in Ireland were invited to partake in the research. Those I did not know from my prior involvement with IAN, NSUE and the Women Together Network 23, I met through my involvement with the Expert by Experience Advisory Group established in 2008 by Amnesty International Ireland to advise on their mental health campaign. 24

**Research Question**

My over-arching research question is how do participants understand, and what are their experiences, of SUI in Irish MHS? This is broken into sub-questions for each of the sample groups, and the detailed interview topic guides are contained in Appendix A. The research question was informed by the need to problematise an underlying assumption that SUI will lead to better MHS, a research topic which has received scant attention in an Irish context. In addition my own experience prompted additional sub-questions concerning how power imbalances and recognition issues were experienced. Understanding how SUI is experienced in an Irish context is especially relevant given the international literature available on decades of SUI initiatives in other jurisdictions (reviewed

23 This group no longer exists.
24 Amnesty Ireland’s campaign on mental health ran from June 2009 until May 2013. The Expert by Experience group continues to be the sole user-run independent forum for discursive debate and activism currently available for user/survivor movement activists in Ireland.
in Chapter Two), much of it highlighting critical concerns about the impact of SUI and about the risk that SUI can be subverted for varying agendas. Because SUI is a very new development in an Irish context, and because I sought to hear the breadth of participants’ experiences, the overall research question is necessarily broad.

**Service-User/Activist Perspective**

The research question was posed to service-user participants at the case study site, and to those with a national perspective. The issues explored with these two sample groups included:

- How do they understand SUI?
- How does this understanding support SUI practices?
- How and why did they get involved?
- What do they perceive as the benefits and challenges of SUI?
- How are power imbalances and the politics of recognition understood?

**Service-provider Perspective**

The service-providers are all employees of the HSE who work within the same local MHS, apart from one participant who was a top manager. The research questions with this sample sought to explore what SUI means for mental health professionals/service-providers given the context of the different philosophies informing practice.

- How do different health professional groups understand the concept of SUI?
- How does this understanding support SUI practices?
- How is it influencing service-provider attitudes and practice on the ground?
- What are the benefits and challenges for their practice?
- What are their understandings of the inherent power imbalances and politics of recognition?

**Piloting the Questions**

All of these questions formed the basis of interview topic guides (see Appendix A) although the interactions were not constrained rigidly to these
issues. As I sought a dialogic interaction, the issue of concern to participants informed the direction of the interviews. The topic guides were developed and piloted with three service-users and a service-provider, and amended following the pilot interviews. Three pilot interviews were carried out in October 2010 with key informants at the case study site, people who identified as service-user consultants. The data provided was so rich, thick and detailed, that it greatly informed the development and improvement of the topic guide for subsequent interviews with the service-user cohort. In addition, as the interviews were so rich, it was decided in discussion with my supervisors that they would be included for analysis as part of the data set with the consent of the participants.

**Data Collection**

Multiple sources of information: in-depth, semi-guided interviews, participant observation of meetings, available documents, and any other records of interest to the topic were used in the data collection stage to provide a detailed in-depth picture of the practices of SUI with the local MDT. The triangulation stage consisted of in-depth interviews with a top manager of MHS and experienced national user/survivor movement activists. There was no participant observation with the second group of participants.

**Observation of Meetings**

Although this study was not conceived as an ethnographical study, opportunities for observation of the local MDT meetings with SUI were sought at the case study site to understand and observe some of the beliefs, language, and behaviour of the MDT. Observation of such professional teams operating within the MHS can offer an opportunity for analysis of the ‘culture’ within the services, a term which Creswell (2007) uses to describe the patterns of the social world under observation and the potential tension between what people say and what they do. The fieldwork over six months at this site offered many opportunities to observe the interactions between service-users and providers at meetings and social encounters. These observations are outlined in the ethnographic summary in the account of fieldwork below. The primary method of data collection involved in-depth interviews to examine both service-provider and service-user perspectives on SUI.
In-depth, Semi-Guided Interviews

Interviews are particularly suited for studying people’s understanding of the meanings in their lived world, describing their experiences and self understanding and clarifying and elaborating their own perspective on their lived world. (Kvale 1996, p.105)

The interviews were in-depth and semi-guided in that a detailed interview guide was developed, but the direction of the interview followed the participant’s lead. A fruitful interview, according to Kvale and Brinkman (2009), results in: detailed rich data, with plenty of information and specifics; explores meaning, and the interviewee's interpretation; a broad range of topics are covered, addressing all the issues identified from the literature; it minimises bias but seeks commonalities in experience; it offers enough information to answer the research question. Kvale and Brinkman suggest seven features of such fruitful interviews: knowledge is “produced, relational, conversational, contextual, linguistic, narrative, and pragmatic” (Kvale and Brinkman 2009, p.53).

As a production site of knowledge, the interview is an opportunity for the actual creation of knowledge through questioning and answering; the dialogue engaged in by the interviewer and interviewee co-constructs knowledge. Kvale and Brinkman (2009) pointed out that qualitative interviews have the potential to produce descriptions and narratives of everyday experiences as well as the epistemic knowledge that emerges as part of the discursive feature of conversations; interviews produce knowledge which is contextual. They remind us of the interpersonal context, therefore the meanings ascribed to statements must refer to the context in which they emerged. This raises the necessity for thick, detailed and contextual descriptions of the settings in order for the reader to evaluate how the meanings generalise to other settings. People tell their stories within interviews, and these stories are the means by which people make sense of their lives and social realities. Storytelling is often a spontaneous means of describing and illustrating significant events in people's lives, and indeed it is a style of communication older than written records. The narrative can inform us of the human world of meanings (Kvale and Brinkman 2009).
Credibility and trustworthiness

Lather (1986) discusses several means to ensure research is trustworthy (she uses the term validity), including triangulation and construct integrity. She writes of the importance of rigor as well as relevance within research. In this study, triangulated data from multiple sources, methods, and theoretical schemes (Lather 1986) was considered a means to establish a chain of evidence (Yin 2003) as well as to clarify meaning and verify the repeatability of an interpretation or observation. The three sample groups provide triangulation, as the experiences of three different groups are compared. Additionally, a sample interview transcript was coded separately by myself and my supervisors to establish consistency of coding and interpretation. All transcripts were returned to participants to verify content, and some participants volunteered to read earlier versions of findings chapters for comment and member-checking. Construct validity refers to systematic, reflexive, interrogation of the theoretical tradition that the researcher is operating within, to consider how the logic of the data has changed the a priori theory (Lather 1986). This is an issue that emerged during the analysis stage when different frameworks were sought to present the emergent themes in the data.

Credibility of qualitative research findings is a concern discussed at length by Silverman (2001). The ten criteria for evaluating research agreed by the Medical Sociology Group of the BSA are reproduced in Table 2.

Table 2: Criteria for evaluating research reproduced from Silverman (2001, p.222)

1. Are the methods appropriate to the questions being asked?
2. Is the connection to an existing body of knowledge or theory clear?
3. Are there clear accounts of the criteria used for the selection of cases for study, and of the data collection and analysis?
4. Does the sensitivity of the records match the needs of the research question?
5. Was the data collection and record-keeping systematic?
6. Is reference made to accepted procedures for analysis?
7. How systematic is the analysis?
8. Is there adequate discussion of how themes, concepts and categories were derived from the data?
9. Is there adequate discussion of the evidence for and against the researcher’s arguments?
10. Is a clear distinction made between the data and its interpretation?

I believe that on the basis of these criteria my research is credible and trustworthy, as the methodology outlined above is transparent and appropriate,
with a clear account of case selection and participant sampling rationale. The research is based on a review of an existing body of knowledge and theory (Chapters Two and Three), answering a significant gap in the literature. The data collection was thorough, systematic and comprehensive, as the three sample groups provided a rich, detailed source of data. The semi-guided interviews allowed the participants to answer the research questions in their own fashion, so that they provided their own understanding of SUI from different perspectives. The analytical process followed the stages outlined later in this chapter, with examples illustrating how the themes, subthemes and categories are derived from the interview data. I believe that my explanation and interpretation of the evidence is transparent and thorough and considers different possible interpretations of my conclusions. My presentation of the data is separate and distinguishable from the discussion, which allows the reader to examine data on which I base my interpretations. The methodological framework applied to the data is transparent and logical, and aids in explaining the dynamics of SUI, from the perspectives of both service-user and service-provider participants.

**Ethical Considerations**

Edwards and Mauthner describe the necessity for the morally engaged researcher to pay constant attention to the specifics of the research context, responding and adapting reflexivity to the emergent ethical issues as they arise (Edwards and Mauthner 2002, pp.20-28). They define ethics as: “the moral deliberation, choice and accountability on the part of researchers throughout the research process” (Edwards and Mauthner 2002, p.14). Research ethics have evolved from the value-free positivism of JS Mills, through the value-neutral position of Weber, to codes of ethics enshrined as the gold standard of good research (Christians 2005). All ethical and professional codes which research must subscribe to have, at a minimum, the basic principles of informed consent, no deception, privacy and confidentiality and freedom from harm. These remain the basic elements of institutional review board application forms. I outlined a statement of ethical principles, adapted by permission from research work by Dr. Iris Elliott to ascertain the views of children of LGBT parents.\(^{25}\) This formed my

\(^{25}\) See Appendix B
framework to deal with the negotiation of informed consent, to address transparency, issues of confidentiality and privacy, and to ensure accuracy of data for participants both in interviews and observation of team meetings or group events. I submitted an application to the Faculty of Arts, Humanities and Social Sciences Research Ethics Committee addressing these basic requirements but also anticipating other ethical issues, and received approval for my research design (approval reference number FAHSS_REC225, see Appendix B).

There is a tendency in some research traditions to consider the hurdle of satisfying an ethics committee’s requirements to have addressed the ethical dimensions of research (Christians 2005). For feminist, and other egalitarian researchers including survivor researchers, the moral and ethical issues are inseparable from the research process (Faulkner 2004; Holland 2007). This requires an on-going evaluation of how the relationship between the researcher and the participants is negotiated in every encounter. Faulkner (2004) proposes eight principles underlying the ethical conduct of a survivor researcher: she must strive for clarity and transparency; seek to promote empowerment; be transparent regarding researcher identity; demonstrate a commitment to change; work respectfully; provide equal opportunities to all who participate; seek to provide a theoretical approach that explains the position of service-users; and finally be accountable to the community.

**Informed consent**

This issue, at the most basic level, requires that individuals partaking in research are fully informed, agree voluntarily, and are fully aware of the duration, methods, possible risks and purpose of the research. On the face of it, this appears self-evident, yet as Punch (1994, cited in Christians 2005, p.144) points out, unthinking adherence to this principle can stifle creativity and the opportunities which present in the field, if new unforeseen situations emerge. The issue of ensuring informed consent became problematic for me occasionally, especially at meetings when a newcomer would come in after the meeting had commenced. On those occasions I could only wait until after the meeting to introduce myself and the research, and retrospectively obtain their consent for my presence at the meeting. This was never an issue with the individuals in
question. On one occasion however, a very informative interview with a very different and challenging perspective on SUI within the local MHS had to be omitted from my analysis because the signed consent form was not returned to me, despite full cooperation from the participant during the interview itself. The participant waved away the missing consent form as unimportant, promising to send it to me afterwards. However, the individual was unavailable afterwards, so I reluctantly decided I could not include the interview in my analysis without it.

**Privacy and Confidentiality**

Ethical standards require that safeguards must be taken to protect people’s identities. Every effort was made to ensure people’s anonymity by removing any identifying markers, and having participants review their transcripts. Christians (2005, p.145) discusses the complexities and ambiguities around the protection of identity, particularly in relation to insiders recognising each other within the small community of people involved in the field. In a small community of mental health activists and reformers, identity is difficult to conceal, especially as I only interviewed professionals on one MDT. This became a significant issue in presenting the research findings, and many times material was not presented because it could have identified participants.

An additional issue with regard to securing information are the legal requirements under the Data Protection Act (1993), and all data held must comply with these requirements. This was addressed in my application for ethical approval (see Appendix B).26

**Protection from Harm**

Another important ethical principle is that of ‘non-maleficence’; the researcher must seek to avoid harm, e.g. undue stress, unwanted attention, loss of reputation, invasion of privacy, or minimise the potential for harm as much as possible. Sometimes research can lead to unintended consequences for

26 A more complex requirement is the idea of defining and discussing confidentiality within the research process. A guideline adopted by advocates working for the Irish Advocacy Network makes clear to people they work with that there can be times when it is not possible to maintain complete confidentiality. If the advocate becomes aware of a potential risk to the other, through that person expressing a desire to attempt suicide, or to harm another, they have a responsibility to bring that to the attention of an appropriate staff member. Therefore any promise made to research participants carries that caveat, which was discussed with them.
participants, resulting in a: “sense of frustration, alienation, potential exploitation” (Kirsch 2005, p.2163).

The principle of protection from harm is particularly relevant to the issue of research with mental health service-users, frequently designated a vulnerable group. Because of attitudes about the perceived vulnerability of people who have experienced psycho-social distress, ethics review boards have been experienced as patronising and paternalistic, especially in user-led research (Faulkner 2004; Holland 2007). When Holland (2007) presented her research proposal to interview volunteers about their self-understanding following encounters with MHS to her institutional review board, she found the response overly risk-focused and reflected: “a limited and overly passive and paternalistic view of people…who might wish to talk about their mental health experiences” (Holland 2007, p.901). Similarly, Faulkner (2004, pp.31-32) reported that service-user researchers believed that research ethics committees are more designed to protect vulnerable people than hear their voice. Davidson et al (2009, p.94) suggest that the most appropriate way to ensure the protection of the rights and interests of service-users is for them to become active members of research ethics committees.

**Research Relationship**

Power is a significant element of the research dynamics and relationships, and as such has received much attention by feminist scholars in particular. As power is such a pervasive feature of MHS relationships at all levels of the system, it will be considered here as it pertains to the research process, in particular, the researcher/participant relationship. Wolf points out that there are three kinds of power operating in the fieldwork research relationship: social (class, gender, race etc); power over knowledge and the research questions; and finally in writing up the research (Wolf 1996 p.2, cited in Harding and Norberg 2005, p.2012).

Fontana and Frey describe a concern of many traditional qualitative researchers when they write:

> Although a close rapport with the respondents opens the doors to more informed research, it may create problems in that the researcher may become a spokesperson for the group studied,
losing his or her distance and objectivity, or may ‘go native’ and become a member of the group and forgo his or her academic role. (Fontana and Frey 2005, p.708)

Of course egalitarian researchers critique this stance, observing as Heron (1981, p.19) does, that: “the inquiry is all on the side of the researcher, and the action being inquired on is all on the side of the subject.” This requires the researcher to be ever more conscious of the dynamics between the position and status of the researcher and researched, of disparities of differing social power and status, of privilege in defining research questions, selecting participants, and how findings are represented. From this standpoint, power is based on mutuality not sovereignty, and solidarity not antagonism (Christians 2005). Heron (1981) distinguishes between knowledge production that generates power-over and power shared with people; respectful research addresses both the generation and application of knowledge.

In anticipation of the ongoing ethical dimension of the research process I sought to create a “protective system” (Stake 2005, p.459). Reflexivity is defined by Frank (1997, p.87) as: “consciousness about being conscious, thinking about thinking”. She adds, citing Myerhof (1978), the challenge of reflexivity: “is not to eliminate ‘bias’ to be more neutral, but to use it as a focus for more intense insight” (Frank 1997, p.89). I found the best time to reflect on the ethical dimension of the research and writing process was on my morning woodland walks with my dog. I also kept a journal in which I recorded my ethical concerns about potential or actual ethical dilemmas. These were then discussed with my supervisors and a few trusted peer-mentors, fellow doctoral students, Dr Odette Clarke and Dr Iris Elliott in particular. This also provided a safeguard in examining the assumptions I brought to the research as result of my life history.

Hesse-Biber and Leavy (2006) discuss the insider/outsider issue and observe that insider status offers the researcher insight into the shared experience of the group. Oakley (1981 cited in Hesse-Biber and Leavy 2006, p.136) notes that sharing some of the status characteristics with respondents reduces the power and status imbalances in the interview situation. As a survivor researcher, I was an insider with two of the sample groups, which certainly helped me create a more equal relationship with the service-user/survivors participants. I was an outsider with the professional group and my experience interviewing the professionals
was more fraught. There was one interview especially which was daunting for me in that I felt slightly in awe of the professional with whom I had a previous relationship as recipient of the MHS. I was hesitant and cautious about how I approached sensitive issues such as the power attached to their role, vis-à-vis service-users. The participant could not have been more supportive, and my trepidation disappeared over the course of fieldwork.

Difference is an interesting aspect of the insider/outsider issue. Hessy-Biber and Leavy (2006, pp.138-139) discuss how with women respondents, female researchers will have commonalities but differences also. These differences can be significant, as no group is homogenous and neither is the user-movement. While I shared the experience of belonging to the user/survivor-movement, many differences are also present. Some obvious differences could be gender, class, education and my status as a doctoral researcher. Other less obvious, but important differences, were employment experience and the level of experience of SUI that different participants had, and their exposure to counter-hegemonic contestations of the MHS. One of the pitfalls of insider status I fell into was accepting ‘shared knowledge’ (Hessy-Biber and Leavy 2006, p.140) and not probing the participants for more detail about how they interpreted a shared experience.

**Account of Fieldwork**

I negotiated entry to the field by obtaining the co-operation of the consultant psychiatrist heading up the multi-disciplinary mental health team (MDT); my fieldwork was primarily located in the headquarters of this team. The fieldwork consisted of participant observation over a nine month period and semi-guided interviews with eight involved service-users, followed by eleven service-provider participants, of whom seven were members of the MDT. The MDT consisted of representatives of all the professional disciplines working in this sector team (the wider team consists of over 100 staff, mostly nursing professionals). The professionals on the MDT were very welcoming and supportive of my study, and

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27 This mental health multi-disciplinary team (MDT) will be referred to simply as the team in order to maintain anonymity. When I use the term MDT I am referring to this group of participants, who have regular meetings with SUI. When I refer to the larger, entire team I use the phrase ‘wider team’.

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made every effort to be facilitative and cooperative. Their base was a bright, modern building and service-users engaging with their SUI initiatives had full access to public space in this building, including the security code to the front door, the conference room where all the meetings and training occurred, and the kitchen. The kitchen, where people gathered before and after any meeting, was the main social space for all users of the building, including the staff. It was evident from observing the interactions in the tea-room that there was a good, amiable relationship between the involved service-users and the professionals on this MDT. Shortly after I engaged in the field, I was invited to a lunch arranged by members of the MDT to mark the contribution of a service-user who had decided to take time out from unpaid SUI activities. This was my first introduction to many of the professionals on the MDT and was a relaxed and comfortable event, with no discernible divisions apparent between service-users and service-providers. I also attended several meetings between the local advocacy group and members of the team.

**Meetings with SUI**

Service-user and carer participation was actively sought by members of this MDT for all team meetings with an operational or strategic agenda. Over a nine month period I attended 12 working meetings of this team (nine Stakeholder, two Research and Audit and one Steering Group meeting) as a participant observer. The Stakeholder meetings included two service-users, a peer-advocate and two carers; all regarded as equal members. The Research and Audit meeting had similar involvement. The membership of the Steering Group was very broad with links to the wider community, including nurse educators and employment support specialists in associated services, and also included SUI.

These meetings were chaired by the consultant psychiatrist or the social worker, who was the regular chair of the Stakeholders meeting. The primary objective of these meetings was organisational change and how interactions with service-users could be made more client-focused. Recovery was always the first item on the agenda, and meetings lasted about an hour. The Research and Audit

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28I did not attend any clinical meetings, although an invitation was extended to me. I confined my observation to meetings with SUI.
meetings were established towards the end of my period of fieldwork, and these also were of one hour duration, after the Stakeholder meeting. A summary of the range of meetings with the MDT which had regular SUI is provided in Table 3.

Table 3: The range and purpose of MDT meetings with SUI

<table>
<thead>
<tr>
<th>Meeting title</th>
<th>Stated Purpose</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stakeholders</td>
<td>Discuss and manage operational matters (e.g. plan training, seek funding for projects, “customer care issues”)</td>
<td>Fortnightly</td>
</tr>
<tr>
<td>Research and Audit</td>
<td>Plan, prepare submissions for funding Review ongoing research being conducted by the team</td>
<td>Monthly</td>
</tr>
<tr>
<td>Steering group</td>
<td>Advise on strategic goals for the team and maintain relationships with external partners</td>
<td>3 monthly</td>
</tr>
<tr>
<td>Meetings with local service-user groups</td>
<td>Develop team relationships with, consult with, and support local SUI</td>
<td>Ad hoc</td>
</tr>
</tbody>
</table>

There was a convivial atmosphere at the meetings, albeit task orientated and focused, and the service-users were active participants, frequently offering comments on topics under discussion. Two service-users appeared confident and outspoken, another was less forthcoming with opinions at meetings. They, (and the carers), were treated very respectfully and equally by all present.

Most of the meetings I attended had service-users and service-providers present. Service-user only meetings were the exception. One such was the training that was occurring as I entered the field (and one advocacy group meeting with many new people as I exited). The former was a four day capacity training course attended by ten service-users. The trainer was a peer-advocate, and the format consisted of presentation of material on Recovery concepts and peer-advocacy developed by the Irish Advocacy Network (IAN) for advocacy training, followed by group discussions. During one exercise they discussed at length how service-users framed psychosocial difficulties as opposed to the medical interpretation. People did not believe they had choices about medication or any other treatments; they described being told what to do by doctors, rather than having their acquired experience of staying well acknowledged. Another issue frequently mentioned was the power differential between themselves and
professionals and how important it was to change how the MHS treated service-users. One observation made was that even well-intentioned professionals did not realise the effect of their attitudes and behaviours on service-users. People spoke of the frustration with the slow pace of change in the MHS.

Professionals from the team came in for the last hour of the final three days. On the first occasion the occupational therapist (OT) gave some information about the structure and organisation of the local MHS, and the roles of different professionals. On the second day the consultant psychiatrist listened to service-users’ stories of neglect and abuses of power. He was challenged about sole reliance on medication and how the MHS controlled peoples’ access to doctors of their choice. The service-users appreciated an opportunity to be heard by someone in a position of authority, representing the profession for those present. (He, however, was clear he could not speak for other psychiatrists, merely give his own opinion.) Most of the people attending the training were under the care of other teams in the MHS. Their experience of being listened to by a consultant psychiatrist was obviously something new to most. It became obvious from later interviews that SUI practices were not occurring in the other seven mental health teams in the county. The same two professionals, the main leads on SUI on the MDT, attended on the final day. On the agenda was a discussion about how there could be more collaboration between service-users and the MDT. The professionals spoke about the value of SUI and extended an invitation to all present to become more involved at operational team meetings.

This was my first opportunity to observe how professionals on this team responded to challenges from service-users. My observations were that they listened carefully, acknowledged the rightful grievances expressed, outlined their own areas of responsibility, and suggested different problem-solving approaches focused towards the responsible areas of the HSE or MHS. There was a noticeably different dynamic within the room when the group was service-users only - the discussions were more free-flowing with a sense of equal time given and taken among those present. When the professionals were present everyone’s attention was focused towards the service-provider at the table.
During my fieldwork I also became aware of various operational supports provided locally for SUI. The local administrator (then recently retired) was a strong believer in the potential of SUI to make a difference within the MHS. He had used his power to allocate resources towards supporting SUI. Over the previous decade he had supported the development of peer advocacy, the formation of a local advocacy group and funded several capacity training courses for service-users (and carers), which helped create a pool of service-users with some preparedness for SUI. Funding for expenses and a small gratuity was made available for service-users attending meetings with the MHS.

**Method of Analysis**

Spencer *et al* 2003 describe the principles and processes of qualitative research analysis, with an emphasis on: “understanding and interpreting substantive meanings” (Spencer *et al* 2003, p.209). They address some issues which are relevant to provide an understanding of the way I approached the analysis.

Data can be considered as representing phenomena, whether that be feelings, perceptions, experiences, or events which exist independently. In this understanding, accuracy of the data is of primary importance, as is the analyst’s account. The data represents peoples’ experiences and understandings of the processes of SUI. The status accorded the data determines the focus of analysis. While some approaches do focus on the language and construction of speech, my focus is concerned with understanding and interpreting “common sense, substantive meanings” in the data (Spencer *et al* 2003, p.202). Qualitative data includes extensive interview transcripts, field notes, a research diary, and copious memos during analysis. Some method for reducing the data was essential. I used several strategies, such as coding, thematic summaries of content, developing an overview of the analytical categories, identifying an overall structure in the data, and diagrammatic representations (Miles and Huberman 1994) to make the data manageable over the course of analysing the interview transcripts. I initially developed general, ‘in vivo’ codes from each interview transcript, defined by terms and meanings from the data. These developed into hierarchies of

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29 He made himself available for interview, notwithstanding his retirement.
categories or concepts, layers of more analytical, abstract concepts, forming sub-themes and themes, informed by my own understanding of the field, and insights from the iterative cycle of returning to the data. This is in contrast to grounded theory where the aim is to develop more abstract theoretical concepts in a very early stage (Strauss and Corbin 1998). The later stage of interpretation was informed by the methodological framework of the power cube (Gaventa 2006), which provided a framework to present the findings about power in Chapter Eight. The theoretical lens of recognition politics (Fraser 1997; 2005; Lewis 2009) was used in conjunction with the power cube to further interpret the empirical accounts.

There are different approaches to the extent to which the context is retained in the analysis. Richards and Richards (1994 cited in Spencer et al. 2003, p.170) emphasise the importance of retaining links with the original data, and revisiting the data constantly through the iterative cycle. This is important, as I believe the context aids and illuminates understanding. For this reason the integrity of the individual accounts are maintained in the text, and metaphors or phrases from participants’ accounts serve as labels for most sub-themes, in order to represent the essence of the relevant issue. The diagrammatic format also illustrates the complex connections within textual narrative of the findings, and aids understanding of how themes are generated.

Spencer et al. (2003) refer to Hammersley and Atkinson (1995), who identified various approaches to differing levels of abstraction, from rich, thick description, to describing patterns, developing typologies, local explanations, or explicitly developing general theory. They also refer to Miles and Huberman (1994) who argue it is not enough to name and classify what is out there, we need to understand the patterns, the recurrences, the whys.

**Summary of the analysis method**

Spencer et al. (2003) use a very compelling analogy to describe the process of data analysis. They use a ladder and scaffolding imagery, where the stages in the process are like steps on a ladder, leading to various viewing platforms, which allow the analyst to gain an overview of the process. The analyst can easily move up and down the ladder or structure of analysis. As the data is
worked with through increasingly refined levels of categorisations and interpretation, it is often necessary to return to the raw data to ensure fidelity with it, and the analogy of a ladder with viewing platforms can represent this process in a useful visual way. It is a structure that represents the approach I took to data analysis: a thematic, largely cross-sectional analysis based on interpretations of meanings. This is schematically represented in Figure 4 below.

**Figure 4: The Analytical Hierarchy from Spencer et al (2003, p.212).**

<table>
<thead>
<tr>
<th>A depiction of the stages and processes involved in qualitative analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Seeking applications to wider theory/policy strategies</strong></td>
</tr>
<tr>
<td><strong>Developing explanations</strong> (answering how and why questions)</td>
</tr>
<tr>
<td><strong>Detecting patterns</strong> (associative analysis and identification of clustering)</td>
</tr>
<tr>
<td><strong>Establishing typologies</strong></td>
</tr>
<tr>
<td><strong>Identifying elements and dimensions, refining categories, classifying data</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Summarising or synthesising data</strong></td>
</tr>
<tr>
<td><strong>Sorting data by theme or concept (in cross-sectional analysis)</strong></td>
</tr>
<tr>
<td><strong>Labelling or tagging data by concept or a theme Identifying initial themes and concepts</strong></td>
</tr>
<tr>
<td><strong>Raw Data</strong></td>
</tr>
</tbody>
</table>

The first stage refers to data management, which involves generating a set of themes and categories as the raw data is coded, labelled and synthesised. I used
NVIVO initially as a means to manage and synthesis data at this stage. The second stage generates descriptive accounts of the synthesised data. The features considered at this stage included the actual words and metaphors used by the participants in order to give a sense of the richness and colour in the data and the substantive content, which includes both description and assigned meaning of peoples’ accounts through memo writing. This second stage also includes developing categories which represent different segments of the social world.

The third stage is that of explanatory accounts. Patterns of association were sought in order to attempt to explain why they occur. Linkages can be explicit associations occurring in the text, between sets of phenomena, or links between the experiences, behaviours and perspectives of the participants. Memo writing was critical at each stage in the process of refining my analysis, as it provides space for thinking about each element of the emerging jigsaw. My explanatory accounts are informed by two primary sources, Gaventa’s (2006) power cube and recognition theory as initially outlined by Fraser (1997; 2005), as well as my own experiential understanding of the field. The emergent themes became apparent from constant review of categories, subthemes, returning to the original recordings, transcripts, field notes and memos, and the process of writing and refining conceptual explanatory accounts.

Reviewing some of the arguments around universal deterministic causes, or rather the impossibility of achieving that level of explanation in social accounts of the world, Spencer et al (2003, p.216) conclude that it is sufficient to strive to say why patterns and outcomes in the data have occurred, using: “causal logic in a loose, non-universal, non-deterministic sense”. This is also my understanding about the status of the explanation that it is possible to offer from my research.

**Researcher Positionality and Reflexivity**

The reflexive approach necessarily situates the researcher in relation to the entire research project, including but not limited to the data generation and interpretation processes (Mauthner et al 2002). This research process was shaped, influenced and informed by my own experience, both as a service-user and as a participant in many forums to represent the service-user/survivor

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30 NVIVO is a Computer Assisted Qualitative Data Analysis Software.
perspective. The research question was, in part, informed by my own experience, as outlined earlier. My focus on power dynamics and social justice was informed by a priori assumptions based on years of sitting in committee rooms. These dynamics also emerged in shared discussions with other activists about their experiences. I have also worked with professionals seeking to change the ethos within MHS, but on occasion experienced encounters with some psychiatrists and nursing professionals which indicated they were not cognisant of, or indifferent to, the impact of power imbalances. While these biases were present in approaching the research participants, I was cognisant of the need not to predetermine the outcome of the findings, and sought to keep the questions as neutral and non-leading as possible, instead taking my lead from the narratives that emerged within the interviews.

I discussed my insider status with service-user participants above in terms of power dynamics. But also the insider status opened up doors for me which may be closed off to a regular academic researcher, given the research fatigue experienced especially by movement activists (Beresford 2010a). I experienced a tremendous amount of goodwill, co-operation and trust, for instance my peers articulated support for my research enterprise, believing there is a story to tell about SUI from service-users’ perspectives that must be told.

Doucet and Mauthner (2002, p.125) describe reflexivity as: “holding together methodology, epistemology, and ethics”. They conceptualise reflexivity not just in terms of social location but also: “the personal, interpersonal, institutional, pragmatic, emotional, theoretical, epistemological and ontological influences on our research.” In a discussion of data analysis, Doucet and Mauthner (2002) discuss the ethical dilemmas that occur when the researcher chooses her epistemological and ontological frameworks, which determine her relationship with the data and subsequent analysis. These ethical dilemmas include the relationships with the research participants, what to include and omit from the data, and what it means to “know well” or “know responsibly” and achieve a high degree of “epistemic responsibility” (Doucet and Mauthner 2002, p.124). These questions guided my critical reflections in my research journal (Frank 1997) and these reflections, in turn, became part of the ethical and methodological discussions with my supervisors in terms of both managing, and
representing the data and emergent themes. Deliberations about what to include
and omit were an ongoing concern during my analytic process, as it became
necessary to omit many issues that were of concern to participants, such as their
relationships with professionals in non-user-led SMOs in the mental health field,
as well as significant social topics such as gender, class and conflict within the
user-movement itself. It was necessary to omit much rich data on interesting
topics due to space constraints and to keep the focus on the substantive issue of
SUI.

The months I spend on the analysis, and returning to the recordings,
transcripts, field-notes and my research journal engendered not just immersion in
the data, but attachment to the perspectives of each participant, especially the
service-user interviewees who are my peers. My concern was not just to be fair
and transparent to the accounts but also how my interpretation would be received
among my peers and in the wider mental health field, and research and academic
communities. I found myself wanting to protect the feelings of service-user
participants whose everyday accounts of their experiences were translated into:
“academic, theoretical and policy related knowledges” (Doucet and Mauthner
the gazed upon, the knower and the known; reflecting on the damaging
experience of having one’s lives constructed as data, and manipulated for the
betterment of theory.” I was particularly sensitive to this because that has been
my experience as a research respondent; discussing aspects of my experience and
reading these later in abstracted, objective language was an alienating
experience. It was therefore very important that I represented the participants
varying viewpoints as accurately as possible, which presented a difficulty not
just in presenting their words but in choosing what words, phrases (and ideas) to
include and omit.

It had been my intention to develop opportunities for dialogue with
participants around the analysis, but this proved logistically impractical as
deadlines for completion came and went. In the end, I chose a pragmatic
approach of completing the analytic chapters without active participation of
research participants. However, I intend to present and dialogue with them about
the findings once the thesis has been submitted. My perspective of having used
MHS and having worked in a professional role in the health services informed my analysis, and my relationship to the knowledge generation processes. It informed my subsequent adoption of the methodological and theoretical lens of power and the social justice issues of recognition, as I too have experienced the disrespect, psychiatric disqualification, non-recognition and cultural domination described by participants, and felt the power inequities they described. I have also experienced the support of allies in the emerging spaces of SUI, and like some survivor participants, I was cognisant of the risk of alienating allies by my interpretation of their accounts of implementing SUI. I respect all the participants’ generosity and courage in sharing their experiences around SUI, and wanted to reflect these faithfully in the subsequent findings.

**Reflections on Shaping this Thesis**

The research process was emotionally challenging and lonely at times; rewarding, stimulating and fulfilling at other times. Some of the academic literature was challenging because of my personal standpoint; it was frequently painful to read detached, objectifying, unsympathetic texts about issues and groups I identify with. On the other hand, it was inspiring to read critical literature that opened up new ways of thinking about psychosocial distress, the MHS, and the challenges of SUI. It was also affirming to read literature supporting a survivor perspective, and learning about international developments in the user/survivor-movements. I was privileged to be funded to conduct research on the MHS without having to consider funders’ agendas. Due to the requirements of the Graduate Research Education Programme, I gained sociological training which prompted me to de-construct practices I had not critically examined before.

As a survivor researcher, I orientated towards feminist standpoint epistemology as a starting point to develop a survivor epistemology that builds on the situated knowledge of having survived and ‘recovered’ from 13 years under the influence of MHS. One of my most significant personal achievements has been re-claiming who and what I am and re-building a satisfying, fulfilling life, throwing off the devastating, internalised stigma of a service-user identity. I am more comfortable with the critical perspective on the politicised end of the
spectrum within the survivor movement, while recognising I may still have occasional need for wise, humane support from individual practitioners, but on my own terms. Survivor epistemology, I have argued, is a doubly advantaged perspective because it possesses the knowledge of the oppressed, as well as understanding the taken-for-granted privileged epistemology of the oppressor. Part of the challenge of this situated knowledge is to engage in the process of “knowing responsibly” (Doucet and Mauthner 2002) and engaging deeply as a “movement intellectual” (Baker and Cox 2002), while maintaining credibility and trustworthiness in the interpretation of the research. I find the struggle is to express the truth as I perceive it, in a way that is authentic, without being unduly influenced by concerns about how professional allies and service-users will receive my findings. It is a balance between acknowledging uncomfortable realities while maintaining or deepening the possibilities of future alliances. As a process, it reflects the tensions that are present for the participants, service-users/survivors in particular, as they negotiate how to engage with the MHS, given the realities of inequitable structures and an ethos of resistance to meaningful reform within the mainstream Irish MHS.

**Strengths and Limitations of the Research**

This research has many strengths. Overall, the interviews provided rich, textured data on the experiences of participants around SUI. The experiences of service-user participants provide much potential learning that can contribute to their allies’ understandings of the conditions of participation. The triangulation of the local case study with the national perspective provides the potential for wider applicability. From the particular experiences here, many lessons emerge which can inform those seeking to develop SUI in other areas of the Irish MHS. The research has a positive focus because of the commitment of one local MDT to find ways to work with the vast disparities of power, and to seek ways of improving their practises around service-user/carer involvement. It would have been so much easier to focus on prevalent examples of tokenistic practise; I wanted to find some rays of hope. Without the contributions of the allies and supporters of SUI, the results would have been much bleaker. It is salutatory, therefore, to remember that my findings occurred in a positive context for SUI.
This study has its limitations. The focus of the research question on the experiences and understanding of service-users and service-provider proponents of SUI practices necessitated an in-depth focus on just one aspect of a spectrum of issues within the mental health field. Detailed examination of the Irish user/survivor health social movement was beyond the scope of the study. This study did not set out to address the social situation of service-users, nor many intersectional factors impacting their positioning.

In terms of gaps in the data, there was no opportunity to observe how the local Consumer Panel interacted with senior MHS management in the area, as permission to attend their meetings was not obtained. Therefore, I only observed positive interactions between the MDT and service-users, rather than other dynamics service-users reported. Due to ethical procedural constraints and my safety as a researcher, I had to omit a key interview from the analysis which was much more critical of SUI in the area, albeit not with the local MDT.

Qualitative research produces an overwhelming amount of data, and I could have managed this more effectively had I used a more user-friendly CAQDAS\textsuperscript{31} than NVIVO. However returning to the paper, scissors and card method once initial coding was complete, ensured my analysis became more embodied and real. My insider status may have produced a respondent bias in that my peers and the service-provider participants may have selectively chosen to include or omit information about their experiences of SUI, congruent with shared understandings within the critical mental health community. My data analysis would have been richer had I had an opportunity to return and discuss my findings with participants, this would have increased credibility of the findings.

The focus on one multi-disciplinary team meant the service-provider sample only included one individual from most occupational groups, which due to ethical commitments to conceal identity, limited my scope to present data provided by some of the participants. Criticisms of the ethos and culture of the MHS they work in have implications for their future working relationships, so in some cases they were not presented or not associated with their occupational roles. This may weaken the impact of the findings, because it is useful to

\textsuperscript{31} Computer Assisted Qualitative Data Analysis Software.
contextualise critical comments as who is offering the critique is as important as the critique itself. Concealing identity also applied to the user-movement activists. However, participant safety and confidentiality is paramount.

Summary

I have presented an outline of the methodology, an instrumental case study, informed by feminist and survivor standpoint epistemology, and social constructivist ontology that influence my understanding of the social world. This in turn influences how I engaged with the worlds of my participants, in exploring the nature and practices of SUI. I discussed the research methods used: semi-guided interviews and meeting observation. My sampling framework was explained as were the methods I used to identify and engage the sample participants in the study. I have presented the questions I used to stimulate discussions with my participants during in-depth, richly informative interviews, and some of the measures that were used to determine the credibility and trustworthiness of the research.

In reviewing some of the literature around the ethical dimensions of research I anticipated some of the issues that surround the politics of knowledge creation. Recognising that the entire project must problematise the moral nature of our relations to each other, and cannot be satisfied by simply obtaining a rubber stamp from research ethics committees, I sought to address some of the common topics of institutional ethical procedures, informed consent, anonymity and confidentiality, data protection, and protection from harm. My study was granted ethical approval. In addition I have examined some of the dimensions of power that are present within the relationship between researcher and researched.

I presented an account of the fieldwork in this chapter to introduce the setting and engagement between the local service-user and service-provider participants, as their accounts are presented separately in the next two chapters. I have also provided an account of my approach to the analysis of the data, which is presented in the coming empirical chapters. I laid out my positionalitity as a researcher and how this informed my study, and the reflexive approach I adopted in order to overcome any assumptions arising from my life history. The strengths and limitations of this research are also outlined. Thus my methodology chapter
presents an account of how I undertook this research project on SUI within the Irish MHS and introduces the study site for the next two chapters.
Chapter Five:

Local Service-Users’ Perspectives
Chapter Five: Local Service-Users’ Perspectives

Introduction

This chapter presents empirical findings and analysis of the perspectives of eight involved service-users at a local mental health service (MHS), which was the location for a case study to examine service-user-involvement (SUI) in the MHS. The overall research question was what do service-users understand by SUI? This was operationalised by asking the participants about what motivated them to become involved in SUI, what their experiences have been, and how they evaluate those experiences?

The overall theme to emerge from the data is the inherent tensions in SUI from the service-user perspective. There are three emergent themes which highlight the overall tensions and challenges of SUI. These themes are: contestation of the service-user positioning vis-à-vis the MHS; negotiating the conditions for collaboration; and navigating the structural barriers to SUI within the MHS. These are illustrated in Figure 5 following the participant profiles. The data and findings in each theme and sub-themes will be outlined in sequence before an analytic discussion considers the significance of the findings. The chapter commences with background data about the participants, including a brief account of their SUI activities and why they became involved in SUI initiatives.

Participant Profiles

I interviewed eight service-users about their experiences of SUI in this MHS area. Four interviews were conducted in the team headquarters, four participants chose to meet me in their own homes. Three of the participants were employed by the Irish Advocacy Network (IAN). One was a (non-paid) member of the National Service-User Executive (NSUE). Five had been involved with the capacity training course observed during the fieldwork (See Chapter Four). Each participant is given a pseudonym, and identifying comments altered. The context of their own prior experiences and personal history of engagement with MHS influenced participants’ perspectives, both of the MHS and of SUI. Table 4
summarises participants’ SUI activities and is followed by a profile of the participants.

**Table 4: A Summary of Participants’ SUI activity.**

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Period active</th>
<th>Employed/Paid for SUI</th>
<th>Areas of SUI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ann</td>
<td>8 years +</td>
<td>Yes</td>
<td>Peer-advocacy, Committee work with MHT, Training, Consumer Panel, Research</td>
</tr>
<tr>
<td>Brenda</td>
<td>5 years +</td>
<td>No</td>
<td>Peer-advocacy, Committee work with MHT, Training, Consumer Panel, Research, Completed DCU Leadership training</td>
</tr>
<tr>
<td>Cathy</td>
<td>3 years +</td>
<td>No</td>
<td>Committee work, Consumer Panel, Completed DCU Leadership training</td>
</tr>
<tr>
<td>Dan</td>
<td>5 years +</td>
<td>No</td>
<td>Committee work with MHT, training, support group facilitator</td>
</tr>
<tr>
<td>Elaine</td>
<td>12 years +</td>
<td>Yes</td>
<td>Peer-advocacy, Committee work, Training, Research</td>
</tr>
<tr>
<td>Frank</td>
<td>1 year +</td>
<td>No</td>
<td>Committee work, Trainer, support group facilitator, Completed DCU Leadership training</td>
</tr>
<tr>
<td>Gerry</td>
<td>5 years +</td>
<td>No</td>
<td>Committee work, Trainer, support group facilitator, Completed DCU Leadership training</td>
</tr>
<tr>
<td>Harry</td>
<td>3 years +</td>
<td>Yes</td>
<td>Peer-advocacy, Committee work</td>
</tr>
</tbody>
</table>

Ann had experienced not being asked what she wanted as a service-user, and being treated with medications that caused unacceptable effects on her body. This sparked a passion for working in peer-advocacy to effect change in how people are treated by the system: “…for us it is about being listened to, being heard, having an influence and participat[ing]…it is about my life or the service-user’s life…”

Brenda was involved in unpaid SUI activities, attending the Stakeholder and Steering groups established by the MDT at the study site. She was recruited as a volunteer by IAN and was motivated by: “…the injustices that I had suffered in the system…” She described trying to advocate for, and support, a suicidal friend.

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32 Committee work refers to attending meetings to represent the service-user perspective. On many occasions these were policy planning meetings within the local MHS. Where participants were involved with the MHT’s stakeholder group this is indicated.

33 The Leadership Initiative in the School of Nursing and Human Sciences at Dublin City University (DCU) was established in 2007 and is a collaborative educational project which works with teams of three (a service-user, carer and service-provider) from various MHS areas around the country to focus on learning to work together in a “communicative approach” to participation. The pedagogy is influenced by Habermas’ critical theory. A team from this area has attended annually. (For further information see MacGabhann et al 2010).
in crisis, but failed to get adequate support from the system. She had experience as a peer-researcher, including working on a research project for the MDT.

Cathy was also active in unpaid SUI activities. A manager herself, she had clear ideas how she expected to be treated by people in authority. She believed in speaking her mind and speaking out on behalf of others who confided in her: “…if I can do something I will. But that’s not looked on in a good light in the MHS, not when you’re a service-user…” Both Brenda and Cathy had experience of SUI outside the local site, including membership of boards of national service-user organisations.

Dan facilitated in a local peer-support group and had trained other service-users for an NGO in the sector. He was involved with the MDT’s Stakeholder Group. His experience of SUI work was influenced by his positive treatment by his consultant psychiatrist and his awareness of how things could be improved for other service-users: “The type of input from the service-user point of view, I mean that didn’t happen twenty, thirty years ago…the services have come on in a lot of ways.”

Elaine had been active in SUI work for many years. She spoke about the challenges of stepping into a role which identified her as a service-user, widely regarded as a shamed, stigmatised position. She described disclosure about having used the MHS as being similar to ‘coming out’ with a LBGT identity. She was also very aware of her own personal growth and recovery as she learnt to deal with the challenges of being a peer-advocate: “What kept me going was I believed in the [Irish Advocacy Network], I believed in what I was doing…So every time I took a step for a service-user I could then do that for myself.”

Frank had been involved for about a year on the Consumer Panel, which he joined: “to see can I help improve things basically, try and get my opinion across”. He had had prior experience of having local services cutback without any consultation.

Gerry had experience of voluntary committee work and training service-users, and he too got involved by facilitating in a local peer-support group. He wanted to improve how the MHS treat people, and he believed SUI would help staff: “…to get a better insight into people, into their difficulties and how they can be helped, and not to be patronising”.

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Harry was employed as a peer-advocate and had completed postgraduate studies. He referred to his working class background as inculcating a strong sense of social justice. He believed SUI was a social justice issue, and considered his work as an advocate: “…to be twofold, meeting people, trying to resolve whatever difficult situations they find themselves in, but equally to actually challenge the system.”

**Figure 5: The Tensions Inherent in SUI.**
Contestation occurs in the dynamic political space service-users move into once they begin to challenge how they are individually treated and collectively constituted as subjects by the MHS. It is a counter-position against a controlling, de-valourising, hierarchical system, which on the whole fails to recognise service-users’ perspectives. The participants’ accounts of contestation invariably begin with the position of service-users within the MHS, and many of these accounts provide testimony of the fear reported to, or witnessed by, the participants (and sometimes, directly experienced), which prevents many from speaking out. The participants see their involvement in SUI in terms of giving moral imperative to those experiences by asserting a claim to better treatment and social inclusion for all service-users, not just in the healthcare domain but as equal citizens in society. However, a key tension for participants lies in defining the value of their role in SUI, seeking recognition and making a difference in influencing change within the MHS by leveraging policy engagement with human rights and social justice discourse. (See illustration in Figure 5).

“A Fearful, Captive Audience”

The first subtheme illustrates the de-valourised fearful position of service-users within the MHS. The title comes from a metaphor Harry used in arguing for the importance of SUI for service-users: “That’s why I’m arguing for more SUI, because the MHS have a captive audience…you don’t have that power to take your custom somewhere else.” He was referring to the fact that people have no choice about who provides their mental health care, and that a significant minority are treated against their will. What emerges from the data is not just lack of choice but the strong sense of fear that service-users have in speaking out.

Ann discussed how choice and meaningful occupation are missing in the lives of “patronised and smothered” service-users, who might give the impression they lack decision-making capacity but this is a result of institutionalised living: “…they can’t make up their mind because they were never given a chance to make up their mind.” Brenda carried out research with 25 residents living in MHS hostels. She found people “…needed blankets for the beds but they wouldn’t speak up in case they got into trouble.” Eight of the 25
residents spoke to her of: “things being taken in the houses and they wouldn’t speak up because they’d be bullied by the people in the house if they spoke up.” They believed they would not be protected. Harry reported the same fear among service-users who refused him permission to advocate on their behalf about issues they raised: “…because there’ll be consequences and I’m worried and you won’t always be there”. Other participants commented on the position of long-term service-users and their accounts suggest those most dependent on the MHS have even less autonomy and are the most fearful.

As a consequence of this positioning, many service-users have internalised a lack of entitlement to express expectations for better treatment and conditions. For instance, Harry observed that most service-users: “…haven’t got the self-belief that will allow them to understand that their opinions…have value, they are important, they have a right to get answers to [their] questions.” Cathy commented on the learned helplessness of many who feel their opinions are worthless:

They’ve learned over years that they don’t make a difference, it [does not] matter what they say, what they do, there’s never a change…they don’t expect there to be a change so they don’t get involved. (Cathy)

Fostering self-advocacy among people who have never been encouraged to believe they have this right is a central concern of SUI for the participants. However, Ann articulated the key challenge: “…it’s not just…that service-providers don’t want them to participate. They won’t because they feel they are not good enough.”

Fear of the consequences of speaking up is not just affecting those living in MHS accommodation. It was a feature of the participants’ own struggles to advocate for themselves and others. Participants were concerned that speaking out could impact on their own therapeutic relationships with service-providers. Cathy expressed this well: “…It could affect my treatment…they might stop listening…I’ve experienced that myself.” Brenda referred to being “…terrified of the consequences…” of her stand against mistreatment by nurses when advocating for her friend. She was encouraged by a peer-advocate to write a letter of complaint to the Director of Nursing but was very worried there would be repercussions in her future relationships with her treating team. There are
formal procedures to address grievances but many service-users do not trust these. Frank referred to the HSE policy document *Your Service, Your Say*, which outlines official complaints procedures, as “…not being worth the paper it is written on.”

In this subtheme, the key finding is the dependency and learnt helplessness of service-users locked into the MHS by fear of speaking out against their position. This fear among service-users was observed by the peer-advocates, and reflected as a personal concern by some participants who were still availing of services from the local MHS.

**Injustice as Motivation and Leverage**

Arising from the context of the positioning of service-users within the MHS, participants use human rights and social justice discourse to highlight abuses and demand fundamental rights (see Figure 5). Some participants referred to the injustice inherent in service-users’ position within the MHS as their motivation for engaging with SUI initiatives. For instance, Cathy declared: “I have a habit of sticking my head above the parapet…I hate injustice…it was a case of that, along with wanting to make a difference so that it’s better for other people.” Elaine knew that using human rights to advocate against injustices within the MHS was a powerful weapon: “…it’s something that we can say…I’m sorry but you can’t do this because you’re breaking human rights laws.” A significant thread throughout other interviews was the importance of empowering people to speak up for themselves, to know their rights and take control over their lives. Ann regarded empowering service-users to be a matter of fundamental human rights. Elaine also made the link between SUI, empowerment and changed relationships for individual service-users: “…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.” SUI can result in empowered service-users who, due to a greater awareness of their rights, are more assertive about what they want from the MHS.

Several participants used rights discourse not just to argue for better treatment of service-users but to leverage for SUI. For instance, Harry made a case for SUI as an instrumental right. He made a cogent argument about the
imperative on the MHS to consult and listen to service-users when planning services. He argued for SUI to be given a mandatory status as a statutory requirement as it is in other jurisdictions. He believed that if SUI was a prerequisite, rather than an optional add-on:

   You would actually transform the situation overnight...Instead of the service existing to benefit the service-user; the needs of the service-user [must] fit in with the needs of the system, that’s a perversion of the way it should be… (Harry)

The key finding to emerge in this sub-theme is the awareness and use of human rights and social justice discourse as both motivator and leverage for SUI. The injustice inherent in the position of service-users within the MHS provided the motivation for SUI. Such discourse provided moral force for change within the MHS, both in contesting the positioning of service-users within the MHS, and in relation to garnering support for SUI.

Struggles for Recognition

Emerging from how service-users are positioned in the MHS, the central struggle for the participants was recognition. All participants struggled with being a service-user representative because of the de-valourised status associated with being a service-user. Even at meetings with the MDT who initiated SUI, status and recognition issues remained problematic for participants. This was much more so for those participants who encountered more hostile attitudes towards SUI at other meetings within the MHS beyond the remit of the MDT.

The struggles for recognition were evident in efforts to name and frame the work they were engaged in. Not being service-user representatives or peer-advocates, Brenda and Cathy did not have the status associated with representing a service-user group. They had conferred about how they were regarded by those on the MDT who encouraged their participation:

   The service-providers were saying [we] were experts by our experience...so we came up with the idea that we were service-user consultants...Well, they’re taking our experience and they’re using it in a positive way and I think that’s a consultancy, what they’re asking of us… (Brenda)

Even though Cathy thought that using the term service-user consultants: “…made a difference straight away…because we started getting seen as, okay, we’ve got something more valuable [to offer]”, Brenda noticed a different
reaction from some of the professionals on the team to their role title: “…there was a little bit of resistance…looks and stuff.” Elaine, the most experienced of the participants in SUI, pointed out the tenuous hold that those involved in SUI have over title status because of the negative attributes associated with having used the MHS: “…service-user consultant, service-user advisor…at the end of the day it’s a service-user.” Frank gave his impression of how senior management regarded service-users participating in the Consumer Panel:

We’re only a number to them, we’re only part of the system and ‘what would they know about running anything? These people are sick, how would they know how to run a place…These people are mentally ill…they couldn’t think right…what opinions would they have? Their opinions would be stupid.’ … (Frank)

Frank named the assumptions that most professionals still hold about those diagnosed with mental illness. In spite of all the rhetoric of inclusiveness, participants felt that the service-users’ contribution is not given equal weight to that of professionals as Harry explained:

They have the attitude…I’m a highly qualified healthcare professional, I know what’s best for someone...’ In other words, their opinion, because it’s an expert opinion, is worth more than the service-user’s perspective…There is still an element of, well, some people, they make their disdain pretty obvious. (Harry)

Many participants referred to experiences of tokenistic involvement, but Harry was most explicit about naming the fact that service-users are brought in to be seen to be present, without addressing any of the conditions necessary for genuine collaboration. He asserted:

I have come across far too many meetings where…service-users have been there but they’re there to tick a box. It’s optics that’s all it is. ‘Yes we got the service-user involved’ but did it make any difference though? They want the service-user to be sitting there quite quiet. (Harry)

The key finding here is the struggle for recognition as participants contest the unspoken assumptions many professionals still hold about mental illness, which lead to discrimination (participants embody the stigmatised service-user identity), lack of equal recognition and tokenistic involvement. These tensions are all barriers to full and equal participation. The findings in the theme of
Contestation will be discussed further in the overall discussion of the empirical findings for this chapter.

**Negotiating the Conditions for Collaboration**

Next I present the conditions of collaboration\(^{34}\) from the perspective of service-users, and consider how the participants have negotiated some of the barriers to, and burdens of, SUI inherent within the current ethos of the MHS. Leveraging support from allies and seeking solidarity with other service-users were some of the emergent strategies in negotiating the barriers to SUI. The participants’ accounts illustrate substantial barriers to collaboration occurring around inter-personal communication, including negative attitudes and resistance to SUI by professionals encountered at many meetings, and the consequent emotional burden of the work of SUI. Finally participants’ accounts illustrate how service-users effectively subsidise SUI within the MHS while the necessary conditions of collaboration remain largely unrecognised and unfulfilled. This theme, with its sub-themes, is illustrated in Figure 6 below.

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34 Collaboration is operationally defined as the process of participation by service-users in the MHS: involvement in planning, service delivery, research, professional education and peer-advocacy. Servicer-users engage with the clear intention that their collaboration will help improve service-users’ experiences of care in the MHS.
“Providers in your corner”

The first sub-theme considers the value of positive relationships with professionals as a favourable condition of collaboration. Accounts are presented of support and solidarity from allies of SUI, of being listened to, treated with respect, as human beings rather than service-users. Cathy referred to the importance of having “…providers in your corner” at difficult meetings, hence the title of the sub-theme. For instance, many participants noted that the consultant psychiatrist leading the MDT “is a driving force” for what is currently happening in SUI in the area. Ann commented that:

Dr. X is always encouraging service-users and carers…the message is, ‘we don’t want any tokenism…because the services are about you not about us’. People actually feel they can say what’s on their mind… (Ann)

There was warmth evident in participants’ accounts of such allies. Some individual nurses were noted to be on the “Recovery track”, as people who come into meetings as human beings, and who leave their “hats outside the door”. Cathy explained: “Having the connections with the ones that want the Recovery system in place, who want Vision for Change, that makes a hell of a difference.” She described how helpful it was to have a debriefing with the providers when issues that arose during meetings were talked over with supportive professionals afterwards. Elaine commented on good dynamics towards SUI in the national policy planning office: “…I feel if I go into a meeting that I’m 100% equal…if I have an opinion, I can put it out there.” Others spoke about different forms of support provided by such allies, such as social lunches or opening up access to their facilities to service-users.

These supportive relationships developed as a result of getting to know each other through increased interactions in informal settings. For instance, a few participants spoke about how social contact with professionals ‘humanised’ their perceptions of service-providers and helped them gain confidence. As a result of SUI activities, especially the DCU Leadership Initiative, Brenda realised:

They were just the same as us…humanity was the common thread…I got the confidence to speak up with professionals which I wouldn’t have had before; I would have been in a subservient role as a service-user. (Brenda)
These warmer personal relationships lessened the impact of power and status differentials that were the more common experience with professionals, so that participants could feel somewhat more equal. Other participants who had completed the DCU Leadership Initiative also reported similar relationships. There was a marked difference among participants in their attitudes towards service-providers. Those who reported more social contact with professionals were more positive about them and SUI as a result.

The attitudinal change occurred in both directions. Cathy noted how some professionals, primarily nurses, who were non-committal initially, had shifted in their attitudes towards SUI by the completion of the year’s training. Ann also believed that local training on Recovery for nursing and other staff was altering the attitudes within the MHS: “…you can see the changes…where meaningful participation, not just tokenism, is possible.” A few participants linked better relationships with service-providers with reduced risk of tokenistic SUI.

A key finding in this sub-theme is that those participants who developed a rapport with professional allies experienced more positive conditions of participation. The critical role played by allies of SUI in improving the conditions for collaboration and reducing the fear of tokenistic SUI is another finding. Finally, increased proximity through SUI at meetings, targeted training and informal occasions, provided opportunities for attitudinal change, and less of an ‘us and them’ on the part of both service-users and service-providers.

“Sometimes my Head goes into a Spin”

The next sub-theme considers interpersonal communication and the two-way exchange of information, which is a minimum condition of SUI. The issues participants raised around communication fall into three broad categories: being listened to, speaking one’s mind, and the use of technical jargon. The accounts reveal different tensions participants had to negotiate in their collaboration with the MHS. The title is taken from a comment by Ann about the complexity of the jargon, and trying to follow what was being said: “…sometimes my head goes into a spin.”

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35 A few participants had been consulted about the content of the training courses on Recovery at two different levels of accreditation, FETAC 5 and HETAC 8 in the local School of Nursing.
The importance of being listened to was strongly expressed throughout the interviews, especially in relation to clinical encounters. Many accounts referred to listening as an imperative at the individual level of SUI in the treating relationship. Harry reiterated the need for service-providers to hear the voice of service-users, linking the individual level of SUI to a broader commitment to SUI within the MHS: “…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.”

Some participants focused on improvements that have occurred. Dan and Gerry believed that younger professionals were better at listening than had been their experience in the past. Ann and Elaine attributed improved listening skills to recent developments on professional training courses, which increasingly include some input on service-user perspectives. Frank emphasised how vital it is for professionals to listen to what people wanted, but he was very critical of the care planning process: “…care plans are a good idea if they’re stuck to… [It] doesn’t help the service-user, if they’re listened to for five minutes and then it’s discarded.”

Another aspect of communication within the accounts was a constraint on the participants’ freedom to express their voice. This was different in quality to the fear of speaking out found earlier; here the tacit rules of engagement restrict participants saying clearly what they think. For instance, Harry had to decide how much resistance was possible to attitudes and decisions he did not agree with:

…how forcefully do I make an argument? Do I brutally point out to somebody, who I may have to work with in the future for clients, that what they’re talking is essentially bullshit…Do I put it that brutally and then you get a reputation. (Harry)

In order to advocate for service-users, he had to be diplomatic in stating his views to maintain build good working relationships with key senior managers.

Participants’ accounts attest to the need for negotiation and diplomacy skills in dealing with the attitudes, behaviour and decisions from service-providers that they consider unacceptable. In order to negotiate inherent power imbalances, and to advance their agenda for SUI, participants needed to abide by the tacit rules of engagement, which for some participants constrained how freely they could
express their opinion and call “a spade a spade” (Cathy).

Another condition of collaboration is comprehension of what was going on at meetings; jargon was identified as a significant obstacle. Harry was emphatic that barriers to understanding, such as policy speak and technical jargon impeded meaningful SUI: “Attendance is not participation. Just because you happen to be at a meeting, if you don’t fully understand or are not being listened to, then you’re not participating.” Other participants also revealed feeling “stupid” and excluded as a result of not understanding what was going on. Some had, over time, developed the confidence to ask for clarification at meetings. For novices at SUI it was more difficult. At a training session that was run by peer-advocates for service-users about the jargon used by the MHS: “…one of the girls got really upset…so we spent a day at it then, just on language” (Frank).

There was an emotional tone to these accounts of how jargon undermined participants’ confidence, making them feel stupid and inadequate. Whether or not this is intended by those using jargon, the impact of exclusionary language was identified as an obstacle which all participants had to overcome.

There are four key findings about communication. Participants did not feel listened to or heard by many professionals, both in therapeutic encounters and in SUI work. Improved listening skills by younger professionals were linked to SUI in professional training. Participants’ acceptance of the tacit rules of engagement signalled the transition from contestation to collaboration. Finally, there is an emotional impact to failures of communication. These findings demonstrate that SUI is about far more than simply inviting service-users to the table; they suggest that communication is a condition of collaboration that needs to be addressed.

“I felt Belittled and It Bloody Well Hurt”

Optimal conditions of collaboration must include a safe and fair process, yet this was not what participants generally experienced. The frequent accounts of the emotional impact of not being listened to, and being disparaged, ignored, hurt and side-lined in hostile meetings are considered in this sub-theme. The title is taken from a comment by Ann, who described difficult meetings where she felt: “…belittled and it bloody well hurt.” Elaine illustrated this emotional cost in her account of non-recognition: “I’ve been to meetings where the consultant
psychiatrists, and nurses, have completely ignored me; I mean you would not be there for them.” The exclusionary dynamics of non-recognition were subtle and so could be denied or minimised by others at the same meetings: “…it’s not tangible, but you know the way you’re being excluded, that there’s no eye contact.” She described the impact of non-recognition: “I’d be quite frightened, my self esteem would get lower and lower, I’d be powerless…sitting in a big blob of fear, not able to talk.” Her sense of fear and intimidation at these meetings undermined her in contributing what she knew were valuable ideas. Cathy described similar experiences of non-recognition: “I have experienced cases where psychiatrists especially, have come into meetings and just taken the whole attitude of ‘you don’t know anything’.”

Many other participants highlighted power dynamics whereby powerful actors can ignore those of lesser status, thus undermining their ability to contribute, and imposing a significant emotional burden. There were a few attempts at resistance to exclusionary tactics spoken about, for instance in strategising about the best position to sit in order to break up blocks of powerful actors who controlled speaking opportunities at meetings, but this also meant the service-users lost the comfort of proximity.

Some participants spoke about the difficulty of being on one’s own at meetings. For instance, Brenda described isolation and paranoia and the need to have someone else to check out her interpretation of the unspoken tensions in the room: “…because there’s only one service-user and there’s a whole room of service-providers and sometimes…I’d pick up on tensions and think it was me and it is very hard when you’re the only one in there.” She struggled with knowing whether the inter-professional tensions were real or a symptom of her own distress, and found reassurance in de-briefing with professionals who had also witnessed the tensions playing out.

The key finding here is that resistance from powerful professionals and consequent denials of recognition are contributing significant emotional burdens to the work of SUI. SUI is difficult and those service-users engaging with it have to be strong, courageous and committed in order to deal with isolation, discrimination and exclusion at meetings.
Coping strategies

Participants developed strategies to deal with the emotional burden of SUI and to resist the negative attitudes from service-providers identified above. Their accounts show how they coped with hostile meetings, including taking back power from professionals and moving into a sense of personal power. The accounts also highlight the supportive networks service-users developed with each other.

Elaine and Harry used the metaphor of removing professionals from their pedestals. Elaine described learning through experience, growing into personal power:

I’ve learned that most of the anxieties and fears that I had sitting around the table…were my [own]. I was putting the professionals on pedestals. I think they’re on them, but certainly when I took them off in my mind, then it was okay. (Elaine)

One important coping strategy emerging here is that of learning to take back personal power given to professionals. Other participants described how they dealt with difficult meetings by preparing well and de-briefing afterwards. There were a few accounts of shared laughter at the disparity between the reality of service-users’ lives and the concerns of service-providers. Ann dealt with intimidation by keeping the purpose and simplicity of service-users’ demands to the forefront in her mind. She spoke of preparing before meetings in order to: “…prevent any nasty surprises.” Brenda discussed the importance of debriefing after meetings, especially when she had been the sole service-user present and had been affected by inter-professional tensions. Elaine referred to the difficulties of being a pioneer; and acknowledged the phone support she received from her colleagues in other locations. She subsequently provided a sounding board to other service-users about their contributions at meetings.

All participants referred to the importance of a strong support system. Such support occurred both informally, through phone conversations or a meet-up with other involved service-users they were friends with, or the more formal line-

36 There was significant evidence of awareness of tensions between professional groups because of the hierarchical nature of the MHS, with several accounts of allied professionals, and nurses, experiencing frustrations, and powerlessness, due to the dominance of the psychiatric profession. These findings are not presented for lack of space.
manager arrangements of the peer-advocates. Other participants referred to the
ing the importance of support from people in their personal lives to deal with the
emotional burden of SUI.

The metaphor of “chipping away” was used by a number of the participants
revealing a resolve to persevere in spite of the emotional burdens and barriers to
SUI. For instance, Frank referred several times to the need to “keep chipping
away” at “the brick wall” of resistance to service-users suggestions. Harry also
used the same metaphor: “So all I can do is keep chipping away…at every
opportunity I have.” Ann said “it’s about baby steps and chipping away.”

SUI is a slow, incremental process that requires patience and perseverance.
The key finding from this sub-theme is how participants’ deployed personal
strength, supports such as pre-and de-briefing before meetings and supportive
relationships as strategies to negotiate the difficult and sometimes hostile
conditions in many SUI situations.

“Somebody Else Can Pay”

The next sub-theme considers how service-users are compensated for
SUI. The title comes from an observation by Harry that senior management were
unwilling to resource SUI. There were divergent experiences between those in
paid employment as peer advocates (whose work extended beyond the study site)
and the unpaid volunteers. For those participants who were active in unpaid SUI
work, reimbursement for their time was important as a matter of principle and
recognition, but not a motivating factor.

Harry mentioned at least two SUI initiatives which failed in his area
because no financial support was forthcoming from the MHS. Therefore, he saw
an impasse in terms of progressing SUI and ironically observed: “There isn’t a
problem with senior management…with the involvement of service-users, as
long as somebody else can pay for that involvement.” He went on to illustrate
this resistance to resourcing SUI in the following conversation about Consumer
Panel meetings with a senior manager, who said:

…‘Well, we go to these meetings and we’re not paid for them
either’, and I said ‘…there’s no equivalence between a highly
paid healthcare professional and somebody on disability
allowance and expecting them to subsidise or to support the
system.’ (Harry)
The proposal from management was that bus fares would be reimbursed even though there were no available buses. Harry’s account illustrates a professional mindset that is unwilling to recognise the contribution of service-users, or to support SUI by adequately resourcing it. This was in stark contrast to the attitude of the allies of SUI who freed up resources to support SUI at the study site.

All participants regarded payment for time as recognition for the value of SUI. For instance, although he was willing to contribute voluntarily, Dan pointed out: “Well, the doctors…the nurses are getting paid to do it, so one probably wouldn’t mind getting paid to do it.” There was a payment available to service-users doing the DCU Leadership course\(^\text{37}\), which was: “…a real appreciation of my time” (Gerry). Cathy described the effort many service-users put into SUI:

All the meetings are during the day when the providers are getting paid… And I think you do start to question…I’m putting in all these hours, almost like a full time job, and it’s actually making money tight because I’m paying out for things. (Cathy)

Cathy and Brenda, both unpaid, reported being left out of pocket for some time before they got any expenses reimbursed.

There were other difficulties reported by participants using personal resources for SUI. These included: MHS related emails “clogging up” personal email accounts, the cost of printing SUI related documents, and the cost of phone calls to service-providers. Brenda identified the lack of boundaries that can result from service-users using their own resources:

If service-users knew you were involved they’d be ringing as well. I got a phone call at 9 o’clock on a Sunday morning, and night times. Service-providers…can switch off their phone at 5 o’clock but…you can’t, so people would ring you out of hours. (Brenda)

Another issue was raised by a few participants, whereby the availability or willingness of participants was sometimes taken for granted. Elaine explained

\(^{37}\) There was an arrangement in place to pay a reasonable fee and travel expenses to those who were attending the DCU Leadership in Mental Health course. Payment had been negotiated by the course organisers as a matter of principle. As it involved a team of three people, a service-provider, a service-user and a carer from each MHS service area involved, working together as equals, it was considered imperative to recognise this and reward people for their commitment to doing the course. This had been worked out in complicated arrangements between DCU, the HSE and an NGO.
that when there are only a few service-users involved: “they want you to go to everything and you’re really pulled in many, many directions”. Ann described the situation of an unpaid volunteer: “…they started loading more and more work onto that person…and the reimbursement didn’t follow…she was working a fulltime job basically.” Brenda described feeling taken for granted and overwhelmed. She took a break but returned after “re-charging [her] batteries” because she missed being involved. Plus arrangements were made to recognise her contributions by offering her a gratuity, and she felt more optimistic and wanted to be part of the positive changes she saw occurring. Cathy was also feeling the pressure of being asked to go to lots of meetings and contribute on a voluntary basis: “…you start getting a bit burned out…exhausted.”

Failure on the part of the MHS to adequately resource SUI despite national policy and the rhetoric surrounding SUI leads to funding at the discretion of local allies. The findings here show this failure resulted in service-users effectively subsidising MHS reform efforts. Non-payment for time was a failure of recognition while non- (or late) reimbursement of travel expenses was discriminatory, posing a serious barrier to service-users on very low incomes. Also, those who volunteered time and personal resources felt taken for granted, over-burdened with lots of work and with no office-hour boundaries.

**Navigating Structural Barriers to SUI**

In addition to the above challenges to SUI there are structural barriers within the MHS (See Figure 5). Participants were very cognisant of the hierarchical structures within the MHS and the tensions these posed for SUI. Two professional groups in particular were identified as posing structural barriers to SUI. Consultant psychiatrists populate the highest levels within the hierarchy, and featured prominently in accounts of struggles around both power and recognition. The participants also identified structural barriers within the profession of mental health nursing. Nurses comprise the majority of employees of the MHS, dominate the management layers throughout the MHS, from senior and middle management to frontline staff. There were accounts of differing

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38 Since I completed the fieldwork, both Brenda and Cathy have decided to pull back completely from SUI work.
attitudes within management of the MHS towards SUI, ranging along a continuum from those who resist the policy of SUI, to those who are advocates of change and support SUI initiatives. The Occupational Therapy and Social Worker professions were experienced as being the most receptive to the service-user perspective. In addition there were several accounts of inter-professional tensions between different professional groups, especially psychiatry and mental health nursing, whereby nurses and allied-health professionals were perceived to be experiencing similar power imbalances to service-users.

Despite national policies for SUI, support for SUI initiatives is at the discretion of local holders of power. One member of the local tripartite management structure is a general manager referred to as the administrator. The administrators are holders of significant power within the local MHS structure, as they hold discretionary budgetary and decision-making power on the overall operational and strategic direction of the service, along with the other two holders of power, the Clinical Director (always a consultant psychiatrist) and the Director of Nursing. These two professions are considered in turn below. As there are only two administrators discussed by participants there is insufficient data to constitute a standalone theme. Nevertheless, there is an important finding about a marked difference in commitment to SUI from the two administrators the participants worked with. One administrator was very supportive of SUI, arranging funds for training and to provide a stipend and travel expenses for service-users engaged in SUI. All participants mentioned this individual as an ally of SUI. By contrast Harry was annoyed by the attitude of the administrator in his area who failed to provide any support for the Consumer Panel in his region. In fact, the comments Harry made about service-users subsidising SUI within the MHS specifically referred to this administrator’s reluctance to financially support SUI. Yet, the administrators are also constrained by the bureaucracy and resistance to change within the system. As Frank observed about the supportive administrator: “…his hands were tied as [he] went up the ladder.”
“The Doctor was the Boss”

The first subtheme considers participants’ accounts of the power of psychiatrists and the different forms that power can take, especially in relation to SUI.

There were differences apparent in how participants regarded the power held by individual psychiatrists. For some participants, the experience of psychiatric power was more benign than others. For instance, Gerry compared his current experiences with psychiatrists to how things were in the past: “There could be a slight power imbalance between us and the doctor, but it’s not a huge chasm like…years ago, the doctor was the boss.” Gerry’s minimisation of the power imbalance may well be because he had observed a shift in this between service-users and younger psychiatrists: “Younger doctors coming up…will not force anything on you, they will ask you how you feel about that. Twenty/thirty years ago you were told that’s what you’re going to do.” He welcomed the improved relations for service-users with an apparently less coercive and open MHS. Also unspoken but implied is the legacy of past institutional power of psychiatry. Dan also referred specifically to the past omnipotence of consultant psychiatrists. He considered SUI to be essentially about improving service-users’ individual relationships with their care providers. For instance, he believed SUI makes it easier: “…for the service-providers and the service-users to get on as doctor/patient or nurse/patient…it’s a newer, more modern way of communicating.” For these two participants, the improvements over their years of MHS-use meant that a benign use of the psychiatrists’ power was not problematic. A positive use of power was also evident in “Providers in your Corner” in which the consultant psychiatrist leading the MDT was identified as “a driving force” for SUI.

Other participants had a more critical perspective on psychiatrists and how psychiatric power manifests in relation to SUI. Earlier Elaine and Cathy described the impact of being ignored by psychiatrists at meetings. Other accounts revealed how psychiatric dominance constrains the choices and autonomy of service-users. Elaine contested the sole reliance on a bio-medical system which denies choice and autonomy: “It’s no good saying…we’re a Recovery-focused service but all that we’re offering you is a psychiatrist and
drugs.” Harry was more forthright about the coercive power of psychiatry. He highlighted service-users’ awareness of the systemic power of psychiatry, and how culturally and legally entrenched this power is. For instance, he discussed the role of psychiatrists in Mental Health Tribunals and commented particularly on the independent consultant psychiatrist who reviews a patient before their Tribunal: “Are you ever going to get one psychiatrist to question the competence of another psychiatrist? So what’s the feckin point of a tribunal?”

These accounts highlight the predominance of visible psychiatric power, which was sometimes normalised, and gratitude was apparent that younger psychiatrists are better listeners than in the past. For some participants this visible power was benign, when an individual psychiatrist supported SUI. Other participants placed greater emphasis on the coercive and constraining aspect of psychiatric power.

A few participants were cognisant of the structural powers of psychiatry within the MHS impeding SUI. Some accounts refer to the less apparent dimensions of power (hidden and invisible) shaping SUI. The profession of psychiatry, and other powerful agents, can determine who is and is not invited to the decision-making table, a power Harry named as gatekeeping. Harry explained hidden power:

If you’ve ever studied…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…certain people…can manipulate situations where the service-users do not become involved. (Harry)

He commented on the hidden power of professionals to influence the process and practices of SUI. He reported instances of hidden power excluding service-users altogether in operational spaces. An acute unit was establishing a process for evaluating their service. They adopted a system developed by the Royal College of Psychiatry. Harry, however, observed the SUI component in this evaluation: “...hasn’t translated into the Irish version, SUI has somehow magically disappeared from the system’s transportation across the Irish sea.” The

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39 Hidden power is that held by those powerful actors who can influence the agenda, and decide who, and what perspective, is included and the discourses that underlie attitudes towards SUI. Invisible power is that of the underlying, unquestioned orthodoxy that accepts bio-medical explanations of psycho-social distress as truth.
second incident related to a committee set up to provide educational material for patients in the same acute unit. On being invited to join the committee, he asked whether other service-users had been consulted and was met by silence. He concluded that all the decisions in that case had been pre-determined and his contribution was not going to make any difference.

Harry was also cognisance of latent, invisible power shaping the ethos of the MHS. For instance, he questioned the power of psychiatry to determine ‘best practice’, asking rhetorically whose perspective mattered: “…the perspective of the service-user or the perspective of psychiatry?” He also explicitly referred to the cultural mindset within the MHS: “…‘well I’m the healthcare professional, I know what’s best’…it’s such an integral part of their mindset that it’s virtually impossible to change.” Other participants also referred to encountering the pervasive ethos that the professional knows best, which for service-users compounds the ‘them and us’ attitude.

There were other instances when the hidden and invisible power of psychiatry was discernible in accounts of incidences at meetings and encounters with psychiatrists. For instance, Ann related an interesting anecdote. She was at a meeting with a peer-advocate who presented material on the service-user perspective. Afterwards the peer-advocate received a clap on the shoulder from the psychiatrist present, congratulating her on a job well done. Ann commented on the status differentials by reversing the gesture, suggesting that if service-users went: “up to the consultant, tap his shoulder and [say] ‘oh well done, oh didn’t you do great there, well done…how did it feel?’ I don’t think that would be appreciated”.

There are findings that participants contested psychiatric power at different levels. Invisible power was not often explicitly addressed, yet there was a challenge to the lack of alternatives to the bio-medical approach and the unassailable orthodoxy of the expert whose perspective determines best practice. Hidden power was challenged by naming gatekeepers who hinder SUI. Visible power was challenged at the level of therapeutic relationships. At this level a finding emerged about differing perspectives among participants: some normalise visible power as benign, and thus unproblematic. Other participants
were more cognisant of psychiatric power constraining choices for service-users and SUI. These findings are discussed later.

**Nursing Power and Resistance**

The second sub-theme considers power in relation to how participants experienced mental health nurses. As well as psychiatrists, nursing professionals have significant power in relation to SUI (and over service-users’ lives), not least because they make up the vast majority of staff numbers and populate most management positions. Nurses were found to be resistant and fearful of SUI. In identifying resistance to change, many of the participants point to the legacy of the old institutionalised system on current practices.

Elaine discussed two instances of resistance to change within nursing ranks. In the first case, during a user-led research project, senior nurses in some units wanted to remain in the room while service-users were being interviewed. Elaine believed they felt threatened: “…I think they’re fearful of…what the service-user is going to say about that particular service, so they’re anxious.” In this case, the service-user researchers resisted the attempt to censor service-users’ responses to the research. In the second case, nurses in a day centre threatened with closure attempted to bolster resistance to the closure by galvanising the service-users and seeking the support of peer-advocates. The peer-advocates were approached directly by nurses initially, who were informed that IAN never advocated at the behest of a third party, only when freely requested by an individual. Elaine (and Ann) then began to receive phone calls from previously unknown service-users about that service, who Elaine believed had been encouraged to call by the nurses. She concluded that the peer-advocacy service was being used to serve the agenda of nurses who were seeking to preserve their working conditions in a day centre rather than promoting community integration for service-users. She observed that the day centre was in effect operating as a mini-institution in the community. She maintained that SUI, and some service-users, were clearly exploited in that instance.

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40 The Irish Advocacy Network was sub-contracted to conduct research nationally with service-users for a Mental Health Commission (MHC) funded project. This project is discussed more fully in Chapter Seven.
The instances described by Elaine point to different forms of resistance arising from institutionalised practice. In the first case, the nurses sought to censor service-users as they felt threatened by what might emerge in the research. In the second case, nurses again sought to resist changes to their practice and working conditions, except in this case they sought to use SUI in their struggles. These accounts illustrate participants’ awareness of the tensions inherent in SUI, especially in relation to co-option, in that service-users can be manipulated and become embroiled in the political struggles of certain groups to resist change.

Nurses in middle management ranks were considered by several participants to be the most obstructive. Elaine believed that senior management and frontline nurses were generally favourable towards SUI, but she detected: “…a reluctance in middle management”. Frank, on the other hand, thought a minority of senior management supported SUI: “…but in [management] overall, no!” As he saw it, management was comprised of nurses who had risen through the ranks, without necessarily keeping up to date with modern ideas of client-centred care. He had a very pessimistic attitude to the potential of SUI to achieve anything in the face of the powers of this layer of management. He also believed that service-providers pursue their own agenda and that if service-users come up with a suggestion that suits the management’s agenda all the better, as this looks good for management. There was a sense of powerlessness to affect change running as a very strong thread throughout his interview: “Whatever they have decided to do, it’s going to be done whether we have a say in it or not.” (Frank).

Frontline nurses were not without criticism from participants either. Brenda described an instance of resistance to SUI from some frontline nursing staff when she was conducting a research project on behalf of the MDT. She was given operational freedom once the methodology had been agreed. On going into one MHS hostel to interview residents, she met with some blatant hostility. After she had a door shut in her face by nurses, she was supported by a cleaner who helped her use a phone to contact her respondent. She had the support of a strong
ally in the consultant psychiatrist, who afterwards informed the entire team he expected co-operation with the service-user researcher.41

Ann discussed a different expression of power by nursing staff. She explained how control was exerted through the mechanism of policies and rules and regulations. She observed that some nurses thought that sharing power or responsibility with service-users would diminish or threaten the nurses’ position and so they used rules and regulations to bolster their power:

I have the suspicion that [they think] if you give more responsibility to a person it means you’re losing a little bit of power and in order not to do that you can hide behind duty of care, and health and safety…They need a policy, and emotionally can detach themselves from the service-users because they have a policy in place. (Ann)

The context discussed was a health and safety prohibition on people making tea, where tea-making becomes a site of control and resistance. Ann was also aware that rules and regulations can become an emotional barrier, an effective boundary between professionals and service-users. Nurses can deploy policy and professionalism to distance themselves from service-users.

A key finding in this sub-theme is how nursing professionals can use their power within the MHS hierarchy to hinder SUI. There were instances of the legacy of institutional practice underpinning resistance to SUI, and of some nurses seeking to co-opt service-users to maintain the status quo. Nurses were also found to be non-cooperative with research conducted by service-users, and to use professional boundaries and policies and procedures as a strategy to emotionally distance themselves from service-users. Another finding is that nurses resisted SUI because they did not want to lose power over service-users. Given their predominance in the ranks of management and their resistance to sharing power with service-users, the nursing profession was found to constitute another structural barrier to SUI.

41 The Consultant Psychiatrist (in Chapter Six) discussed the insufficient preparation of staff as a failure on his part but explained the need to find a balance between anticipating all possible problems and initiating the research.
Discussion of Inherent Tensions of SUI

The inherent tensions of SUI revolve around three key themes; contestation of service-user positioning vis-à-vis the MHS, negotiating the conditions of collaboration and navigating structural barriers to SUI. The key findings around contestation relate to how participants position themselves vis-à-vis more powerful actors within the MHS. All participants referred to the powerless position service-users occupy within the MHS and the consequent fear of speaking out against this. Arising from this context, social justice and rights discourse are leveraged both as tools of contestation and as motivators for SUI. Participants engage in a constant struggle for recognition and legitimacy.

The first finding is consistent with the literature which describes a devalorised, marginalised, stigmatised existence which deprives people of personhood (Rogers and Pilgrim 2003; 2005; Hyde et al 2004; Sayce 2000; Spandler and Calton 2009; Wallcraft et al 2003). Both my data, and the literature, illustrate that service-users’ experiences are more about “coercion and control than consent and choice” (Forbes and Sashidharan 1997, p.490). With the legal right to determine what is in someone else’s best interests, psychiatry has the power to infantilise people dependant on the MHS (McGruder 2001). By asserting control over every aspect of people’s lives, service-users can live in a state where they lose autonomy and control over the simplest aspects of life (Barham and Hayward 1996) and this is apparent in how participants describe the dependency and fear of long-term residents, and the challenge to develop self-advocacy.

The reported fear of service-users speaking up against their situation is a striking indictment of the MHS. This fear is about the consequences of speaking up for oneself or others, a fear there will be repercussions if they speak out against unsatisfactory treatment. This is understandable given the powerlessness all service-users experience vis-à-vis the MHS, most especially for the long-term residents, given their daily interaction with nursing staff where they live. Pilgrim (2009, p.28) defines fear as: “the behaviour and experience provoked…by real or perceived threats.” Lewis (2010, p.3) observes how the experience of using MHS and the constant threat of compulsory treatment and/or detention create a culture of fear and domination, a form of “affective power”. This will necessarily impact
on the environment for SUI and is a key feature of the inherent tensions of SUI. The fear evident from participants’ accounts relates to the power dynamics operating within the MHS: it is a consequence of the perceived threat of a negative response to contesting their position. This fear is not abated by having an advocate because they will be going back into a situation where they believe the advocate cannot protect them. Hence an environment of fear can become pervasive, as suggested by participants’ accounts. Fear about speaking out is a key finding about the position of service-users and contextualises their position within the MHS, increasing the challenges of SUI for participants. The participants understand and identify with the position other service-users are in because they have had similar experiences – experiences that provide strong motivation for the participants in this study to become active in SUI.

The next key finding was an awareness of the potential of human rights and social justice discourse as a tool for contestation of service-user positioning and leverage for recognition of service-users’ right to be involved in decision-making within the MHS. Participants used human rights and social justice discourse to advance their claims for better treatment, and for the right to participate in MHS planning. SUI was framed as an instrumental right: a moral and democratic assertion that SUI should be mandatory policy, which must always be implemented when new initiatives are being considered. Empowerment was linked to the right to participate by some participants, echoing an argument made by Chamberlin and Schene (1996) when they listed 15 elements of empowerment, including the right to decision-making. For other participants, being listened to and being heard was a basic minimum human right. This is in alignment with research on what service-users want from the MHS (Brosnan et al 2002; Faulkner 2000; McDaid 2009; Read and Reynolds 1996; Rose 2001). Service-users also expect to be treated with respect and dignity, which are core components of Fraser’s (1997) understanding of conditions necessary for parity of participation discussed in Chapter Three.42

42 Fraser’s theory of social justice is used as a lens across the entire theme, while this sub-theme highlights the presence of justice and human rights discourse being used by participants as a tool for change.
Human rights discourse plays a significant political role in social movement demands, including in the mental health field (Lewis 2009a; Carpenter 2009; Cresswell 2009; Perlin 2007; Pieterse 2007; Stammers 1999; Williams 1987). Cresswell (2009) argues that human rights, while not always justiciable, nevertheless provide a means to demand symbolic and political legitimacy for the survivor movement. He proposes that experiential rights could signify the survivor movement’s expression of:

“a double trauma and a double demand: (i) an original interpersonal trauma with a demand for welfare provision; and (ii) a second institutional trauma issuing from welfare provision itself, which results in further demands on the state” (Cresswell 2009, p.323).

Stammers (1999) argues that the construction and use of rights discourse by new social movements challenges the cultural hegemony that denies their right to recognition, self-determination and power to affect change. Here participants used rights discourse to express instrumental demands (concrete political, economic and social demands), such as the right to participate, to be reimbursed for SUI work, and for recognition of their contribution. They also presented the expressive dimensions of rights (values, norms, and lifestyles) such as the need for empowerment, freedom from stigma and to have their perspective listened to and recognised.

Arising from the context above are struggles for recognition. The service-user identity is shaped by the unspoken assumptions many professionals still hold about mental illness and their own epistemological claims to authority. The data in the sub-theme Struggles for Recognition resonates with much of the literature discussing disempowering attitudes towards service-users’ competency and the need to address limiting attitudes on the part of service-providers (Bowl 1996; Eastman 1996; Rose 2003; Sayce 2000; Johnstone 2000). The accounts of the ‘sick role’ and associated stigma of the service-user identity underpin many service-providers’ paternalistic attitudes towards SUI. The politics of recognition

43The Convention on the Rights of Persons with Disability (CRPD), with the participation of service-users in the drafting of the text, could potentially be a paradigm changer as it outlaws the detention of individuals on the basis of a disability (Bartlett 2009; Dhandha and Narayan 2007; Mégret 2008; Méndez 2013; Minkowitz 2007). Human rights instruments, including the Convention on the Rights of Persons with Disability (CRPD), form the basis of Human Rights Based Approaches (HRBA) to working with marginalised and dispossessed people and thus offering a potential tool for social movements.
(Fraser 2004; Lewis 2009) permeate the accounts in the sub-theme, *Struggles for Recognition*. Non-recognition occurred as service-users were denied a voice, many silenced by fear. Leveraging the title ‘Service-User Consultant’ was an attempt to contest the devalorised status inherent in being a service-user. Holding onto the idea of being an expert by reason of one’s experience was a strategy to counter mis-recognition and status subordination and to assert their right to be at the table. Nonetheless, all participants had experienced disparagement by virtue of being a service-user; a form of Bourdieusian symbolic violence (Cresswell 2005; Crossley 2004; Lewis 2009; Speed 2002), where the illness construct is overlaid on what service-users have to say, so they are constituted as unreliable sources (McCarthy 2011).

Linked to the struggles around recognition, the devalorised service-user identity and valorisation of professional expertise, was an awareness of the very real risk of tokenistic SUI, whereby SUI becomes a box-ticking exercise. Read (in Reynolds and Read 1999, pp.423-424) and Wallcraft (2008) both describe the tensions for service-users when SUI is experienced as a tokenistic exercise. Wallcraft and her colleagues felt compelled to resign from the Service User Research Group in England (SURGE) because their survey on obstacles to SUI in research was suppressed by their employer, the UK Mental Health Research Network, for political reasons. Lack of adequate funding, dismantling of effective platforms for SUI and a failure to develop national standards for SUI provided the service-users additional reasons to suspect a token commitment to service-user-led research in spite of rhetoric about SUI (Wallcraft 2008). Reynolds and Read (1999) described how a project to develop academic course materials on mental health with SUI almost faltered as funding dynamics and academic requirements over-rode the mutual learning and growing consensus built up by the original team who had initiated the project. Decisions were taken that left Read, (the service-user consultant) feeling betrayed and angry, and Reynolds (the academic ally) unsure whether, despite a reversal to the original decision to produce a book written by service-users, decision-makers on the new team would over-ride decisions made in good faith with service-users. In both cases, tensions arose because the power dynamics in operation led service-users to suspect and challenge tokenistic SUI. Similar concerns arose for my research
participants; tokenistic SUI arises as an issue across all the themes in this chapter. If service-users are invited onto a committee as ‘window-dressing’, then SUI is meaningless. Worse, it lends legitimacy to changes to services or decisions that are not in service-users interests. Many writers (Carey 2009; Forbes and Sashidharan 1997; Rutter et al 2004) suggest SUI can be incorporated into the MHS’s agenda, that the presence of service-users at the table conveys a veneer of legitimacy to the MHS while denying them any real influence over the changes they seek to affect. The risk of tokenism, linked to failures of recognition, constitutes a core tension for participants who seek to realise changes to how the MHS operates. These issues are the background context from which participants seek to negotiate the conditions of collaboration.

**Negotiating the Conditions for Collaboration**

Given the above positioning of service-users and SUI, this theme illustrates how the participants sought to leverage improvements within the constraints of SUI. The first finding, the positive relationships some participants had developed with supportive professionals and allies for SUI, throws into sharp relief the otherwise hostile environment for SUI. Increased social contact through SUI activities allowed for familiarity and camaraderie to develop between some participants and service-providers. Positive relationships with the allies of SUI allowed for closer collaboration, and the development of a sense of common purpose in reforming the MHS. They also afforded opportunities for positive recognition to enhance the status of participants. This is resonant with literature that reports on the positive relationships that can develop as a result of SUI (Allain et al 2006; MacGabhann et al 2010; Weinstein 2010). Thornicroft (2006) argues that increased proximity and positive relationships with service-users reduce the likelihood of discriminatory attitudes towards service-users. This dynamic can in part explain the more positive attitudes occurring here from service-providers towards participants and from participants towards service-providers and SUI: those with least social contact with service-providers tended to report more adversarial experiences of SUI. SUI activities, such as meetings and targeted training and informal social contact around these, provided
opportunities for attitudinal change on the part of both service-users and service-providers.

The sub-theme “Sometimes my head goes into a Spin” demonstrates that interpersonal communication is highly significant in terms of whether SUI is perceived as a meaningful exercise. Participants named the requirement to be listened to, to be able to speak their minds without constraint, and to understand the language and proceedings of meetings, as minimum conditions for collaboration. Being listened to was a recurrent demand of participants, and is a fundamental component of communication which validates the experience of exchanging information. The key finding here is that while being listened to is a necessary condition of collaboration, it was often not occurring. Most of the evidence in this sub-theme related to the therapeutic relationship, and the importance of being listened to at that most basic level of SUI. Listening is closely associated with issues of respect and recognition (Lewis 2009), as well as being an essential clinical capability of healthcare professionals (Williams and Fulford 2007). However, not being listened to by service-providers in clinical encounters is a very common complaint of service-users (Cutcliffe and Stephenson 2008; Read 1996; Rose 2003). Listening requires time but, as a skill, it is not necessarily privileged in increasingly professionalised, ‘scientific’ healthcare training (Cassells 1982; Freshwater 2007). It was noted by some participants that increased SUI in professional training and local training courses in Recovery were having an impact whereby younger professionals learned to listen to service-users. A basic aim of SUI in professional education is to encourage better listening skills on the part of service-providers in order to improve the experience of those using the MHS (MacGabhann et al 2010). This issue comes up in Chapters Seven and Eight and will be returned to.

Another finding about communication is tension around the tacit rules of engagement, about how honestly participants could speak their mind to powerful professionals because of the need to maintain cordial working relationships. It is a feature of collaborative working and insider status that tact and diplomacy is necessary (Bradley et al 2009; Craig et al 2004). Given the dependence of most SUI activity on HSE funding, plus power imbalances in their differential status with professionals, there was an extra constraint on participants’ freedom to
express their opinions about the practices and beliefs of service-providers. Within this context, freedom to contest unacceptable or coercive practice was constrained by the need to develop working relationships that allowed participants to advance their objectives.

The prevalence of jargon and technical language at meetings was a daunting and intimidating obstacle, a finding which contributed to participants feeling excluded and stupid. The personal investment required by individual service-users in order to comprehend jargon is significant in terms of the commitment necessary for SUI. Knowing and understanding the jargon becomes a resource that those active in SUI can contribute and share with other service-users, as was happening in the capacity training I observed at the study site. Mastery of the language is a signifier of educational capital or status, hence a power issue (Lewis 2009; Lindow 1995; McDaid 2009; Rose 2003). Challenging the use of jargon, asking for explanations also required emotional reserves of self-confidence, which some participants acquired with experience of attending these meetings. Contesting the use of jargon as an exclusionary device was part of the struggle to improve the necessary conditions for SUI. The sub-theme of communication contributes to an emerging picture of the emotional challenges of SUI, as not being listened to, feeling inhibited about speaking freely and daunted by jargon compound the frustrations of SUI.

The key finding in the sub-theme, “I felt Belittled and it Bloody Well Hurt” is the strong negative emotional impact of hostile and difficult meetings, where there is resistance from powerful professionals to the presence and input of service-users. Accounts of the emotional impact of hostility to SUI resonate with the literature (Barnes 2008; Church 1996; Church and Reville 1988; Lewis 2010). Church and Reville (1988) were the first to identify the emotional work required of service-users in the spaces of SUI. Within my data, exclusionary practices from higher ranked professionals provoked emotional responses such as fear, hurt and intimidation. Powerful actors can ignore those of lesser status by avoiding eye contact, and hence making it more difficult for them to contribute to the meeting. Urry (2002, p.259) argues that: “eye contact enables the establishment of intimacy and trust, as well as insincerity and fear, power and control.” The evidence from some participants about eye contact being used to
control speaking time echoes Simmel who considered eye contact to be a sociological achievement, the most direct and pure form of social interaction (cited in Urry 2002, p.259). Participants experienced exclusion dynamics as painful and demoralising, undermining their confidence. Acts of resistance occurred both by recognition of the dynamics of exclusion and being strategic about where they chose to sit. Although some participants had learnt that by changing seating arrangements and interspersing themselves among the service-providers they could interrupt this dynamic, this required a higher level of confidence from them because they lost the comfort of proximity. The issue of power dynamics at meetings are discussed more fully in Chapter Eight.

Being the lone service-user at meetings imposed an additional emotional burden. This was evident in the account of internalising inter-professional tensions at meetings, and the need for confirming the reality of dynamics with professional allies. External validation and reassurance were provided by de-briefing with professionals who had also witnessed the tensions playing out. Many service-users have written of these experiences and the painful process of gaining confidence to overcome the feelings of self-doubt and powerlessness (Read 1996; Wallcraft *et al* 2003; Campbell 1996; Crepaz-Keay 1996; Chamberlin 2005). Having to manage such emotional work contributed to the burden of SUI of participants.

Given the emotional burden of SUI, the next sub-theme, *Coping Strategies*, found the participants displayed resilience and personal strength. De-briefing provided a cathartic release after difficult meetings, and allowed participants to find support and validate their experiences with each other and supportive professionals. Other forms of cathartic release emerged through instances of shared laughter at the foibles of the MHS. Another tactic used was to take service-providers off their pedestals, thereby de-mystifying their power. The importance of support systems was evident in bolstering resilience in the face of hostile and difficult occasions of SUI. This emotional work is consistent with literature on SUI (Barnes 2008; Church 1996; Lewis 2010). The coping strategies deployed to deal with the emotions generated by hostile meetings are part of the journey of growing into self-advocacy, of reclaiming one’s own sense of valued personhood (Lindow 1996) and of taking back one’s agency, which the
participants demonstrated. This emotional work was occurring in claimed spaces, created amongst service-users themselves, and will be returned to in the discussion of the power cube in Chapter Eight.

Another condition of collaboration are the resources required to support SUI. The findings in “Somebody Else can Pay” (about reimbursement, use of personal resources and being taken-for-granted) raise issues about service-users’ contributions to improvements of the MHS and requires consideration of the redistributive dimensions of social justice (Fraser 1999; 2007; Sayer 2005). Borrowing from Fraser (Fraser and Naples, 2004, p.1122), an appropriate slogan, “no recognition without redistribution” could be applied to this aspect of SUI. Several participants pointed out the inherent unfairness of financial non-recognition of the work of SUI. The same point has been argued extensively by feminists in relation to women’s unpaid work in the home and unpaid caring and community work, which is not so much about the status, opportunities and the power money confers, as about contesting the invisibility and non-recognition of such work (Lynch and Walsh 2009; Hook 2006; Leiba 2010, p.16). The reimbursement received by some participants was an important factor in making them feel that their contribution was valued, and recognised. This was in contrast with an argument put forward by senior managers as to why service-users should not expect reimbursement, rebuffed by Harry. The proposal that service-users would be content with their bus fares was deemed insulting. The core issue is the perceived inequity of their financial resources and non-recognition of the contribution of service-users.

The use of personal resources for SUI was a key finding. The practical challenges around the boundaries between one’s personal life and public work of SUI are much harder to maintain when service-users used their personal phones and emails for SUI work, as evidenced in the data. These costs of SUI are part of the energy and capital service-users invest in the unpaid work, which must be recognised as a social justice issue. These findings are congruent with literature on service-users perspectives on SUI (Chapter Two), which highlights the importance of material and financial supports for service-users if SUI is to be anything more than a paper exercise. Linked to the issue of non-recognition is that of service-users being overworked. Without adequate recognition of how
service-users are subsidising the MHS by their voluntary work around SUI, there is a very serious risk that involved service-users can feel taken-for-granted or even exploited by the MHS. Fairness suggests that efforts to improve the MHS should be both recognised and rewarded by re-distribution of resources to service-users. The topic of ‘mal-distribution’ (Fraser 1997) re-emerges in the next two chapters, so will be revisited.

Navigating Structural Barriers

The third theme deals with the key professional groupings within the MHS and how participants experienced these as barriers to, and occasionally as facilitators of, SUI. The key finding here is the lack of consistency between local areas in the support for SUI. The administrator of the MHS at the study site used his power over the allocation of budgets to facilitate various SUI initiatives. This is a feature of power operating at a functional, organisational level to support SUI and is a critical feature of services where SUI has been successful. This was contrasted by the experience in a neighbouring area, where SUI folded or never got established due to resistance and lack of support from key personnel with power. This is a major finding about the discrepancy between how SUI is facilitated in local MHS and points to a fundamental problem in operationalising policy commitments to SUI. If SUI is regarded as merely a box-ticking bureaucratic exercise or an aspirational policy without statutory weight then SUI can be implemented without changing the power relations core to the social justice issues raised by the study participants.

The sub-theme “The Doctor was Boss” contained mixed evidence in relation to participants’ experiences of psychiatrists and their role within the MHS (and service-users’ lives). There were several instances where the power of psychiatry was normalised as benign. The references to the bad old days, 30 years ago, when there were no checks whatsoever on the absolute domination of psychiatry over an entire system that was in awe of them, are an example of this normalisation. As a result of these comparisons, some participants were appreciative of a more modern style of communication with younger doctors who they found to be more consultative. Others appreciated the influence of the consultant psychiatrist leading the team. Power was not considered problematic
when an individual psychiatrist was supportive of SUI, or experienced as being a good listener. This was in contrast to a more critical opinion of psychiatrists in relation to paucity of treatment options, i.e. “a psychiatrist and drugs” and the coercive nature of treatment in many instances, i.e. the discussion of Mental Health Tribunals. The issue of power is discussed more fully in Chapter Eight.

There were frequent accounts of non-recognition and mis-recognition of participants generally by psychiatrists in relation to SUI. This has already been discussed in general terms, but what is noteworthy here is the greater impact of this given the dominance of the profession of psychiatry. The more power, status and influence an individual holds the greater impact their actions will have. As the profession occupying the pinnacle of the hierarchy, how psychiatrists relate to service-users creates the ethos every service-user experiences, whether in their own care or in the practices of SUI. Without the active support of consultant psychiatrists who hold the dominant role in MHS, SUI initiatives are not likely to get off the ground. This is more particularly so in Ireland because of the continuing dominance of psychiatry over the MHS (Hyde *et al.* 2004; Mental Health Commission 2012; 2011, p.89).

There was a reference to Mental Health Tribunals44 (MHT) and service-users’ attitudes towards the role of psychiatrists and the doubts many hold about the impartiality of the independent psychiatrist. This role was seen as an illusionary safeguard because the paternalistic ‘best interest principle’ is applied in the vast majority of assessments. It is little wonder that service-users express doubts about a psychiatrist’s impartiality and willingness to contradict the treating consultant’s opinion. More importantly they understand their powerlessness in the face of the hegemony of psychiatric opinion. This finding is consistent with much of the literature on service-users’ experiences of MHTs and

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44 Mental Health Tribunals (MHT) are a manifestation of the statutory power of psychiatry to detain people against their will for treatment (McGruder 2001; Cresswell 2005, 2009; Spandler and Calton 2009; Carpenter 2009). In Ireland they were established as a 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 (O’Neill 2005). In the Irish system, a MHT is automatically triggered by an involuntary detention in contrast to other jurisdictions where the ‘patient’ must initiate the proceedings. MHT are closed spaces (Cornwall 2004) in that who may attend is prescribed in legislation. There are three members sitting to determine whether the detention is legal. Service-users rarely perceive this to be in their interests, instead usually feel judged themselves.
coercive admissions (Breeze and Repper 1993; Carney et al 2008; Gilburt et al 2008; Perkins 2003).

Hidden power defines the boundaries of what can and cannot be discussed, and undermines the perspective of service-users. Harry highlighted the ability of gatekeeping professionals to prevent SUI in new MHS developments. The auditing system he referred to was developed by the Royal College of Psychiatry (RCP) as a service performance tool to produce data about service delivery, so that outcomes can be demonstrated and measured to justify budgets and efficiency. This ‘value for money’ accounting for how the MHS interact with service-users is one of the main managerial justifications for SUI (Beresford 2005; Carey 2009; Cowden and Singh 2007; Forbes and Sashidharan 1997). The SUI component of the suggested programme developed by the RCP was omitted in the local efforts to implement their audit. This observation resonates with literature, that although a project or monitoring system may be originally developed with SUI, it can subsequently be applied in other areas without sharing the value base of the original development (Wilson and Beresford 2000).

Another observation by Harry moves the focus to the epistemological power that is unquestioned in the MHS. Psychiatry determines what is considered to be best practice based on a system of knowledge, which privileges ‘evidence-based practice’. This includes the construction of a system of diagnostic criteria that determine pharmaceutical interventions (Frances 2012; Moncrieff 2008; Williams and Fulford 2007). This orthodoxy or paradigm of reality is created through the nexus of power/knowledge (discussed in Chapter Three). In the presence of such epistemological authority, the service-user sitting in the meeting is powerless to resist the ideology surrounding ‘best practice’ because of its all pervasiveness and taken-for-grantedness. Harry’s plea echoes that of Gaventa and Cornwall (2008, p.186) for ‘cognitive justice’. The knowledge of service-users about what counts as ‘evidence’ is part of the challenge posed by participants to the epistemological power of psychiatric systems of knowledge. This is a theme discussed in greater detail later as it emerges as a major concern of national activists in Chapter Seven. The ‘professional knows best’ is another feature of unquestioned authority that is indoctrinated into professionals who are trained in the various orthodoxies of their professions, a process which was
discussed in relations between power and knowledge (Chapter Three). Professional standing depends on this authority, which rests on the foundations of psychiatric hegemony underpinned by legislation (Walsh et al 2008). There is a cultural mindset that is resistant to questioning the validity of its precepts because they are handed down as an orthodox truth. The beliefs created are unassailable because they are so much part of the taken-for granted dogma (Chambers 1977; Healy 2011). This is the feature of power that is the most pervasive and impenetrable to alternative discourses, such as service-users’ contestations that there is another way to treat mental distress besides “a psychiatrist and drugs” (Elaine in this chapter). SUI is positioned against this invisible and unacknowledged force field of power.

Psychiatric power is the norm within MHS and therefore may be considered unproblematic by some participants, especially when it is experienced as benign because of more positive personal experiences with individual psychiatrists. Regardless that some psychiatrists may choose to use their institutional power in a benign fashion to hinder or support SUI, continuing dominance by one profession, apart from being an obstacle to change (Byrne and Onyett 2010), leaves SUI at the discretion of individuals. This point of analysis is returned to in Chapter Eight.

The second major structural barrier to SUI is the power of the mental health nursing profession. As the profession with the greatest numbers, and most contact with service-users, the nursing profession holds immense significance within the MHS. In identifying nurses’ resistance to change, participants point to the influence of the legacy of the institutional system on current practices. The hierarchical system of nursing was observed to consist of many in middle management grades who have risen through the ranks on the basis of seniority and seek to protect gains in terms of the pay and conditions that pertained in the institutional system. This culture of entitlement often went hand in hand with old paternalistic attitudes, whereby they had the power over how service-users needed to be treated and controlled (Johnstone 2000; Sapouna 2012). It is this resistance to change that service managers intent on reform of the MHS, generally at the highest levels of the system and often themselves from a nursing background, are seeking to break down. The greatest resistance occurred in
middle management - nurses at this level were not found to be welcoming of SUI. It is an unspoken truth that many jobs are reliant on what one manager (Chapter Six) referred to as ‘farming people’ into situations of high dependency, a point also made by Brennan (2012). It is this trend of disempowering service-users that participants rejected most strongly and contested in terms of human rights and social justice discourse.

There are macro-level political and vested interests at play within the MHS that undermine the democratising impulses of service-users. SUI can become embroiled in these struggles. The agendas of vested interests were evident in the account of how nurses sought to galvanise service-users as allies in their resistance to changes in their work and conditions. This is consistent with literature reviewed in Chapter Two which highlights the potential for SUI to be used for many different political ends (Carey 2009; Cowden and Singh 2007).

Although there is policy support in Ireland for SUI in research, local resistance was very evident, as it was perceived as a threat by frontline nurses. Review of literature in this area showed that service-users adopting the role of researchers challenge many of the ideas of service-users as ineffectual and in need of experts (McGowan et al 2009; Sweeney et al 2009). Such SUI in research also provides opportunities for service-users to be more honest about their conditions and experiences with peer-researchers who understand the questions that need to be asked (Rose 2001, 2003). In both accounts, service-user researchers had the support of more powerfully placed actors who sponsored the research, in the face of resistance from nurses. The dynamics of allies of SUI using their power in different ways to support SUI is discussed more fully in Chapter Eight, but the issue of resistance is the key finding of concern here. Some service-providers who are resistant may believe that sharing power with service-users undermines their position and expertise, an observation made by some participants. Recognising the agency of service-users may undermine nurses’ status as experts, an issue discussed in the literature review (Chapters Two and Three).

The finding of an environment of fear and control within MHS is further reinforced by the comment on nurses being emotionally detached. The observation was made that rules and regulations can be an emotional defence
against seeing service-users as fellow human beings with comparable needs to the person enforcing the rules. Concern with professional boundaries and controlling risk creates: “emotional constipation:-cool and detached, never offering real friendship which is considered dangerous and uncool” (Brandon 1996, p.297). Foucault (1977; 1984; 1991) described how technologies of control such as disciplinary power, biopower and governmentality create systems of regulation and surveillance which operate to shape how people self-discipline themselves into conforming with socially constructed rules of behaviour. Rules and regulations and how they are applied within the MHS illustrate these systems of control on a micro-level. Often the rationale is that of controlling risk. Risk in the MHS is always associated with hazard, never about the “dignity of risk” (Perske cited in Brandon 1996, p.298). The culture of preoccupation with health and safety asserts control over behaviours such as smoking (Warner 2009), cooking or making a cup of tea. This becomes a means of controlling people, while the underlying message, that the service-user is not capable of using a kettle safely, is a disempowering, disabling belief that can become internalised.

The nursing profession was found to be a major source of resistance to SUI, and a significant structural barrier towards progressing the goals of SUI for service-users. Nurses, along with the psychiatric profession, posed the greatest structural challenge to SUI.

Summary

This chapter presents the data from eight participants who are involved in SUI initiatives with a local MHS. The key question under consideration is, What do service-users understand by SUI? This was operationalised by asking participants about what motivated them to become involved in SUI, what their experiences have been and how they evaluate those experiences. They explained their understanding of SUI with reference to both the position of service-users in the MHS and their own experiences of SUI.

There are three overarching themes emerging from the data. The first key finding is the tension inherent in SUI between contestation and collaboration from the perspective of service-users. Contestation primarily focuses on the positioning of service-users within the MHS. All of the participants refer to the
devalorised and stigmatised positioning of service-users within the MHS. There are reports of fear among service-users of the consequences of speaking up against their conditions. A number of participants refer to this fear, either in expressing their fears that speaking up will affect their own relationships with treating professionals, or posing an obstacle to advocating on behalf of others who fear the negative consequences of speaking out about their condition. A pervasive atmosphere of fear and control over service-users, who have internalised feelings of worthlessness and lack of entitlement to social justice, is another key finding. The participants recognise that changes are occurring in the MHS at structural and policy level; however they also point to the continuing legacy of an institutionalised system of care across a continuum of control from coercion to paternalism. Contesting this position is the rationale of SUI for these participants. They see this as a question of social justice and human rights and use such discourse to demand a seat at the table in order to influence positive change for service-users.

Some participants are cognisant of the risk that their invitations to attend meetings are simply compliance on the part of the local MHS with top-down policies on SUI. This finding emerges in relation to their fears that SUI is merely a box-ticking exercise. However, given the strong dynamic of contestation of their status within the MHS and in SUI forums, and the recognition struggles they were engaged in, the tension between co-option and collaboration, while always present, was mitigated by their awareness of the social injustice of the condition of service-users generally, and their efforts to improve these conditions by engaging in SUI. As a result, they are quick to detect and challenge tokenistic involvement.

The second theme presents findings about negotiating the conditions of collaboration for service-users with the MHS. This theme reveals how supportive professional allies mitigate some of the hostile conditions of collaboration and provided resources, both material and emotional, that facilitate SUI. The hostile conditions of collaboration include failures around interpersonal communication, challenging emotional demands on participants, resistance to SUI from powerful actors and denials of recognition. The position of service-users in general is reflected in the participants’ own struggles in carving out a legitimate role for
themselves in SUI, which can be understood in light of Fraser’s politics of recognition. Participants struggle with their devalued social status as service-users at meetings and the associated mis-recognition accorded to them. All participants gave accounts of hurtful and disparaging attitudes linked to the status of being a service-user. Their accounts include psychiatric disqualification (feeling their contributions were dismissed because they were service-users), status subordination (feeling unequal because they were service-users) and non-recognition (being ignored at meetings) from psychiatrists and middle management nurses in particular. All of these failures of recognition make SUI challenging and difficult. However, the resilience of participants to negotiate the resistance to SUI and to persevere in spite of the challenges is an important finding. The last finding discussed in this theme is how failures to adequately recognise and support SUI result in service-users effectively subsidising MHS reform efforts. All participants testify to the demands on them in terms of time, emotional commitment and financial resources given the disparities of recognition with professionals for SUI. The findings reveal how participants must negotiate the challenging conditions of collaboration and draw on their own resources in order to meet their objective to affect changes in the positioning of service-users within the MHS, and society.

The final theme considers another significant challenge to SUI, the structural barriers within the MHS. There is a finding that participants’ experiences of individual psychiatrists shapes their perspective on psychiatric power. For some this power is benign and unproblematic, and SUI is improving relationships with treating psychiatrists. Others focus on psychiatric power as problematic, highlighting lack of choice when the medical model is all that is available. Psychiatric power is experienced as coercive and pervasive by others. Many participants talk about the power of a cultural mindset (Fraser’s cultural domination) in framing policy issues about treatment and best practice, encapsulated in the phrase the ‘professional knows best’ while experiential service-user knowledge does not have the same authority. Some of the participants have found an ally in an individual consultant, which in the context of one mental health team is used as leverage against resistance to SUI from frontline staff. However mis-recognition (feeling dismissed) and non-recognition
(being ignored) by other psychiatrists is reported by many participants. This is all the more potent because of the authority possessed by consultant psychiatrists within the MHS. Another structural barrier comprises of nursing professionals. The legacy of the old institutional system of care is found to be influencing resistance to SUI. Many mid-ranking nurse managers are found to have great influence over SUI initiatives, in either facilitating or obstructing projects and research. These findings about professional power will be expanded upon in Chapter Eight.

The findings reveal two different experiences of SUI for participants. Generally there is a positive experience of meaningful involvement with the MDT members and other supportive allies. The conditions that facilitate this are respectful recognition of service-user contributions displayed by a willingness to act on these, or to explain why not if it is not possible, and to acknowledge SUI by paying a stipend and travel expenses. In these instances some efforts to address the conditions for parity of participation are evident. However, participants are also aware of, or had direct experience of, resistance to SUI throughout the rest of both the local and wider MHS. This suggests that if the conditions of SUI are not addressed in a way that adequately recognises the contributions of service-users, and addresses the lack of parity for participation and the power inequities outlined in this chapter, then the rationale of SUI for participants, improving care and making the MHS more responsive to service-users needs, cannot hope to achieve its aspirations.
Chapter Six:

Service-Providers’ Perspectives
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Introduction

This chapter presents the service-providers’ perspective on the overall research question: What are their understandings and experiences of service-user involvement (SUI)? It commences with an introduction to the eleven service-providers interviewed, all allies of SUI. Three themes emerge from participants accounts. The first contextualises their understandings of the need for reform, given their experience of working within the institutionalised MHS and their awareness of service-users’ anger at past abuses. The second theme outlines the drivers of SUI, including the differing rationales and benefits experienced in operationalising SUI. This includes how participants validate the role of involved service-users, and how attitudes towards service-users, especially at the individual level of clinical encounters and care planning, have shifted as a result of SUI. The final theme considers the tensions inherent in professionals supporting involved service-users, while being cognisant of power inequities and the risk of co-option and tokenistic SUI. The empirical accounts are presented in sequence and then discussed together. The conclusion summarises and outlines the points of convergence and divergence with findings from the previous empirical chapter.

Participant profile

There are eleven service-provider participants. All volunteered readily to be interviewed and were proponents of SUI. Six participants were local frontline service-providers and members of the multi-disciplinary team (MDT). These were: a Consultant Psychiatrist, an Assistant Director of Nursing, a Clinical Nurse Manager, an Occupational Therapist manager, (OT), a part-time OT, a Social Worker, and a Psychologist. Two others were members of the wider team providing care to the service-users under the remit of this sector MDT; a nurse manager of a residential unit, and a care-support worker in a newly established role. I was unable to schedule additional interviews with other team members but also felt I had reached saturation as the wider team members had little experience of SUI at an operational or strategic level. The final interviewee at this site was the recently retired administrator, referred to frequently by participants in
Chapter Five, who occupied a position in top management in the local area (but middle management in terms of the whole MHS). His remit covered the MHS in the county, comprised of eight mental health teams, of which the MDT was one. Therefore he will be referred to as middle management in this study to distinguish him from the final participant. This was an individual in top management nationally in the MHS, a key ally of SUI initiatives. Eight interviews were conducted in the MDT headquarters. Others were in participants’ offices or in a mutually convenient venue. Figure 7 lists the different professional and management roles of the participants.

Figure 7: Participants in Chapter Six

<table>
<thead>
<tr>
<th>Occupational Role</th>
<th>Status re Multi-disciplinary (MD) team</th>
</tr>
</thead>
<tbody>
<tr>
<td>Senior Management</td>
<td>Top management in the MHS</td>
</tr>
<tr>
<td>Administrator</td>
<td>Top management in the local MHS</td>
</tr>
<tr>
<td>Consultant Psychiatrist</td>
<td>Team clinical leader</td>
</tr>
<tr>
<td>Assistant Director of Nursing</td>
<td>Local management of MDT</td>
</tr>
<tr>
<td>Nurse Manager</td>
<td>Local management, unofficial MDT care co-ordinator</td>
</tr>
<tr>
<td>Nurse Manager</td>
<td>Manager of a Residential Unit</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>Overall manager of OT department in the local MHS and MDT member</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>Half time post on MDT</td>
</tr>
<tr>
<td>Psychologist</td>
<td>Member of MDT</td>
</tr>
<tr>
<td>Social Worker</td>
<td>Member of MDT</td>
</tr>
<tr>
<td>Care Worker</td>
<td>Provided support to service-users in community living</td>
</tr>
</tbody>
</table>

I will refer to participants simply as Staff 1 to 11, in order to distinguish them from service-user participants. Except where it is illustrative of a point relevant to a particular occupational group, participants will not be identified by professional role in the empirical account in order to maintain anonymity. When I do identify a professional issue, comments will not be attributed to the usual signifiers of participants, Staff 1 to 11. Likewise, comments which could reveal
vulnerabilities or are sensitive in terms of comments about co-workers will not be attributed to a particular participant.

The three themes, and their sub-themes, that constitute emergent issues with service-provider participants are illustrated in Figure 8 below.

Figure 8: Themes and sub-themes representing Service-providers’ perspectives on SUI
**Structural Context to SUI**

The first theme presents the disaffection and sense of constraint participants experience with the ethos of the MHS. The hierarchical culture and resistance to change across the system leads to a dehumanising, challenging work environment which these participants recognise needs reform. Many are cognisant of service-users’ anger at the abuses they have experienced, although there are different responses evident. This is the background context from which participants adopt SUI as reforming strategy.

**Institutional Resistance to Change**

The cultural ethos of the MHS was reported by several participants to be hierarchical and resistant to change, dominated by a medical model. For instance, Staff 2 described the MHS as being: “patriarchal, hierarchical and consultant psychiatry-led”. Other participants described a system of self-perpetuating practices that induct new nursing entrants into the institutional ethos. A local nurse manager described resistance to change as endemic and explained the socialisation of nursing students by the practices they encountered on their clinical placements: “…the biggest barrier to change is that, as you bring people in…the existing staff…structures…and existing culture will permeate.” He explained how the attitude of the Clinical Nurse Manager 2⁴⁵ (CNM2) permeates the atmosphere of the units they work in, and that as they resisted any changes to their working conditions, this influenced the willingness of nurses to engage with SUI. Given that nurses constitute the vast majority of staff within the MHS, their resistance to the changes in attitudes and practice necessary to implement SUI across the system is a significant systemic obstacle to SUI. Staff 1 also commented on a general ethos of resistance to change in spite of the lip service given to team working, SUI and Recovery: “although…we talk a lot about multi-disciplinary team-working…inclusiveness and the Recovery perspective, it is an awful lot of talk and very little action.” A middle manager observed a more open

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⁴⁵The Clinical Nurse Manager 2 (CNM2) is the most common grade of nurse manager in the nursing management structures of the HSE.
attitude to SUI amongst newer staff and allied-health professions: “…it would have been explained to them what the purpose of it is…the older generation of staff, it takes them much longer to adjust…social workers, psychologists seemed more open to it than consultants or nurses.”

Several participants revealed that working in the MHS was a challenging, and alienating experience. For instance, one participant spoke about barriers to trust and openness among colleagues arising from the institutional ethos, which resulted in a sense of constraint and disaffection. This participant also reported a pervasive stigma within the MHS about personal experiences of psycho-social distress and withheld personal information as self-protection. Another described how the predominant culture: “…makes it difficult to reconcile the values…of my professional training…and the expression of those in day-to-day work.” Yet another identified with service-users’ experiences of patronising attitudes and frustration at the pervasive bio-medical approach because his profession was sidelined and dismissed by the more dominant medically-aligned professionals. The key finding here is of a hierarchical, oppressive MHS which is institutionally resistant to change, within which participants experienced being disaffected and constrained by an inflexible and stigmatising work environment.

**Institutional Abuses and Legitimate Anger**

While the institutional legacy is associated with ongoing resistance to change, many participants also associated this legacy with past abuses and consequent service-user anger. Staff 2 believed that the motivation for SUI was linked to the past: “it’s come out of past huge mistakes and gaps in service provision, awful things that have happened in the past…the needs of people being totally neglected.” Staff 10 acknowledged the past harms done to service-users: “…what happened in the past with Irish institutions wasn’t right, wasn’t meeting human rights and was a flawed way of delivering…services.” Staff 4 referred to the effect the institutions had on the people living in them:

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46 Allied-health professional is a term used to refer to those professionals trained in humanistic rather than medical disciplines. It includes Social Workers, Clinical Psychologists and Occupational Therapists in this study.
47 This term is used to refer to the professional disciplines trained in medical models; psychiatrists and mental health nurses, as distinct from the allied-health professionals.
“[They]…have been taught how not to do things for themselves…and [were] rewarded for not standing up for yourself.”

Some participants discussed the discomfort they experienced when faced with the anger many service-users still express about how they have been treated by the MHS. Staff 6 stated: “You sometimes have service-users…[who] constantly bring up being locked-up, being given medication against their will” and admitted feeling defensive: “they have to understand…I believed I was doing the right thing. However, when I look back, it wasn’t right. I think we can all look back and say we shouldn’t have done things that way.” Another participant acknowledged the need to hear service-users’ anger:

There’s been a lot of expressed concerns and anger about services generally...about...psychiatrists or mental health managers...[There is a] need for service-users to ventilate…I’d see that as a valuable part of SUI. That’s something I need to hear, that professionals need to hear and to understand, before we can meaningfully build useful, effective partnerships that are about improving services.

He noted, however, a lack of possible forums to facilitate working through legitimate anger. He observed there was no overt hostility towards service-providers at MDT meetings.

Other participants expressed different perspectives; a few participants referred to the need for service-users to “move on” and “look to the future.” While some acknowledged the legitimacy of service-users’ anger, this was qualified by framing such anger as a barrier to change. For instance, Staff 10 stated: “I suppose it’s very easy for me [but]…it’s very difficult for a client to remain emotionally detached because…their opinions stem from...what’s happened in the past.” He maintained that although there was a place or time to “speak from the heart”, when service-users were trying to influence change at operational or strategic levels of SUI, they should: “try not to personalise it…When you start personalising your opinion and your feelings…I think that’ll hinder change.” The suggestion was that emotional expression from service-users is a barrier to change, thereby privileging the non-expressive bureaucratic rules of engagement, and of course the hegemony of psychiatry’s role in containing irrationality.
The main finding here is a recognition by some participants that the institutional past gave rise to abusive practices about which service-users have legitimate anger. However, the right to express this anger provoked different responses. Some acknowledged it as legitimate but currently unrecognised within the MHS, whereas others were more defensive and regarded emotional expression as a barrier to change and to SUI.

**Drivers of SUI**

Arising from the institutional culture presented above, the next theme considers the factors influencing the development of SUI locally and nationally. Participants’ rationales and the drivers which propel their efforts to operationalise SUI reveal different perspectives between national policy and local leaders. Attitudinal shifts in service-providers emerge as an outcome of the operationalisation of SUI. Finally, changes in service-providers individual engagement with service-users arising from SUI were also reported. This theme with its constituent sub-themes is presented in Figure 9 below.

**Figure 9: Drivers of SUI**

“**How Far Up the Ladder?”**

The first sub-theme considers participants’ understanding of the rationale for SUI. There are two perspectives here, the national and the local. The title comes from a participant in top management who used the ‘ladder of participation’ model to explain his understanding of SUI:

48 Arnstein’s (1971) model of citizen participation is the most widely known and referenced model of different levels of citizen control in consultation exercises. The levels of control move from manipulation through to citizen control. It recently appeared in the British Psychological Society’s (2010) *Guidelines for Service User Involvement.*
...how far up the ladder [are] we willing to go? Is inclusion about telling you [what is] going to happen? or...‘I’m going to talk to you first about something that’s going to happen’, or ‘I’m going to ask you, should this happen?’ or ‘I’m going to invite you to make it happen’, or ‘I’m going to let you do it’...

This comment demonstrated an understanding of the nuances of power with regard to influences on service development. This participant sought reform towards less institutionalised, more person-centred ways of delivering services because: “I’ve a customer who has no choice but to avail of the service, either economically or when detained...that puts an extra obligation on me to ensure it’s really good.” His rationale for SUI was expressed in managerialist discourse, drawing analogies between getting a car serviced, buying a suit or going to McDonalds for a burger. He presented SUI as a form of quality assurance monitoring:

It’s much easier for me to monitor the quality of a service if the customer actively manages the quality of the service. I need customers who will...continuously ask...‘why is it done this way?’...I need a discerning customer as distinct from a compliant...or a hopeless customer, or someone who...surrenders to the system.

The assumption in his argument was that having articulate and assertive service-users overseeing how the MHS operates would ensure that services would become more responsive to service-users’ needs, while also providing better value for money to the tax-payer, because better decisions would be made about services and budget allocations.

He linked the rationale for SUI with responsibility, accountability and governance, asserting that involved service-users have equal responsibility for decisions taken within the boardrooms they attend. He used the example of the National Partnership Process49 (NPP) to argue for collective responsibility for decisions made at meetings. According to him, all parties were willing to accept the benefits but not the responsibility: “when it went badly, you looked over your

49 This is a reference to the national social partnership structures established by Fianna Fail governments in the 1990s, which developed negotiating arrangements between various ‘social partners’, the employers groups, trade unions and other lobby groups such as farmers, and the government. This process of national negotiations was considered by supporters to have established social stability, by preventing industrial unrest, a feature of the previous period, and allowing the economy to grow. The community and voluntary sector was later given a place at the table. Critical commentators have observed that as a result of this process, many voices of protest were subsumed into a national consensus (Murphy 2002, 2011; Varley and Curtin 2006).
shoulder and where were your partners gone?” He believed the same dynamics apply for SUI. If a service-user representative is on clinical governance teams which include clinical and ‘business’ managers, he believed it was not acceptable for service-users to abdicate responsibility for poor decisions:

…you’ve to go back to your constituency and explain, ‘collectively we all screwed up, we got it wrong’ and apologise whatever. So you’re not just there representing your own viewpoint, you’re representing your constituency, same way as I’m mandated by my organisation.

However, missing from his analysis was an understanding of the power imbalances between service-users and the vested interests within the MHS, such as psychiatrists, nursing and professional representative bodies. Such a position overlooks the necessary conditions for parity of participation and was also at odds with the nuanced understanding of power evident in the opening comments of this participant.

Local participants had a different understanding of the rationale for SUI. A middle manager explained it as being about designing services that: “…meet the service-user’s needs as opposed to what policy makers decide.” He believed SUI also ensured professionals were more responsive to service-users’ needs. The priority of the service-provider agenda was evident in a comment by a nurse manager on the MDT, who expressed his understanding that dialogue with service-users results in: “services that meet the needs of service-providers as well as meeting the needs of service-users.” Many participants regarded SUI and service-users as allies in resisting cuts and supporting a move towards community services. Staff 3 explained his understanding of SUI as an alliance between service-users and providers in “operational and strategic” development. SUI is about: “saying we don’t have all the answers, we’re not experts, we need advice from other people.” While another nurse manager pointed out that most spending decisions are non-negotiable, as nearly all the budget is already committed in salaries, nonetheless, he saw possibilities for SUI in deciding how staff should be allocated: “let’s say to community rather than…bed provision, it’s only when you have people in at that level that you have full involvement.” Staff 7 maintained that service-users need greater influence nationally to protect budgets, as well as to shape policy: “They don’t seem to be making major inroads nationally in the policies because you see all the cuts…coming down the
line and the frontline services aren’t being protected so I’m just wondering, have they as much clout as they should have?”

The key finding here is that participants regard service-users as allies and leverage SUI to support their differing agendas. Local participants seek to align with service-users in resisting service cuts and reallocating resources to community initiatives, whereas the national perspective was focused on institutional reforms and governance structures. At a national level involved service-users were regarded unrealistically as sharing equal accountability with all other parties for decisions made in corporate boardrooms without an acknowledgement of the inequitable conditions for participation.

“That's the Way the Flag is Blowing”

This sub-theme considers the motivators for SUI within this MDT, including the reported benefits. Staff 5 used the title metaphor as evocative of the climate towards SUI. Speaking about SUI generally, he observed: “certainly that’s the way the flag is blowing, all the policy…is moving in that direction.” Although it is national policy, all participants acknowledged that the operationalisation of SUI depended on local and middle managers driving initiatives, particularly in light of the prevailing resistance to SUI evident in earlier sub-themes. For instance Staff 3 stated: “…the consultant was in favour of it and that…set a marker for the rest of the staff that this is the way it’s going to be, so get used to it whether you like it or not.” Staff 4 highlighted the weakness in the model of ad hoc local support, which is personality-led rather than process-led: “…if another consultant came in here in the morning and didn’t believe in [SUI], I don’t believe it would last.” The consultant psychiatrist’s role in promoting SUI was noted by all participants on the team, except by the same consultant who attributed it to a local culture of inclusiveness which existed prior to his appointment, due to one individual in middle management in particular. The OT manager was also acknowledged as having an important leadership role. The support for SUI permeated the whole MDT, according to Staff 9, who observed everybody shared a similar “mind-frame”. One participant highlighted that SUI was not driven by the user-movement but is a top-down MHS initiative:
The Irish Advocacy Network was an encouraged movement, NSUE\(^{50}\) is an encouraged organisation, it didn’t naturally form, there wasn’t people getting together in houses and thinking we’ve got to change the services. Both IAN and NSUE have been government-led and service-led in developing their structures. (Staff 3)

As a result of the top-level endorsement of SUI, there were rewards for this team’s initiatives around SUI in terms of more resources. An alliance of service-users, carers and service-providers benefited the whole team: “this is our reward, more resources, more staff.” (Staff 10)

While SUI was perceived as a ‘top-down’ policy, once the local participants initiated SUI at their meetings, they reported many benefits in terms of heightened emotional well-being and job satisfaction. Every participant was enthusiastic about SUI and focused on intangible personal rewards such as increased job satisfaction and more meaningful relationships with service-users. Some of the enthusiastic comments included: “a very positive experience”, “team meetings [are] less artificial, more meaningful”, “a demystification of roles and a humanising affect just from having more contact”, “it’s a recognition that what you’re doing is right, it drives you on”, “It’s about a hundred times more satisfying than working any other way”, “there’s more sharing, more honesty, less threatening”. One participant described how SUI changed the atmosphere of team meetings:

…just the language even that’s used is very alienating, very often dehumanising and professional-speak and it was just lovely to hear somebody say what they thought in ordinary language and in a very positive way, so for me it was a breath of fresh air, like a human had come into the room. (Staff 4)

Staff 1 spoke of developing more reflective practice as a result of SUI: “I learned quite quickly to reflect on my own use of language…to reflect on my practice generally”. He commented on SUI providing an enriched dimension to both professionals and the MDT itself, which went beyond work outcomes and patient or staff satisfaction: “…that experience itself has had a huge impact personally, but I think very importantly across the team.”

Other participants reported that SUI at meetings changed their perception of service-users. Getting to know service-users as people and colleagues rather than

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50 National Service User Executive (see Chapter Two)
as patients: “…really helps you to hold onto that hope for other people who are more unwell that they can develop in their Recovery as well” (Staff 2). Three participants suggested SUI also challenged stigma within the MHS because the atmosphere of MDT meetings changed as service-users began to attend. Thus it became possible for some participants to consider disclosure of personal experiences of mental distress because of more positive perceptions of service-users.

The findings reveal that SUI is a top-down policy encouraged by the MHS, implemented at the discretion of local leaders, rather than a service-user-led initiative. There are rewards both professionally and personally from initiating SUI. Such rewards included: improved working conditions and job satisfaction, recognition for better practice, reduced stigma towards mental health within their workplace and more positive perceptions of service-users.

**Professionals have “Travelled a Journey”**

Given the culture and ethos of the MHS, the next sub-theme considers the values and attitudes of participants towards SUI, and the personal journey this was for some of them. The title comes from an account of the attitudes of nurses from areas unaccustomed to SUI attending local meetings with service-users present:

…they don’t seem to get what’s going on at all, they can really stick their two feet in it…they haven’t travelled a journey. That’s one measure…of what we’ve done here, is that lots of our nurses have travelled a journey… (Staff 3)

He observed that attitudinal change was the biggest challenge and was the most important, albeit unquantifiable, change as a result of SUI: “…providers getting used to sitting around the table with service-users and not thinking that they have to know best…that’s where I see a lot of big change.”

This journey or attitudinal shift was not easily or quickly accomplished for many professionals. Staff 6 observed how SUI shook-up the cosy consensus of those unaccustomed to having to justify their decisions. The middle manager recalled the “uneasy” responses at initial meetings: “…there was no culture of service-users asserting themselves…If a service-user queries something…maybe they’re viewed as challenging the professionals. I remember everyone felt challenged by it…” Staff 1 remembered: “I felt threatened myself when I had my
first experience of a round table…meeting with service-users.” His account conveyed how disconcerting initial experiences of SUI can be:

…initially I wasn’t aware of their roles…that these weren’t colleagues from another service or some part of the management team but…when it became apparent to me…I was taken aback, surprised and I felt a little inhibited in participating. (Staff 1)

The allied-professionals discussed the humanistic values in their training which predisposed them to welcome SUI. They spoke of: “…partnership with the people you’re working with,” and about building personal relationships as part of the way they worked. One participant found personal values more significant than professional background: “…the personal characteristics and the attitudes that they bring from their own lived experience often appears to be a stronger determinant of good practice…rather than what discipline they’ve come from.”

A personal journey of attitudinal change emerged in all medically-aligned participants’ accounts. One nurse manager spoke about his training inculcating an attitude of professional certainty which was resistant to SUI:

I knew best as a [professional], I knew what a patient needed, I knew what they wanted, I knew how to make them better. …service-users were a threat…I thought how would people who are maybe more under-qualified than I am know how to deliver a service, especially after all [my] years experience and training?

He reflected on how training abroad had been important in offering a different perspective on SUI. Now he considered it was: “…impossible to deliver service without SUI.” Two other medically-aligned participants referred to similar experiences with SUI in other countries in learning to adopt a service-user (or carer) perspective. Another spoke about his own experience using physical health services, which had sensitised him to power issues in relation to the patient role. The local participants knew that the ethos of SUI within their team was not widely shared, even in their own locality. One worked part-time on another team with no SUI, and reported a very different attitude there.

The findings reveal that medically-aligned participants underwent a personal journey of attitudinal change and learnt to value the perspective of service-users, sometimes through training and/or working in other jurisdictions. Many had to
let go, to some extent, of their professional certainty, that they had all the answers. In spite of the overall resistance to SUI within the MHS, and an initial sense of being threatened by SUI, all participants now regard SUI as valuable, and have moved beyond regarding service-users solely as recipients of care to agents in their own right with a contribution to changing the ethos of the MHS.

Validating the Service-user Role in SUI

Given their experience of implementing SUI, participants discussed the recognition of service-users’ roles. SUI was a core feature of the way the MDT operated, for example in developing local policy. Staff 6 stressed that: “all new documents, policies, Recovery practices, care plans were…drafted and…vetted by service-users.” Staff 3 believed that SUI added value: “At an operational level…[all our] documents and stuff are way better.” Indeed, the process of developing local policy with SUI was identified by Staff 1 as key to changes in work practice: “it’s more the process…how you involve people and generate a new policy that seems to be contributing most to our…more effective Recovery work.”

The MDT was seeking to develop a peer-support project for service-users, and two of the participants discussed their aspirations around this. Staff 1 explained the MDT regarded: “…peer-support as very important…something that we’re trying to develop.” Staff 3 discussed the value of a service-user “educator role” in training staff and other service-users and observed the lack of clarity nationally about roles available to service-users: "there’s no peer Recovery-support worker role…no service-user advisor/consultant role, they’re not really out there yet nationally". Some participants understood that developing new SUI initiatives was a process that took time, as Staff 1 explained: “…you just have to set simple, achievable goals and build in a stepwise way.” The challenges for the MDT included not just funding for the peer-support role but capacity and time requirements on staff to provide support for service-user workers.

There were varying expectations of service-user performance at meetings. Some of the local participants were concerned that service-users be supported in attending adversarial meetings and prepared for the mixed reception they could
expect from professionals, ranging from dismissal of SUI as a token exercise to an expectation that they perform as full equals. Another opinion emphasised the importance of dialogue and debate between service-users and providers who challenge each other’s opinions. A local nurse manager believed that service-users needed to be able to defend their opinions:

being questioned about your knowledge, your opinion and what would you know as a service-user…You have to be very confident…and know what you’re talking about as a service-user, as much as you do as a service-provider.

This higher expectation was also present from top management:

I want robust people coming to a meeting, some of the meetings are very difficult, very passionate, where people get hurt, get upset, their ideas get trashed, I don’t want someone pulling out the hanky and saying, ‘I’m a service-user, leave me alone’.

This manager, who regarded service-users as allies in reforming the institutional structures, believed service-users needed to able to: “come in and argue your cause and succeed in your argument because you have good arguments, or you make them well.” He certainly was not envisaging paternalistic, token involvement where service-users are: “…only brought in for pleasant stuff…that’s not the real business.” Yet the way the word robust is used above suggests a lack of recognition of SUI issues, especially from a service-user perspective.

Another aspect of role recognition was the absence of a national policy for resourcing SUI. Two participants believed it would be preferable to have funding for the service-user movement sourced independently from the HSE. Staff 11 noted the independence of the user-movement could be perceived as compromised by receiving funding from the HSE or the MHS. For Staff 3 the essential requirement was funding:

…there’s a need for a paid role…if service-users are…coming to committee meetings, [doing] research. We need more money in the service-user movement…across every part of it. The MHS need to be explicit in budgeting for SUI… (Staff 3)

He identified the need for service-providers to proactively champion and negotiate for funding given the lack of resourcing structures. Speaking specifically about the research project with SUI undertaken by the team, he explained: “…if it isn't supported, it won’t happen automatically…there has to be
someone who will literally go and say, ‘we need the funding for this research…and how are you going to pay this person?’” The lack of a national resourcing policy for SUI was hindering local efforts to establish, consolidate and build services with SUI.

All participants believed service-users should be paid for the work they do for the MHS. The top manager argued that those engaging in SUI should be paid: “…you can’t just ask someone to travel 40 miles, have their kids minded, spend the afternoon with well-paid staff.” He described the arguments with colleagues in financial management in the HSE as he negotiated funding to pay service-users and carers participating in the DCU leadership course. The HSE financial department agreed to pay trainees’ travel and accommodation expenses, but resisted paying for their time. He argued for parity of esteem: “…‘Well actually, their time is the most valuable thing they’re giving… Aren’t the staff members getting paid for their time?’”, and also asking professionals whether they valued service-users’ contribution and whether they could afford it, concluding that they should not be initiating SUI if they could not afford to pay service-users.

There are three key findings regarding the validation of service-user roles. The value SUI contributes to the MHS is universally recognised. Firstly, there are no nationally recognised roles for service-users engaged in new SUI developments, such as peer-support or peer-education work; these were being developed through local practice. Secondly, there were different expectations placed on involved service-users; on the one hand that they needed to be prepared to deal with professionals who regard their presence at meetings as a tokenistic requirement, but on the other hand that they be able for the rigors of adversarial meetings, and be prepared to defend their arguments against more powerful actors. Thirdly, given the lack of national policy on resourcing SUI, participants struggled to obtain necessary resources, as they believed involved service-users should be paid for SUI, and that the user-movement was not adequately nor independently funded to support SUI.

“Service-users own the Care Plan”

This sub-theme considers the impact of SUI on the individual clinical relationship with service-users. For all participants, without exception, the
individual level of SUI was the most important. Care planning was considered synonymous with improving the therapeutic relationship. Staff 6 explained that the care plan: “dictates how we practice. They own the care plan, they own their Recovery, they own the way they want staff to deal with them.”’ The use of the term ‘own’ signals a core concept within Recovery51 discourse; that service-users should be in control of how they are treated by the MHS. The term Recovery appeared frequently in every participant’s lexicon, “Recovery plans”, “Recovery policy”, “Recovery team”, to describe both their work; and their hopes for those they provide services to. Local participants regarded individual care-plans, co-designed with the service-user, as key to achieving their aspiration of reforming paternalistic styles of working towards more “Recovery-focused” practice. Staff 1 described the MDT’s emphasis on the language used in care-planning, that of “strengths and needs”, and focusing attention on the: “…expressed wishes…what service-users say they want…” rather than imposing staff assessment of needs. Staff 3 observed that attitudes towards care-planning have changed in the team as a result of SUI. He explained that: “it’s the attitudinal change that’s the most important…, amongst the team it’s certainly improving all the time.”

However, one local nurse manager observed that care planning was an area where nurses, in particular, found it difficult to surrender their power. Staff 9 also commented on the changed interactions with service-users that nurses, especially, have to learn:

Staff have always…thought for the person…because maybe in the past, probably still at the present time, staff feel the service-user can’t make those decisions for themselves and that it’s too time consuming to let that person make the decision for themselves. (Staff 9)

51 A point to note is the frequency with which the term ‘Recovery’ was used by participants. This is evidence of the presence of a specific discourse which is code for a re-orientation of practice away from traditional, paternalistic, coercive treatment models towards practice which seeks to ‘empower’ and include the service-user, recognising strengths and basing decisions on the person’s needs rather than a diagnosis. It is a commonly occurring discursive phrase used by members of the team in conversation and in titles for buildings, committees and documents. Although it is a much abused rhetorical term, and has lost all definitive meaning because of the vastly different understandings of it (Pilgrim 2008; Stickley and Wright 2011a; Stickley and Wright 2011b) in this case one of its functions, as used by participants, is to distinguish this team from the more traditional service-providers they are surrounded by.
The key finding here is that, without exception, SUI at the individual level was considered the most critical level of involvement and was synonymous with care-planning. All local participants referred to improved care-planning with SUI, equated with a Recovery-focused way of working. Power dynamics and decision-making autonomy still remain issues in care-planning for nurses especially, but overall staff attitudes towards care-planning were positively influenced by SUI.

**Tensions of SUI**

This theme outlines how participants negotiated the inherent tensions in supporting service-users without unduly influencing their critical perspective, the question of a representative mandate with SUI, negotiating power imbalances and risks of co-option and tokenistic SUI. The three sub-themes are illustrated in Figure 10 below.

![Figure 10: Tensions of SUI sub-themes](image)

**“It’s a Big Ask for Service-Users”**

The first sub-theme presents participants’ awareness of the demands of SUI for involved service-users, how the service-users responded to these challenges and how the MDT sought to support them. The title comes from a comment by Staff 1: “we’re finding it’s a big ask for service-users.” Staff 3 commented that most people coming into the MHS just want to get treated and get on with their lives. Staff 5 observed: “maybe it’s unfair to lob a person into the middle of [challenging meetings]…Some people don’t want to get involved.” Staff 4 identified some of the demands on service-users: “If it’s challenging for us to work in this system, then what’s it like for someone from outside the system, to
come in and try and put forward their point of view,” and maintained that at least two service-users should attend all meetings to support each other.

Several participants observed that service-users developed a stronger voice due to learning and support from others. Staff 6 commented: “[previously] service-users…mightn’t have had a strong enough voice. They’re stronger now because they’re more self-assured and they’re more knowledgeable about Vision for Change and about services in other areas and about what they want…” Staff 2, like Staff 5, expressed the opinion that SUI had benefits for service-users who got involved: “I’ve seen that growing confidence.” Staff 1 commented on the capability of the service-user researcher, who: “…was a very competent…capable…insightful, very smart person who knew how to negotiate with staff.”

It was apparent that local participants were cognisant that SUI is demanding for service-users and appreciated how they dealt with these challenges. A few participants discussed supports the MDT offered involved service-users, such as strategies to prevent burn-out. One well-known service-user was being invited to every event within the MHS, with lots of staff asking her for advice although she was not getting paid. Some members of the MDT sought to support her in maintaining strong boundaries. As a result, the service-user’s phone number was not given out and she could only be contacted at meetings or through the two mentors established by the MDT. Staff 3 explained: “that sounds quite restrictive. That doesn’t mean we want to control it, it means the opposite, we want to enable that person to make clear choices.” A tension emerges here between preventing excessive demands on involved service-users and allowing them control their own boundaries.

The MDT initiated a dual mentoring arrangement involving both a professional and a peer-advocate. Most participants saw the value of a professional mentor providing practical, moral and emotional support, including de-briefing, to service-users. Staff 10 suggested that a service-provider mentor could support service-users in overcoming the barriers that staff interactions with each other posed to a newcomer. Staff 1 was cognisant of the possibility for undue influence inherent in a service-provider mentor and regarded this role as
facilitating access to practical resources\textsuperscript{52} and providing information rather than a conventional mentoring role, which should be more appropriately provided by a peer-advocate. Staff 2 summarised the tension for service-providers supporting involved service-users. Professionals needed to be:

\[\ldots\text{really mindful of how do you help them to find their own voice…to represent the views of the service-users even though they might be in conflict with the team because that could be a very difficult thing to do. (Staff 2)}\]

Another tension around SUI concerned the representativeness of involved service-users. Staff 3 recalled the detailed discussion by the MDT about the rationale for bringing service-users to MDT meetings which resulted in a job description\textsuperscript{53}: “it’s their experience that we want, that’s the validity…they’re experts by experience and that’s the value of what they’re bringing to the table.” He explained there was no expectation that the involved service-users had to return to a group of other service-users: “they’re not representatives…they’re advisors and that was quite an important change of title.” Yet Staff 4 spoke of the importance for the “service-user rep” to maintain: “a link with the actual service-users on the ground…to be constantly in touch.” She believed such links would be of benefit to involved service-users but questioned: “…how answerable are they to the service-users?” A constituency was considered a pre-requisite by the top manager who was emphatic that involved service-users were representing a constituency of other service-users, and explained that the HSE had resourced the development of NSUE to ensure the voice of service-users and carers would be represented at national level.

There is a key finding about lack of consensus about the representativeness of involved service-users: whether they are representing others or advising on the basis of their own experience. Within the local MDT, the two main instigators of SUI considered that service-users attend meetings in an advisory capacity based on expertise by experience, whereas other team members referred to service-user

\textsuperscript{52} Resources such as the use of meeting rooms, printing and photocopying facilities, access to computers, etc ‘within the gift’ of the local team’s resources.

\textsuperscript{53} In summary, the ‘job description’ outlines the meetings that the service-user would attend and what is provided in terms of supports. It refers also to training that they would like to see the service-user advisor undertake, either prior to or during their period of advising the team. This was the local training provided by IAN or the DCU leadership course. It includes a reference to two mentors: a HSE professional, i.e. the OT manager, and the IAN peer-advocate. For further detail of the job description, see Appendix C.
representatives, with a benefit accruing from links to local groups. However, from the national perspective, involved service-users derived their legitimacy from a constituency.

Another key finding in this sub-theme was that participants recognised the growing confidence and empowerment of service-users but also the challenges of SUI for service-users, admired their ability to meet these challenges and sought to support them in doing so. Participants were cognisant of the tension between supporting service-users taking up a challenging position, yet not overly influencing their voice.

“A minefield of power”

Given the context of power imbalances between professionals themselves, and between providers and service-users, this sub-theme considers how participants negotiated the tensions that power poses for SUI. The title comes from a metaphor used by Staff 1 in the context of a discussion about power. Staff 3 described the three positions (the Clinical Director, the Director of Nursing and the Administrator) with power to affect change locally as “the seats of power”. He regarded meetings as unequal places, even before service-users attended, an observation backed up by Staff 11: “even with powerful professionals…they have to sort themselves out into who is most powerful, least powerful.”

When service-users entered these meetings they were indeed walking into a minefield of power, as this comment on the dynamics at initial meetings with service-users illustrated:

Service-users didn’t feel that they could speak openly or honestly and service-providers…felt that they needed to monopolise…they needed to set the agenda…[This was] a reinforcement of a power imbalance, by just not giving people the time/space to talk…(Staff 1)

One participant was frank about the power wielded by psychiatrists and sought to find agreement about ways to share this with both colleagues and

54 The Clinical Director is the most senior consultant psychiatrist in an area. In the Irish context, the role of Clinical Director is exclusively the preserve of psychiatry. These three people, Clinical Director, Director of Nursing and the Administrator make all the decisions about the application of policy, how the local MHS operate and how the discretionary budget, after salaries and other fixed costs, is allocated.
service-users. He referred to the research project with SUI when members of the MDT and service-users had many discussions about the power dynamics involved in the research. This participant discussed the tension between nurses’ perceptions of a psychiatrist’s use of power as potentially offensive and/or critical of their professionalism and the need to: “empower the service-user researcher and the service-user correspondents to give an honest and more reliable reply.” He acknowledged there was a failure to prepare frontline nurses in advance, who: “…might have felt threatened…what exactly this service-user was doing in a clinical facility asking questions.” Another participant also spoke of failure by the MDT to instruct staff that this was: “…really deadly serious research…you cannot obstruct it in any way, shape or form.” Both participants maintained that what was most important in this project was not the research tool or statistically robust results but: “who was asking the questions.” Several participants recognised the subversion of power dynamics in having service-user researchers enter clinical facilities, where nurses hold power, to elicit the opinions of service-users.

The underlying legislative power of the MHS to treat people against their will was mentioned by only a few participants (but never in relation to how it might impact on the process of SUI). One manager reflected on how legislative power skewed the relationship between the majority of ‘voluntary’ service-users and service-providers. Another participant referred to involuntary admission as part of: “…a whole spectrum where that balance between power and responsibility needs to be made clear.” He concluded that it was: “almost impossible, perhaps it is impossible, to properly subvert what is institutional power.”

Although legislative power over service-users was not mentioned in the context of operational or strategic SUI, several participants discussed this in relation to clinical decisions in terms of a tension between their ‘duty of care’ and ‘positive risk-taking’. Staff 5 referred to the tension of putting the service-user’s preference to the fore but, at the same time, maintaining responsibility. Staff 1 argued that: “the expectation that [professionals] must retain and discharge power and do it exclusively” is a serious obstacle to new practice. He understood that delegating and relinquishing power was beneficial to the
individual service-provider, to the team and to the MHS as a whole, because: “it frees-up time...[and] mental resource, it allows you to think more easily in new ways” and thus leads to: “empowerment of staff through new ways of working and...positive risk-taking.” Therefore shifting the attitude of service-providers from one of control and coercion to one of trust for the autonomy of service-users would have benefits for the professionals themselves.

The key finding here is that participants experienced SUI as a means to unsettle and subvert existing power relations. Overall, psychiatric power, although in the background, was not identified as a current obstacle, given the support of the consultant leading the team for SUI. Nurses were the professional group that were most resistant to SUI. Another finding is the recognition that moving from less coercive relationships with service-users and adopting positive risk-taking strategies would have benefits for professionals.

“Domestication of the Service-User Perspective”

This sub-theme considers tensions surrounding the question of the co-option of involved service-users, as well as the concerns raised by some of the participants about tokenistic involvement. The title comes from a phrase used by a participant in top management who discussed the risk: “of a cosy consensus, or domestication of the service-user perspective.” Several participants had not considered the possibility of co-option until asked; one local manager, in reply responded that service-users had no alternative but to engage, as change would not occur otherwise. He explained why he considered it imperative for service-users to seek to influence change through SUI: “...Sometimes a bottom-up approach is very, very difficult, sometimes it needs to be a top-down approach, when you sell it at the top level then it comes down the line.”

Staff 1 believed that they had made some progress in getting the right balance between the independent voice and the risk of co-option but: “I don’t think we’ve resolved it at all yet.” Staff 4 used the term ‘colonised’ when discussing assimilation of the critical service-user perspective: “…where people stop seeing things, where they came in with a different viewpoint and that gets lost.” Staff 3 discussed a major risk of service-users coming to accept the
excuses or reasons why things are the way they are - professionals being late for appointments, or not listening to service-users because they are too busy:

...you can see things from another person’s perspective too much and if people are very convincing about why they’re doing things in a certain way that you can forget what you came into the room for in the first place...if the service-user representatives start believing those things, it’s more difficult to fight against them. (Staff 3)

During the interview with the participant in top management, I asked his opinion about an observation in the literature that the voice of protest of the user/survivor-movement had been co-opted into the MHS agenda because of the movement’s focus on improving conditions for service-users. While he maintained that insider engagement was the only strategy which could affect change, in his response he drew a direct analogy between the topic of co-option in SUI with the perceived co-option of the trade union movement in the National Partnership Process. He argued that because of their close relationship with the government, and the benefits accruing to them as a result, (such as staying in expensive hotels and playing golf with government leaders) the trade union leaders lost their critical independence and connection to the workers that they were there to represent. The implication was that service-user movement actors run the same risk of co-option if they accept similar personal benefits arising from close association with those in power.

The issue of co-option arises precisely because of the lack of influence service-users have within the MHS. This was evident in the discussions about tokenistic SUI. For instance, Staff 2 recognised that at meetings there can be an assumption that everybody understands what is going on: “but there needs to be consideration of, ‘well hang on a minute, does everybody understand where we’re coming from with this?’” She described how, having observed a shy, reticent service-user at a meeting, she was compelled to reflect on: “the differences between a box being ticked, [and SUI]...being implemented in a real way.” Staff 6 also referred to similar situations: “they may get lost, they may not be prepared to discuss what’s going on if they haven’t been fully briefed or if they didn’t understand...what was going on.” Staff 11 gave an ironic description of a tokenistic exercise in SUI when professionals who believe in their own rhetoric claim: “…‘oh we consult the service-users on everything’.” He parodied
an exercise of picking a random service-user from a day ward: “…‘you’re not to be sitting here smoking, come up and join our management team’. So you get something that’s tokenistic and endorses our view of what’s happening here.”

The middle manager revealed that SUI aided the MHS to implement decisions that had already been taken: “if there are closures or running down a service they have an involvement…an input, so that’s major, it’s not being imposed upon them.” Discussing consultation about the closure of a day centre, another local participant pointed out that it was closing regardless, as the decision was: “…made up at the top, it’s not for discussion basically. I think it’s a staffing issue, they’ve no staff left.” She spoke about the need for openness to all solutions, rather than preventing some options even being considered.

Apart from tokenistic consultation about decisions already made, some participants suggested that it was important to pick the “right”, “balanced” service-users so that meetings can move along in an orderly fashion. One local manager referred to the desirability of: “…orderly discussion…if it’s chaired well and minuted properly…it’s a good vehicle for managing situations.” The middle manager believed that involved service-users should understand both the service-user and the service-provider perspective; what he did not want was: “another form of trade unionism.” The implication is that these managers wanted to contain SUI within acceptable parameters which would not disrupt how the MHS conducts its normal business.

The findings here suggest differing levels of awareness and concern among participants about the potential for co-option and/or tokenistic SUI. Some local participants recognised the risk that service-users could become acclimatised to, and accepting of, excuses for poor practice, thereby losing their critical focus. Others focused on the risk of tokenistic SUI, whereby service-users were out of their depth at meetings and SUI was a box ticking exercise. Some participants indicated that service-users were consulted to make implementing difficult decisions more palatable. Despite the risks of tokenism or co-option, two participants, at local and top management level, considered SUI to be the only strategy available for service-users seeking reform. Two participants in local and middle management believed in selecting service-users who would not be overly
assertive or upset the rules of engagement. These findings reveal that the concerns of service-users about tokenistic SUI are well-founded.

Discussion of Findings

The first theme presented the structural context from which SUI emerges and why participants engage with efforts to reform the MHS through promoting SUI. The first important finding is how the hierarchical and depersonalising ethos of the MHS, institutionally resistant to change, created an inflexible and stigmatising work environment, which resulted in participants feeling disaffected and constrained. The participants’ description of the MHS is consistent with literature, both internationally and in Ireland (Beresford and Wallcraft 1997; Johnstone 2000; Hyde et al 2004; Rogers and Pilgrim 2005; Sapouna 2006; Turner-Crowson and Wallcraft 2002). The self-perpetuating system, which socialises new staff, especially nursing entrants, into the old institutional mould of practice, also resonates with the literature (Hyde et al 2004 p. 235; Johnstone 2000, p.135). As nursing accounts for the largest proportion of staff in the MHS, who have most contact with service-users, this has serious consequences for systemic change across the MHS (Bowl 1996; Breeze and Repper 1998). Hence, the findings and the literature indicate that institutional resistance within the MHS is a serious obstacle to changing practice and to SUI in particular (Bennetts et al 2011; Church 1996; Nelson et al 2001).

The MHS ethos also contributes to a de-personalised culture, within which recognition politics, in terms of status differentials, was affecting everyone within the hierarchical culture, professionals as well as service-users. Allied-health professionals occupy lower status within the current structures and hence identified with the patronising attitudes service-users report around SUI. This is resonant with the mis-recognition described by Fraser (2000), where higher social status is used to delegitimise the opinions of those of lesser status. In addition, literature on the impact of alienating work environments suggests that poor management practices, where staff are taken for granted, given inadequate support and denied opportunities for consultation, result in workers feeling worthless (Eastman 1995). Another finding is the evidence of stigma towards mental health within the MHS itself. This has also been discussed in the
literature, by both professionals (Johnstone 2000; Thornicroft 2006; Sayce 2000) and service-users (Chamberlin 1977; Lindow 1995; 1996). Stigma is pervasive in society, so it is not surprising that it exists within the MHS too. This also contributes to the finding of an inflexible and depersonalising culture, resistant to change, where professionals also experience denials of recognition in an alienating work environment.

Given the legacy of the institutional system (Brennan 2012; Hyde et al 2004; Sapouna 2006; Walsh and Daly 2004), service-users’ legitimate anger as victims of a harmful system needs to be acknowledged. There were different attitudes evident in terms of how participants reacted to service-users’ anger about injustices, incarceration or enforced treatments. While participants did not specify what practices or aspects of the system of mental healthcare provision they considered harmful, there was general acceptance that what happened in the past was wrong and that service-users have legitimate reasons to be angry. There was an assumption by most of those who commented on this anger that it related to aspects of the system that belong in the past. This association of harmful practices with the past can be understood as a defence against the moral ambiguity of working in a coercive system. There was an acknowledgement by one participant that those in power in the MHS, psychiatrists and nurse managers in particular, need to hear and acknowledge this anger. This was considered to be a valuable aspect of SUI, a prerequisite to building genuine partnerships, yet there are no forums or processes to allow people express their anger. Indeed, there was resistance to expressed emotion by most participants who privileged rational discourse. Some were defensive and/or guilty about the past and wanted service-users to move on and look to the future, regarding expressed emotion as a hindrance. Given the cultural resistance of the MHS towards emotional expression, it is unlikely that ‘emotional spaces’ (Barnes 2008) for service-users to legitimately express their anger as victims of harmful practices will be created within the Irish MHS in the foreseeable future.\(^{55}\)

This finding is understandable in light of the culture of emotional ‘etiquette’, endorsed by the unspoken rules of professional comportment at meetings,

\(^{55}\) Organisations such as Mad Pride Ireland, MindFreedom Ireland and Critical Voices Network are providing spaces for this anger to be expressed.
described by Church (1996). Emotional expression is shut down by the rules of bureaucratic engagement (Barnes 2008; Church and Reville 1988; Lewis 2010). That these rules are effective in controlling emotionality is suggested in the empirical account of a lack of overt anger or hostility at operational meetings. This emotionality was more evident at ad-hoc meetings, arranged to engage with the wider service-user community, described in my account of fieldwork in Chapter Four.

**Drivers of SUI**

The second theme presented accounts about the various drivers for SUI, including participants’ rationales and motivations for developing SUI initiatives. It also presented what they had learnt about SUI as a result, their experiences of validating the role of involved service-users, the changed attitudes of service-providers and other benefits that resulted, including changes to work practices, such as care planning.

The first sub-theme, “How Far Up the Ladder?” found differing perspectives on the rationales for SUI between national and local participants. The rationale for SUI, as articulated by a participant in top management, resonates with Beresford’s (2002) categorisation of consumerist drivers for SUI, whereby a neoliberal ideology of ‘value for money’ and the ‘consumer is king’ is used to drive institutional reform of wasteful, inefficient practices. A managerial focus will be concerned with improved demonstrable efficiencies in service delivery, which this participant links to a discerning customer. This pronounced use of managerial discourse, while linked to an evident passion for reform of an institutionalised system, does not accord with regarding SUI as a social justice issue. According to Rutter *et al* (2004), managerial approaches to SUI, which do not recognise the specific philosophical and ideological grounding of the service-user’s experience, have failed on many occasions. If there is no real engagement with the human rights concerns and contested understandings of psychosocial distress articulated by service-users, then SUI becomes a cosmetic exercise. Given the pervasiveness of managerialist neoliberal discourse throughout top management of the health service, it may be the cultural milieu of those holding senior management positions to regard healthcare as a business and SUI as
quality control. Nevertheless, there is a tension between managerial discourse and the recognition of the lack of choices available to service-users within the MHS which was resonant with the finding of a captive, fearful audience in Chapter Five, so there was evident empathy and understanding of the service-user position vis-à-vis the MHS.

The expectation that involved service-users will assume equal responsibility and accountability with the other players in the boardroom is an extension of neoliberal ideology. The position of top management was that service-users are representing a constituency, and they must accept equal responsibility in front of their constituency for the consequences of decisions made in the boardrooms of power. NSUE has received significant resources from the HSE to develop a representational voice for service-users and carers and it is from this group of elected representatives that robust people are expected to emerge, who are capable of influencing decisions in the interests of service-users against the powerful vested interests of those who uphold the biomedical psychiatric hegemony. And it further appears they will be expected to align themselves with those in power and defend the decisions taken, thereby increasing distance and possible alienation from those they were elected to represent. Such processes are commented on by Beresford (2010a) who discusses the failures of this form of representational political participation to meet the needs of the user/survivor movement.

To expect equal accountability without equal power is unjust; it bolsters the position of the powerful, while providing them with a scapegoat for unpopular or unjust decisions. Service-users are evidently unequal and perceive themselves as unequal in MHS forums (Chapter Five), therefore they cannot have equal control over decision-taking as well-paid, well-resourced and higher status professionals. Without equal control over decisions made, equal accountability is unjust, and a way of blaming others for lack of progress or disappointing outcomes. This position contradicts the earlier nuanced understanding of participation and the social injustice of the position of service-users by the same participant. Given the highly complex nature of operationalising SUI, with the inherent tensions and the contradictory drivers, such as neoliberal ideology on one hand and social justice/human rights demands on the other, it is little wonder that significant
ambiguities exist for professionals opening a door between service-users and power holders within the MHS.

The rationale of local participants for SUI was more closely aligned with the rationale of service-users, to democratise the MHS. There was a recognition that SUI can help develop and design better MHS, as service-providers were acknowledged not to have all the answers. This is consistent with findings in literature on SUI that the service-user perspective is sought to improve service-delivery (Barnes and Cotterall 2012; Bennetts et al 2011; Weinstein 2010). However, the concerns in evidence, especially from local and middle management participants, were about service-providers’ agendas, developing community services to some extent, but certainly about protecting frontline services from cutbacks. In this case, front-line service-providers have aligned their perspectives with those of service-users, in that they regard the protection of MHS budgets to be in both their interests. Certainly, services and supports to service-users are more vulnerable to budgets cuts than salaries. The expectation is that SUI will strengthen the argument to protect frontline MHS from budget cuts. This re-emergent finding, that SUI is being leveraged to support the interests of front-line professionals, is resonant with critiques of SUI (Forbes and Sashidharan 1997; Carey 2009; Croft and Beresford 1995; Lindow 1999).

What is heartening from the evidence in this category, however, is the acknowledgement that service-providers do not have all the answers about how to design services that support service-users. This is a welcome exception to the view of mental health professionals as infallible experts (Healy 2011). Talseth et al (2004), who researched mental health professionals working with suicidal people, suggested that service-providers relinquishing the need to have all the answers allowed for a more real and human response to deep pain and distress. Is it not logical to extend that observation to humanising contact with service-users in the forums of SUI? If service-providers accept that they do not have all the answers then dialogical space opens up for alternative viewpoints (Thomas and Bracken 2008).

The findings in the sub-theme “That’s the Way the Flag is Blowing” confirm that SUI is a national top-down policy implemented at the discretion of local leaders. The finding that SUI and the service-user movement, certainly locally, is
a sponsored ‘top-down’ development rather than an organic social movement will be discussed in Chapter Eight. There was evidence of a dynamic process underway in this MDT, of engagement with the idea of SUI as a positive development, supported by middle management in the area.

Given that SUI is a policy priority for top management, implementing SUI offered tangible rewards for this team, such as increased validation of their work and more resources in terms of staff allocations and funding for projects. As a result, this team are regarded by top management as exemplars for a modern MHS. Many other positive benefits from SUI for service-providers were found, primarily in terms of emotional and job satisfaction. Perhaps the enthusiasm for service-users attending meetings is understandable given the earlier evidence of an alienating and depersonalised work culture. Considering the weight of evidence that SUI resulted in a better emotional tone at meetings, more openness and honesty, and participants feeling validated and re-affirmed in their thinking and ways of working, it is little wonder that this MDT welcomes SUI. It is likely that humanising meetings and encounters with service-users is good for staff mental health too. There is a need for service-providers, not just service-users, to attend to their emotional well-being (Bolton 2009; Eastman 1995; Hochschild 1979; Rabin et al 1999; Reynolds and Read 1999). Clearly SUI is good for more than just getting feedback on ways to deliver better care to service-users.

SUI had a positive benefit in reducing negative attitudes towards service-users, allowing professionals to see them as more rounded, competent individuals and has helped some participants believe in the possibility of Recovery, that others too could overcome mental health difficulties. Thornicroft (2006) suggests that positive social contact results in decreased negative stereotyping of people with psycho-social problems, a factor that is operating in this case. In this instance, SUI was evidently reducing stigma and opening the possibility that professionals could admit to their own experiences of emotional or psycho-social challenges, given the increased recognition of the competence and capability of service-users.

participant observed that the individual traits or values that people bring from their life experience often influence practice to a greater extent than professional training. Rogers and Pilgrim (2005, p.2) argued that those psychiatrists who display non-typical values and attitudes have been influenced by humanistic disciplines. The allied-health professionals and some of the medically-aligned participants displayed humanistic values in their discourses and practice. Similarly, some of the group revealed that their experiences of working abroad, where SUI has been a feature of MHS for decades, has changed their perceptions of how MHS should interact with service-users. The culture of Irish MHS has been much slower to adapt to the implementation of SUI as standard practice due to the more pronounced institutionalised legacy of MHS in Ireland (Brennan 2012; Sapouna 2006; Walsh and Daly 2004), and the continued dominance of the psychiatric profession in comparison with other countries (Hyde et al 2004). Most promising, perhaps, in terms of the findings was the journey that medically aligned participants had taken as a result of SUI, whereby their attitudes towards service-users and SUI had shifted perceptibly as a result of their experiences.

The findings also provide evidence of changes to ‘epistemological certainty’ (Pilgrim and Rogers 2009). The experiential knowledge of service-users can provide a reality check for service-providers, especially when the reported experiences do not concur with service-providers’ understanding of the impacts of their treatment practices (Cutcliffe and Happell 2009; Wilson and Beresford 2000). Ramon (2003) refers to the uncertainty that practitioners may experience as a result: to be confronted, or even to anticipate confrontation, about one’s whole professional training and belief system can be threatening for service-providers. After all, the whole integrity of the MHS and its biological treatments may be called into question by service-users (Beresford and Wallcraft 1997; Rose et al 2003; Wallcraft 2010).

The findings in Validation of the Service-User Role relate to evolving expectations about the roles of involved service-users, including reimbursement for SUI. As yet, SUI is a relatively new development in the Irish MHS, and no national guidelines have been established to aid the operationalisation of SUI, including definition of roles for service-user employees and indeed how and whether service-users are to be supported and paid. Bennetts et al (2011) note a
similar lack of clarity on roles of consumer employees in Australia, although there is a long established track record of employing service-users within the Australian MHS.

Another finding was the expectation that involved service-users be able to hold their own in tough negotiations, which suggests an assumption of equity in SUI situations even though participants do not have equal resources, power or status. Yet, for this participant, a defence of ‘I’m just a service-user’ is tactically unproductive. There is no place at the table for those who cannot play by the tacit rules of engagement, and the challenge presented to service-users is not to undersell themselves. Emotional expression is not welcome in these environments (Barnes 2008; Church 1996; Lewis 2010). Farr (2012, p.80) refers to Young’s (2000) observation that privileging reason and dispassionate argument in deliberative processes of engagement is exclusionary. What is implied in the data is that service-users who engage in tough negotiation should be dispassionate enough to handle all attacks. Potential allies are important to mentor and help service-users develop the skills to engage in meetings such as these. However, allies have much to learn about the conditions of SUI from the service-users’ accounts of misrecognition (Chapter Five). Even this glimpse into the corporate battle ground of negotiations at strategic levels of SUI reveals the challenge for service-users and their allies to develop strategies to deal with this form of engagement.

There was a finding of a firm commitment, both in principle and practice, to paying involved service-users for their work for the MHS, although there is no national policy to resource SUI. Service-users and academic commentators on SUI have argued that service-users should be paid for their effort on behalf of the MHS (e.g. Chamberlin 1990; 2005; Forrest et al 2000; Pilgrim and Hitchman 1999, p.178). In Chapter Five, payment for service-users was found to be a principle of equal recognition and redistribution. Participants in this chapter also affirmed the need for payment to create parity and to equally value service-users’ time and efforts. The principle of paying for SUI was resisted by financial administrators in the HSE, who do not have policy or procedures in place to pay non-employees. Failure to allocate resources to support SUI is an instance of what Fraser (2000) describes as mal-distribution; structural inequities in
redistribution of resources from those who control resources to those who do need them. Local arrangements to resource SUI are dependent on the goodwill and power of allies in middle and top management. Ryan and Brambler (2002) found that, in the UK, the lack of national guidelines on payment for expenses and/or time results in ad-hoc custom and practice which can create misunderstandings, discrepancies in local practice and conflict between those making payments and those expecting them. Resource obstacles to SUI are a concern which requires the development of national guidelines for reimbursement, so that consistent practice develops at local level as the national policy of SUI is implemented more widely throughout the country.

A major finding to emerge in “Service-users own the Care Plan” is that SUI at the individual level was considered the most critical level of involvement, and the focus was on the care planning process as the means to improve care to individuals. There was an evident concern among participants to ensure that nurses engage with the process in a person-centred way in order to address the expressed wishes of the service-user, rather than having staff impose their assessment of needs onto individuals. Talking about strengths and abilities rather than deficits, and letting the person chose their own goals is a core shift in care philosophy and practice (Slade 2009; Reaper and Perkins 2003; Turner-Crowson and Wallcraft 2002), resonant with the social model of disability (Beresford et al 2010; Oliver 1990). Notwithstanding a frequent gap between philosophy and practice, as a strategy such a focus by team leaders can help to bring about attitudinal change in care-givers (Salgado et al 2010; Roberts and Wolfson 2004).

Changing power dynamics in nurses’ care relationships with the people they work with were found to be the most difficult changes to effect, especially in relation to allowing service-users make their own decisions. Part of the process of MHS reform requires service-providers to relinquish some of the control they have traditionally held over all aspects of service-users’ lives (Cutcliffe and Happell 2009; Johnstone 2000; McGruder 2001; Townsend 1998; Walsh et al).

56 The HSE published guidelines for paying travel expenses to volunteers going to meetings with the HSE in 2011 but there is no mention of payment for time. The suggested expenses for volunteers attending meetings with the HSE fall far below the level of expenses set for staff, in clear contravention of the principle set down in Vision for Change (2006, p.28): “Service-users should be reimbursed for out-of-pocket expenses at the same rates as health professionals”.

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Relinquishing such control was found above to have positive benefits on staff and the MHS. It is also crucial in how service-users experience the MHS (Chamberlin 1977; Deegan 1988). This is the reform of care that participants expect as a result of SUI in general, but most especially in care planning at the individual level.

**Tensions Operationalising SUI**

The third and final theme to emerge is the tension participants experienced in operationalising SUI. The first of these tensions involved supporting service-users to meet the challenges of SUI, while not unduly influencing their critical perspective. Negotiating power inequalities presented another tension for participants, while the final tension of SUI is the risk of co-option.

The sub-theme, **“It’s a Big Ask for Service-Users”** considered the tensions in supporting service-users, given their understanding of the challenges service-users face. One of the first challenges in initiating SUI lay in recruiting enough service-users to become involved. This issue is consistent with the literature (Crawford *et al* 2003; Rutter *et al* 2004; Weinstein 2010). There are many reasons why people choose not to get involved, ranging from stigma, to non-recognition at meetings, to disinterest (Bowl 1996; Faulkner 2004; Rutter *et al* 2004). Disillusionment with power imbalances, feeling marginalised at meetings and burnout are often the reasons that service-users drop-out after a period (Bowl 1996). Participants were aware that SUI is demanding for service-users and they sought to mitigate the challenges by offering various supports. They also admired the abilities of service-users to deal with the challenges of SUI and observed how involved service-users developed skills and competencies in negotiating difficult situations as a result of their participation in SUI initiatives.

This growth in confidence is consistent with many accounts of SUI (Barnes and Cotterell 2012; Carr 2004; Beresford and Croft 1993; Pilgrim and Hitchman 2002; Weinstein 2010) but it is also to be noted that intrinsic benefits of SUI can be equated with therapy and empowerment (Campbell 2005; Lindow 1999a; Rose *et al* 2010). Nevertheless, the experience of attending meetings provides service-users with an opportunity to develop skills and confidence and accumulate a body of knowledge that can contribute to increased status and...
recognition from service-providers and other service-users, a process described within social movement literature (Brown and Zavestoski 2004; Crossley 2005; Craig et al 2004; Hess 2004). This point of analysis will be developed further in Chapter Seven.

Notwithstanding possible benefits for service-users, SUI places considerable demands on them, and the MDT discussed supportive strategies such as creating boundaries to prevent burn-out, shielding involved service-users from enthusiastic efforts to have SUI at every meeting and event organised by the MHS. Participants also sought to support service-users by providing mentors. Within the literature (e.g. Bozeman and Feeney 2007; Periyakoil 2007), mentoring is well established as a principle to provide guidance for a new employee or student and to help acclimatise to new surroundings and new situations. Mentoring by an existing employee was considered one of eight critical supports offered to service-users taking up employment in MHS (Perkins et al 1997) and in SUI in research (Telford and Faulkner 2004). Some participants recognised the inherent tensions and conflicting roles for professionals acting as mentors for service-users, such as overly influencing their perspectives, yet unless professionals leverage access into the closed spaces of the MHS, SUI will never commence. By providing supports and mentoring, opening access to their facilities, and advocating for funding for SUI projects, individuals on this MDT sought to improve conditions of participation for involved service-users, while being aware of the need to ensure service-users maintained their critical perspective.

There were conflicting expectations about the function of involved service-users. The primary innovators of SUI on the MDT sought individuals to contribute their expertise by experience rather than a formalised representative with links to a larger body of local service-users, as this would require more resources than were available to either the involved service-users or a local user-group. However, many participants referred to involved service-users as representatives, and several spoke of the benefits of links to a wider pool of service-users, in ensuring the critical voice was not lost. This was motivated by a concern to avoid co-option, an issue taken up later. By referring to service-users as ‘experts by experience’ participants accepted the validity of the contribution
that direct experience has to offer to reform how services are delivered. This validation of the service-user insight is resonant with the politics of recognition discussed by Lewis (2009), and participants’ acceptance of service-users’ expertise by experience highlights the positive recognition of the status of service-users by participants.

On the other hand, from the perspective in the national office, although there is an appreciation of the validity of service-users’ contributions, involved service-users require a constituency base to have legitimacy. The legitimacy of service-user representatives is an issue that has bedevilled service-user activists since SUI became established as official policy in other countries (Beresford 2010a; Bennetts et al 2011; Campbell 2001; Crepaz-Keay 1996; Lindow 1995, 1999). The question of legitimacy and a constituency base is not just an issue of representative justice, but participatory democracy. This issue is discussed in greater detail in Chapter Eight, so will not be addressed here, except to emphasise that resources are required to support representative processes, and indeed the development of user-groups. This is resonant with concerns about the need for redistributive justice in resourcing social movements of disadvantaged groups, discussed in the literature (Beresford 2009a; Chamberlin 2005; Fraser 2004; Young 2000). The lack of consistency between local and national understanding of the representative role of involved service-users is a tension which poses potential difficulties in the wider rollout of SUI.

Another tension emerges in “A Minefield of Power”. The power inequities between professionals and service-users require negotiation in order to improve conditions for participation. The visible power held by biomedical professionals over the entire organisational structures of the MHS formed the backdrop to the efforts of this team to develop SUI. The hierarchical organisational structures determine who is powerful based on their rank, consistent with literature on MHS structures and practices (Hyde et al 2004; Pilgrim and Rogers 2009; Walsh et al 2008). Those in the seats of power retain the power to determine who and what is on the agenda, a feature of hidden power discussed in Chapter Eight. Some participants suggested that full involvement will only occur once service-users gain access to these teams.
Psychiatric power was not found to be an obstacle to SUI in this MDT, given the support by the consultant leading their team. Instead nurses were found to present the primary obstacles to SUI. The consultant psychiatrist, because of the benefits he saw in SUI, both personally and for the team as a whole, was using his positional power as a positive force for change, aided by the other champion for SUI, the OT manager. Here, power can be understood as productive in the positive sense of not just weighting lightly on those subject to ‘power-over’ (hence masking how invisible power works) but in seeking to affect a shift in power away from the traditional power holders to service-users.

SUI requires a negotiation of power with service-users, and one powerful professional was attempting to make hidden power visible by open and frank discussion, thereby placing it on the agenda. One participant discussed the idea that personal freedom can accrue to service-providers who relinquish the tight control they have traditionally held over service-users. Not needing to control someone or something has long been recognised as having a liberating effect on the controller or oppressor (Dahlqvist et al 2009; McIntosh 1995; Stoller 2006). More involvement by the service-user in their own care would no doubt free up the energy service-providers have dedicated to seeking to control service-users. Work by Talseth et al (2004) suggests that service-providers who can move from interacting with service-users in overly controlling, power-over relationships to more humane power-to interactions may gain personally. This would be a significant benefit of SUI for service-providers and would have a reformative affect on how MHS interact with service-users, if meaningful changes in power-over service-users were to occur as SUI is more widely implemented.

Despite the underlying constraint of power in all its forms (discussed in more detail in Chapter Eight) the participants in this study were seeking to create ‘constructive partnerships’ (Croft and Beresford 1995, p.69) with service-users. Preparation for the user-involved research project required negotiations around power between service-users and members of the MDT. Power, both visible and hidden, was used to facilitate SUI in the research project, and to mitigate against negative responses from some frontline staff, albeit after the fact. Indeed, SUI unsettled routine power relations, whereby having service-users go into clinical facilities and conduct research with other service-users was subverting existing
power structures. An additional finding is the observation about the critical importance of who was asking the questions of service-users in the research process. This comes back to epistemological authority, and recognition of the influential role of the researcher standpoint in the research process. It is argued by survivor researchers (Sweeney et al. 2009; Faulkner 2004) that having a peer researcher ask the questions may help to generate more reliable responses, as the power differential is not so stark.

The “Domestication of the Service-User Perspective” sub-theme contains findings about the tensions surrounding the risk of co-option and tokenistic SUI. Some participants expressed concerns about co-option in terms of service-users maintaining their independence and critical perspectives. A significant risk of co-option was identified in that involved service-users might begin to believe the excuses offered for the status quo, as an unintended consequence of familiar relationships between service-providers and service-users. Carey (2009), among others, argues that participation can inadvertently justify and promote hegemonic agendas. This includes the risk that service-users accept that MHS are the best, and only, place where psycho-social distress be treated, or that the practices on offer are acceptable, a risk named by one participant. The potential of counter-hegemonic space with other service-users was recognised, which could prevent involved service-users losing their critical insight which, after all, was identified as the important contribution that service-users bring to the table. Yet, the issue of protest was openly acknowledged to be incompatible with participation by one participant: in order to participate, the freedom to protest must be jettisoned. This suggests that the risk of co-option is not simply an unintended consequence of SUI, but potentially a negative consequence of MHS strategies around SUI. As Croft and Beresford (1995), and many since have argued, by participating service-users risk reinforcing the status-quo.

Service-users’ lack of influence over decisions is a major obstacle to meaningful SUI, which links tokenistic involvement to the risk of co-option. It was evident that some decisions were already made before they arose at meetings with middle management in the area; SUI in some instances was found to be about consultation on how to manage these cuts or decisions, consistent with the literature (Forbes and Sashidharan 1997; Carey 2009). That cuts to services may
be beyond the control of local or middle management (indeed top management), particularly in severe recessionary times, is not the point. Not only do service-users have no control over the way services are to be resourced, their attendance legitimises management decisions, a feature of co-option.

The characteristics of involved service-users arose as an issue in two instances. In relation to the issue of tokenistic involvement, the quiet, reticent service-user alluded to in the data may or may not have felt included, but given the dynamics of meetings, and the inequities of power, it is no wonder the participant questioned whether that was an occasion of true participation or the optics of inclusion. Selecting a quiet, compliant service-user, totally unprepared for what is coming, bringing them into a roomful of high-powered professionals, as the final comment illustrated, does not mean the requirement for SUI has been achieved. This data indicates why preparation for SUI by adequate training for service-providers and service-users on SUI is essential. Bowl (1996) explained that the way committee meetings are conducted suits confident full-time professionals; therefore service-providers serious about SUI need to consider the timing, location, pace and format of meetings in order to make it easier for service-users to participate. Service-users, like any other segment of the population, may include confident, articulate individuals, but many are not, due to many compounded social injuries as a result of discrimination, exclusion and poverty. Additionally, service-users may experience diminished mental resources (McDaid 2009) such as lack of motivation or apathy, which may be a consequence of high levels of prescribed medication, and/or the difficulties that brought them into the MHS in the first place.

Bringing unprepared and ill-equipped service-users into situations where there is no serious effort to address the unequal conditions of power and recognition is not just endorsing tokenistic involvement but is setting them up for a third level of trauma. Cresswell (2005, 2009) discussed how survivors of self-harm were doubly traumatised by failures of the MHS to adequately address their original trauma. In the context of the MHS failing to adequately address the conditions of participation, including providing adequate supports to ameliorate the challenges of disrespect, mis-recognition and non-recognition, and power imbalances, SUI can be construed as constituting a third trauma.
Another significant issue related to the characteristics of involved service-users was the indication that those who engage may be selected because they are likely to be amenable to service-providers’ agendas. This suggests that, while there is an expectation from a participant in top management that involved individuals will be robust and able for tough negotiations (as was found in “Validating the Service-User Role”), they are required by middle management to be not too robust, not to perform like a sectoral interest group and to play by the rules of bureaucratic engagement.

Reinforcing the finding about co-option is the manner in which meetings are conducted to keep the discussion civil and orderly, preventing ‘emotional space’ (Barnes 2008) from opening up. This suits the bureaucratic, rational approach favoured by service-providers (Church 1996). It is interesting how minute-taking is described as a tactic for managing situations. Who writes the minutes is a display of hidden power, as inevitably these are written-up by service-providers, or their secretaries. How they are written is also part of the process of control. The language used will inevitably be that of the service-provider (Happell 2008; Cutcliffe and Happell 2009; Walsh et al 2008). Given that issues are often already decided before they arise at meetings, in spite of the underlying goodwill and commitment towards SUI evident from participants, the question remains: to what extent can service-users counter attempts to co-opt their efforts and improve the conditions for participation which currently facilitate tokenistic involvement? This is an issue that the participants in the next chapter passionately contest.

Finally it is highly significant that the concerns identified above are at play in a facilitative, supportive environment where positive attitudes and goodwill towards SUI is well-established and where participants are seeking to improve practice and conditions for SUI. This begs the question, what are the conditions for participation likely to be in situations where SUI is implemented simply to satisfy a top-down policy imperative? Once again the next chapter highlights some of these issues.
Summary

This chapter presents data from eleven participants who are working within the MHS to reform service-delivery through the involvement of service-users. Apart from two interviewees in administrative management, they are all members of one team that has been implementing SUI initiatives. The participants are all proponents of the principle that service-users must be included in how services plan and deliver care, believing that SUI will change the old institutionalised, paternalistic ethos of how care is provided, leading to services which are more client-centred. The chapter examines these participants’ experiential understandings of SUI, the tensions and dilemmas, and the benefits and challenges of SUI. The benefits are found to be both personal and professional. All report experiencing increased job satisfaction as their work environment became less depersonalised and dehumanised. There is a finding of changed attitudes towards service-users, from seeing them as passive recipients of care to recognising them as competent fellow human beings, as a result of working with them on committees and in specific projects. At a professional level, there are reports of improved attitudes from nurses exposed to SUI resulting, for instance, in greater commitments to include service-users in developing their care plan, or allowing service-users more control over determining their own goals for care.

There are accounts of learning from experience. There is no blueprint to outline explicitly how the theory, values and practices of SUI can ensure that the MHS meet service-users needs. Therefore, the MDT face many tensions and challenges in seeking to create optimal conditions for SUI, a new practice in an Irish context. Key challenges in this respect include: attitudinal resistance from an institutionalised and inflexible system characterised by hierarchical and professional tensions; lack of national policy to resource SUI initiatives within local services; staff time and commitment required to establish further initiatives such as peer-support workers; the lack of defined roles for service-users in SUI and lack of required staff resources and training, which in turn, is a barrier to securing staff cooperation.

The tensions include power dynamics within the hierarchical structures spilling over into SUI initiatives, for example when existing or external visiting
staff replicated old institutionalised patterns of interacting with service-users at meetings. There is discomfort evident about service-users righteous anger at abusive practices, which is deemed to refer to past rather than current practice, a mechanism of defence. There are differing levels of awareness among participants about the ambiguity of occupying powerful positions within the MHS and aligning with those subject to a coercive system. Such tensions emerge in relation to issues such as how best to wield positional power to support service-users engaging in new activities, for example service-user research, which threatened existing power structures of nursing practice. Another area of tension is achieving a balance between supporting involved service-users without influencing their critical perspective and/or respecting their autonomy. The risks of co-option are a tension of which some participants are more cognisant than others.

Power emerges as a theme from the data, not least because it affects many research participants in their own professional roles. As a result, some participants are disaffected and constrained by the existing power structures, and identify with the struggles around recognition that service-users experience. One key finding is that SUI unsettles existing power relations with service-providers, especially nurses - the majority profession within the MHS who present the greatest resistance to sharing power with service-users.

The evidence from participants at the clinical frontline is both supported by, and at times divergent from, the perspective of a manager in the national directorate for the MHS. The national rationale for SUI, expressed in managerialist neoliberal discourse, is resonant with Beresford’s (2002) classification of a consumerist, top-down impetus for SUI within the MHS. At a national level, SUI is understood as discriminating customer feedback from involved service-users who would be prepared to collaborate professionally, negotiate and cut the best deal possible for service-users with other powerful vested interests, and be accountable to a constituency of their peers. Local participants, including at middle management level, do not expect service-users to represent the entire community of service-users without the support of structures to enable them canvas, and be informed by an active and involved service-user movement. The local participants’ rationale for SUI is more focused
on combating resource cuts and re-allocating care towards the community, with increasing involvement of service-users in determining their own care goals. To this end, they see themselves in strategic alignment with service-users (and carers) in resisting cuts to services. The national rationale for SUI is focused on reform of institutional practices and structures. However, SUI occurs at the discretion of service-providers and therefore occurs on their terms and conditions, leaving service-users unable to effect real change against the existing power structures.

There was a finding of awareness that service-providers who move from interacting with service-users in overly controlling, power-over relationships to more humane power-to interactions, stand to gain both personally, in terms of humanising their work environment and professionally in terms of additional resources to develop new projects with SUI (such as a peer-support project) and other validations from senior management of the HSE (who are driving the national SUI agenda). However, developing further opportunities for SUI requires recognition of the inequities in power between service-providers and service-users and appropriate policies will need to target the sources of such inequities.

There are key points of convergence between the findings from the service-provider participants in this chapter and that of service-user participants in Chapter Five. Briefly, these concern the status and recognition of service-users within the MHS, how power operates in SUI to constrain the limits of what is permissible, and the role of local staff allies in the success of SUI initiatives. A common finding in both chapters was a recognition that remuneration in the form of payment for service and expenses incurred by service-users undertaking SUI is necessary for parity of participation. Both sets of participants are committed to SUI as the best way to transform care towards a more client-focused approach. However, a key point of divergence emerges from the different positioning of participants. Service-user participants experience first-hand the denials of recognition and the impact of the power inequities in SUI forums, whereas the service-providers are witnesses to these experiences. Therefore the emotional tone of the data in both chapters is different. The service-providers are far more enthusiastic about SUI whereas the service-user participants’ attitude is one of
dogged courage and persistence in spite of their powerlessness being mis-
recognised due to their service-user status. The power dynamics within the MHS
and in SUI forums resulted in service-user participants maintaining constant
alertness for status insults and readiness to contest the pervasive bio-medical
model as a personal affront to their experiential knowledge.

The main finding in Chapter Five is the inherent tension between
contestation of the positioning of service-users within the MHS (a fearful captive
audience) and collaboration to change how service-users are treated, while being
cognisant of the risk of co-option and tokenistic involvement. In this chapter,
while the service-providers are aware of the risk of co-option, there is enthusiasm
for SUI, which is regarded by some as a means to unsettle existing power
relations and for others to leverage better working conditions and maintain
services. The primary tension, particularly for local participants, lay in
reconciling the challenges posed by aligning with service-users to reform
institutionalised practice without access to the necessary resources and practical
policy guidelines to support these innovations.
Chapter Seven:

National Activists’ Perspectives
Chapter Seven: National Activists’ Perspectives

Introduction

The final group of participants, experienced national activists in the Irish service-user/survivor movement, are presented in this chapter. The same research question was posed; What are participants’ understandings and experiences of SUI? The participants are introduced and their experiences of service-user involvement (SUI) presented. The first theme to emerge highlights their contestation of bio-psychiatry and the ethos of expert-led care operating within the MHS and how they frame taken-for-granted practices in the MHS as human rights abuses. Participants highlight the epistemological gulf between their experiences and bio-medical psychiatry and this epistemological challenge contributes to the development of a collectivised political identity and mobilises the movement in its contestation of current practice. The second theme explores tensions that emerge in spite of a common goal to reform MHS provision, as a wide spectrum of opinion exists about the appropriate strategies to pursue. The final theme returns to familiar concerns about the power structures within the MHS, which are generally inhibiting, but occasionally facilitating, SUI. As before, the data will be presented and then followed by a discussion developing different points of analysis. The summary synthesises the main findings and discusses convergent and divergent findings from earlier chapters.

A theme in this chapter is the emergence of a politicised, shared identity, which leads to the development of a social movement. Brown et al (2004) characterise the transformation of personal experiences (with a health condition and failures of health systems responses) into politicised collective action as a feature of health social movements. They characterise the psychiatric survivor movement as an Embodied Health Movement (EHM), because people’s personal experiences frame their organising efforts and critiques of the system and these experiences constitute a politicised collective identity. In this chapter such a process constitutes participants as social, or health, movement actors.57

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57Although I refer to them as movement actors, the focus remains on their experiences and understandings of SUI, rather than considering the bigger question of how the Irish user/survivor
**Participant Profiles**

The twelve participants interviewed are experienced activists at a national level in the user-movement in Ireland. The gender disproportion, nine men and three women, reflects the prominence of men in the national user-movement. Interviews were conducted at a place chosen by the participants, two in their offices, four in their homes, and six in public spaces, such as hotel lobbies. Two people were positive about their own personal experience of care by professionals; the rest were not. The details are necessarily limited in order to protect the participants’ anonymity in a small field where many of the national players are well known and could be identifiable by linking them with NGOs or statutory bodies.

Five participants were employed in the education of mental health professionals, peer-advocacy or mental health training generally and had regular contact or engagement with many different MHS teams and settings throughout the entire island of Ireland. Four participants had experience of SUI on official national policy and statutory bodies. Three participants had experience of SUI in the North of Ireland (NI) dating back to 1985. In the South, SUI has been slower to develop. The Irish Advocacy Network (IAN) was established in 1999 by service-users at a conference in Derry. Seven participants were involved with IAN as employees or members of the Board of Directors; two others were service-user members of the National Service-Users Executive (NSUE), established in 2006. Some were also involved in other service-user/survivor organisations in Ireland.

The criteria for inclusion in this sample were involved users/survivors who came through the user-survivor movement as activists to take up the positions they now hold. Those who hold paid positions in NGOs but were not formerly involved as movement activists were excluded, as the study was focused on how those involved in the emergent user/survivor movement understand and lobby for SUI as a ‘bottom-up’ agenda for social change in the mental health field. I believe the people interviewed represent the wide spectrum of opinion within the user/survivor movement in Ireland. While all contributed to the richness of the movement itself plays out in the politics of the mental health field. This second topic, while significant, is beyond the scope of this thesis.
overall findings and conclusions, some appear infrequently in the data presented because the issues they raised were beyond the scope of the thesis, in particular the status of service-users in society generally and relationships with professionals in the third sector (my focus being the statutory MHS). However, any conflicting or divergent views to the general consensus about the participants’ experiences of SUI were included. All participants are given pseudonyms to protect their identities, and sometimes comments are unattributed in order to further preserve anonymity. Table 5 summarises the participants’ experience and some of the forms of SUI they were active in.

**Table 5: Participants and their experience of SUI**

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Years of SUI</th>
<th>Employed in MH field</th>
<th>Experience of service-user involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jack</td>
<td>15+</td>
<td>Yes</td>
<td>Advocacy, professional education, committees, research</td>
</tr>
<tr>
<td>Kate</td>
<td>10+</td>
<td>Yes</td>
<td>Advocacy, committees, professional education, research</td>
</tr>
<tr>
<td>Liam</td>
<td>15+</td>
<td>No</td>
<td>Advocacy, professional education, committees, peer-support</td>
</tr>
<tr>
<td>Martin</td>
<td>15+</td>
<td>No</td>
<td>Advocacy, professional education, committees</td>
</tr>
<tr>
<td>Niall</td>
<td>20+</td>
<td>Yes</td>
<td>Peer-support, professional education, committees</td>
</tr>
<tr>
<td>Owen</td>
<td>25+</td>
<td>Yes</td>
<td>Advocacy, professional education, committees, peer-support, research</td>
</tr>
<tr>
<td>Patricia</td>
<td>7+</td>
<td>Yes</td>
<td>Peer-support, peer education and committees</td>
</tr>
<tr>
<td>Ruairi</td>
<td>10+</td>
<td>No</td>
<td>Committees, education, advocacy and activism</td>
</tr>
<tr>
<td>Sean</td>
<td>7+</td>
<td>No</td>
<td>Committees, peer-support</td>
</tr>
<tr>
<td>Siobhan</td>
<td>5+</td>
<td>No</td>
<td>Committees, peer-support,</td>
</tr>
<tr>
<td>Thomas</td>
<td>5+</td>
<td>No</td>
<td>Committees, peer-support</td>
</tr>
<tr>
<td>Vinnie</td>
<td>5+</td>
<td>No</td>
<td>Education, committees</td>
</tr>
</tbody>
</table>

**Inherent Tensions of SUI.**

The overarching theme of the inherent tensions of SUI for the user/survivor movement actors is comprised of three main themes emergent from the data, Contestation, Strategy Tensions, and Structural Facilitators and Inhibitors of SUI. These, and their component sub-themes, are illustrated in Figure 11 below.
Figure 11: Emergent Themes and Sub-themes in Chapter Seven

- Inherent Tensions of SUI
  - Contestation
    - "Shuffling round the Streets with the Shakes"
    - "Need for a Paradigm Shift"
    - "De-Junked of Psychiatry"
  - Strategy Tensions
    - "Chain Ourselves to Hospital Gates"
    - "I Ended Up Being on Committees"
    - "Going into the Lion's Den"
    - "Asking for Payment is a Political Request"
    - "Does Activism Become Dampened Down?"
  - Structural Inhibitors and Facilitators
    - "Psychiatrists don't Relinquish their Power"
    - "The Arrogance of Power"
    - "Allies with the Smaller Voice"
Contestation

The first theme to emerge from the data concerns participants’ critiques of the MHS. Their accounts highlight human rights abuses within the mental health system, their challenge of bio-medical psychiatry and articulation of an alternative vision to the expert-led ethos underlying current mental health practices. This political work is about reclaiming positive personal and collective identities and opening up a field of action which includes a demand for dialogue and space at the table in order to influence future service provision. However, tensions emerged among participants as to what strategies of contestation the user-movement should adopt, whether to pursue insider or outsider strategies. Regardless of conflicting opinions about the most effective strategies to pursue, there was a common collective identification around the core issues of contention, naming human rights abuses and challenging the power of the dominant epistemology of psychiatry to structure reality for people in ways that they cannot challenge. The three sub-themes in Contestation are illustrated in Figure 11 above.

“Shuffling round the Streets with the Shakes”

A key issue of contention for these participants is the on-going abuse of human rights within the MHS. The title for this sub-theme is taken from a metaphor by Niall, who referred to the failures of the psychiatric system, which has left a visible cohort of people: “…shuffling around the streets with the shakes.” The over-reliance on a bio-medical approach to emotional distress was contested and named as abuse by most participants, several of whom pointed out the consequences arising from over-use of medication on long-term institutionalised inmates of psychiatric hospitals. Jack, Owen and Thomas specifically cited Robert Whitaker\(^{58}\) and Jack explained the basic theme of his work: “Whitaker’s thesis is that…we’ve created more disability over the last few

\(^{58}\)A visit to Ireland by Whitaker in 2011, sponsored by the Critical Voices Network Ireland, suggested that there is a hunger, as one participant put it, for developing an alternative response to psychosocial distress. Whitaker, during nine very well attended public lectures, discussed his research on the growth in identified disability associated with over-reliance on psychotropic medication since the explosion in prescribing ‘anti-psychotic’ and ‘anti-depression’ medications by medical professionals from the 1970s onwards.

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decades…[which] can be attributed to over-medication, over-reliance upon [a] biological perspective.” Ruairí’s anger at the MHS and the consequences of over-medication was palpable: “I visit the lock-up wards, I see people sixty, seventy years stumbling around institutions…forgotten.” He referred to several recent public campaigns by Mad Pride Ireland and Mind Freedom Ireland to highlight the failures and injustices in the MHS. One woman was: “readmitted 80 times…dragged down in a corridor…in a public area…had her underwear pulled down and force-injected…forced to take electric shock treatment against her will.” He described a young man: “who’s lost all his teeth…who’s got akathisia59 [and]…dyskinesia60, who’s the classic face of the long-term institutionalised patient and he’s twenty-feckin-nine.” He discussed how euphemisms are employed to disguise unacceptable practices:

…assisted admission…it’s such a flowery way of saying that we sent the guards to your house to lock you up... Nutrition enhancement is…still force feeding...Peace rooms are now solitary confinement, restraint is called civil help…we just changed the names, we’re still carrying out…all the same things. (Ruairí)

Niall argued service-users have more legitimate grounds to fear for their safety and bodily integrity than any other oppressed group: “…of all the minority groups: blacks, gays, women, psychiatric patients have more reason for fear than any other group.” As evidence, he cited the impact of technological approaches to the control and elimination of madness throughout the history of psychiatry, giving several examples of the popularity of the eugenics61 and lobotomy movements in the mid-twentieth century, including a specific reference to Henry

59 Akathisia is defined by Whitaker (2010, p.232) as ‘a severe inner agitation… associated with an increased risk of violence and suicide.’ It is one of many recorded adverse effects of serotonin selective reuptake inhibitors (SSRI), a class of drugs used to treat depression (Breggin 1993; Healy 2012; Moncrieff 2008; Morrison et al 2012; Murray 2006).

60 Tardive dyskinesia is a recognised adverse affect of neuroleptic drugs, manifesting as involuntary tongue and mouth movements, as a result of often permanent damage to the basal ganglia, a part of the brain which controls motor movements (Whitaker 2010, p.19). See also (Breggin 1993; Healy 2012; Moncrieff 2008; Morrison et al 2012: Murray 2006).

61 This movement was influenced by Social Darwinism, (culminating in the logic behind Hitler’s extermination camps). It emerged from a focus on genetics and selective reproduction of healthy individuals, and elimination of undesirable traits, (homosexuality, disability, mental illness and Jewishness) from the population. In its least malign manifestation it sought to prevent women deemed to be imperfect from reproducing, resulting in mass sterilization programmes of women with intellectual disabilities and mental illness in the USA from 1907 (Lombardo 1983; 1985). It also provided the rationale for euthanasia and genocide. People with mental illness were among the first to be sent to concentration camps in Germany (Samson 1995; Sayce 2000).
Cotton. He was outraged by the manner in which Cotton was feted by his colleagues for his claims to cure madness:

It turned out that 85% of his patients died and...his bust is still displayed in the American College of Psychiatry...as being a pioneer, I mean it’s like Neary, twenty times worse, and people used come from all over Europe to see him performing these miraculous feats. (Niall)

Owen also referred to human rights abuses within the MHS, and described how service-users began to campaign against these wrongs. Liam likened public protest against psychiatric abuses to Martin Luther King’s civil rights movement: “it goes back to that struggle where you respect people...for me SUI means all that.” Patricia, who referred to the neglected living conditions in some MHS facilities, saw human rights as: “a good stick to bash the government with...because they need a bit of a bashing, so...we got...something here that they can’t ignore.”

Kate spoke of her encounters with mothers losing custody of their children and people who had been otherwise traumatised by the MHS. Jack felt that many people seek help with experiences of abuse only to find that within the system the trauma is repeated. When people with: “trauma...child abuse, whatever it is, they’re brought into a system quite often forcibly...forcibly treated as well...people are re-traumatised...somebody’s taking control of their situation, their body.” He believed that encounters with the MHS can result in double traumatisation.

Some participants described their own personal experiences of treatment within the MHS. Sean referred to how the in-patient environment is contrived to remove any sense of control over one’s life: “…there was a powerlessness inherent certainly in the system...they take your clothes...all your belongings.” He described a particular incident that illustrates the pressure to comply with the

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63 Dr Michael Neary was an Irish gynaecologist/obstetrician, who performed needless Caesarean hysterectomies on 129 female patients over four decades until he was suspended in 1998. The average is five over a consultant’s career. He was finally reported by two midwives at great risk to their careers in 1997. A report into the Inquiry by Judge Clark is available; see The Lourdes Hospital Inquiry: An Inquiry into peripartum hysterectomy at Our Lady of Lourdes Hospital, Drogheda. <http://www.dohc.ie/publications/lourdes.html>
regime within the MHS: “…if one even raises a voice, [one is] likely to be thought of as being obstreperous. I know I got injected once for suggesting that a nurse might have been slightly patronising.” He believed that this reaction to any perceived challenge was part of the ethos of control within the MHS. Vinne related an account of SUI that suggested he was bullied by a service-provider and felt threatened after he challenged her. He also reported fear among service-users at a focus group he conducted in an acute unit: “…absolutely petrified … ‘don’t tell anybody I was down here … don’t tell anybody what I said’.”

The key finding here is how participants frame taken-for-granted practices within the MHS (over-use of medication, ECT, forceful and coercive treatment) as human rights abuses and place these on the political agenda of reform of the MHS. Articulation of these abuses forged a politicised collective identity among participants.

“Need for a Paradigm Shift”

The paradigm of expert-led bio-psychiatry underpins abusive practice within the MHS, against which participants mounted an epistemological challenge, claiming: “the need for a paradigm shift in the conceptualisation of mental health” (Niall). Jack argued that: “the service-user movement…needs to challenge the whole paradigm…which is biological, that idea of diagnosis and all the rest.” Niall challenged the bio-medical concept of the nature of mental/emotional distress as erroneous and harmful:

the lens through which mental illness is understood is totally inappropriate…untrue…it’s trying to squeeze people into a very, very reduced understanding of what a human person is about and it damages them. …all my life I’ve had this argument…Was mental illness a brain imbalance or is it people struggling with the questions of life? And I’m passionately certain that it’s all about learning how to deal with life…with trauma. (Niall)

All participants shared this perspective on the importance of life events in understanding psycho-social distress. However, as Niall maintained: “the authority of psychiatry totally swamps or engulfs the people who come looking for help.” People come to believe they have no choice: “you believe…this is it and the treatment is forced on you, whether you like it or not.” He understood that authoritative power develops through repetition, when a narrative is: “being
spoken by lots of people which gives it power, [which is] how the authoritative voices get their authority.” He suggested the only way to counter the authority of the system is to: “talk about the experiences...you have to find out what it’s like to be treated.” Jack also highlighted the epistemological status accorded service-users’ experience in contrast to the dominant knowledge paradigm. Even though some service-users may gain educational capital and: “spiel off all these sorts of journals and articles...the legislation is there to keep [psychiatrists] in their position...so that’s an illustration of some of the authority.” Many participants rejected the objectification of service-users, for instance in the use of diagnostic labels and as patients, as dehumanising.

Participants discussed several strategies of engagement by which they sought to contest the bio-psychiatric, expert-led ethos. One such strategy was SUI in the education of professionals. Many participants spoke about the potential for professionals to learn and reflect on their practice by being presented with the experiential knowledge of service-users. They believed that listening to service-users’ accounts of how the service failed them, or how people survive without the MHS, could prompt practitioners to reflect on ways to improve the services. However, Martin doubted the impact of once-off sessions with students. Thomas felt it probably would take the next generation before there is real change, given the institutionalisation of professionals.

Jack was one of several participants involved in the education of mental health professionals. He argued that the scientific and empirical emphasis in their education was missing the point of service-users’ priorities: “…it’s way beyond really getting to know what makes the person tick.” He experienced resistance from students to his message, to respect autonomy and experiential knowledge, to listen and deal with the real issues in service-users’ lives: “…they don’t see beyond bureaucracy and the science...and then they become offended and defensive.” He described the gulf between service-users and service-providers: “…we’re living in two different worlds but it’s sometimes hard to bring those two worlds together.” One participant described an encounter with a former student, and reported the paternalistic attitude she had adopted which was particularly disappointing because: “she was a great student and she seemed to be going along with some of the things I was saying.” However, once she
commenced working in the services: “all that didn’t mean anything.” This participant concluded: “So that was just an illustration to me how quick even the best of students, you can lose them. I think it’s short-term, the impact we have.”

Some participants discussed user-led research as another strategy to challenge the dominant paradigm; several had direct experience as researchers. For instance, Niall described research he had conducted on service-users’ experiences of professionals. He highlighted one finding that helpful behaviour occurred before professionals became institutionalised:

…nearly every time professionals stepped outside the system either with words or behaviour was when they were young and they hadn’t been institutionalised, young nurses taking an interest in people. There was one example of a social worker stopping somebody in the corridor and saying, ‘look, I’m not allowed to talk to you, I’d be in trouble…but I think you need to see a psychologist rather than the psychiatrist.’ (Niall)

Some participants commented on the politics of research, such as the standpoint of user/survivor research and research questions. The importance of the research question was highlighted by Jack. He questioned the impact of a research project he had worked on that explored what helped people cope in hospital:

…it just didn’t make any impact. …[They] could still say…‘[we] need hospitals, all we need to do is do this to the hospitals to make it better for people’, whereas the question should really be, ‘do we need hospitals?’ So we need to be careful what we ask and how we ask it. (Jack)

He compared this to other research he conducted which asked people about their experience of therapeutic encounters with nurses and other staff. Most of the findings related to experiences within institutions, and respondents primarily reported negative encounters with staff. These findings were not as easy for service-providers to rationalise by saying they would address recommendations because they fundamentally questioned how staff interact with service-users. He concluded: “it’s the hurtful bits which stick most with people. …That wouldn’t…feed the system…it’s something they don’t want to hear.”

Martin pointed out that mainstream research was not asking the right questions whereas the questions asked by service-user researchers are different because they: “have actually experienced that distress, they’re zoned in on what the real issue is...asking the questions from the right perspective.” Owen claimed
that user-led research could be emancipatory for service-users because they can
determine the direction of research.

Care planning is an example of resistance to changing practice within the
system. This is an area that service-providers usually equate with SUI (Chapter
Six), yet at this fundamental level of interaction there was further evidence of a
major failure to listen to and include service-users’ expressed wishes and insights
into how they want to be treated and what they want to achieve as a result of
service intervention. Kate reported her experience with user-led evaluations of
the Care Planning initiative established by the MHC. She explained the
outcome of a user-led evaluation of this initiative: in spite of six months
interventions by trainers and external consultants with staff at eleven sites, most
service-users were unaware they had a care plan and one of the sites had not yet
established care plans. She concluded by asking:

what is the point of a care plan when we can’t seem to get the
simple philosophy…out there?…We’re trying years, it’s
[written] into the legislation and the Mental Health
Commission can’t enforce it … there’s no answer, we’re not
coming up with an answer. (Kate)

Niall articulated a fundamental reservation about the paternalistic ethos of
care: “Care to me has all these insinuations of lifelong care, we’ll look after you,
when you need ECT, we’ll make sure you get it, even if you don’t want it,
because we know what’s best for you.”

Another illustration of resistance to any questioning of the dominant
paradigm was the preferential selection of positive narratives about treatment by
the MHS. Sean was a member of a committee which was considering the
processes of involuntary admissions. They invited a service-user to address them
in order to get a personal account of experiences of assisted admissions
by

64 The National Mental Health Services Collaborative on Individual Care Planning was
established by the Mental Health Commission to promote the adoption of care planning within
the MHS. Eleven MHS sites were selected for an intensive, ‘collaborative’ learning approach
over a six-month period. This is a methodology developed in the USA for improving healthcare
practices. A final evaluation of the project is available at
65 Assisted admission refers to the process of having Gardai or MHS professionals escort an
unwilling person to an acute psychiatric unit. It occurs when people resist the determination of
others around them to get them into treatment in spite of their wishes not to be treated. Once the
legal process has commenced, i.e. an admission order is sought by either a family member, a
member of the Gardai or an ‘authorised officer’ (a statutory post held by designated MHS
professionals) and corroborated by a General Practitioner, then any necessary force can be used
Gardai. He reported that the committee decided that this account was too negative and therefore dismissed it as unrepresentative. Liam argued for the necessity for the MHS to include and listen to service-users who are: “justifiably angry…because if you don’t, you’re really losing out on really core aspects of why the service has failed people.” He realised service-providers do not want to hear that, instead: “they want good outcomes all the time.”

The findings highlight systemic failures to listen to service-users, either at the level of care planning, or at other levels of SUI, resonant with findings in Chapters Five and Six. Service-user anger is again found to provoke resistance from service-providers, resonant with findings in Chapter Six. The key finding here is how contestation of the epistemological paradigm of psychiatry has contributed to the politicised collective identity of participants as social movement actors. Strategies of contestation included user-led research that problematises current service provision, and SUI in education of professionals. These challenges were however, subject to epistemic politics and resistance from the dominant paradigm.

“De-Junked of Psychiatry”

The articulation of alternative approaches to dealing with psychosocial distress, ideas encapsulated by the user-developed concept of Recovery, were another feature of both contestation and the development of a collective politicised identity. The title comes from comments made by Owen about his first encounter, 28 years ago, with a peer-run therapeutic community, Anam Cara, which opened his eyes to alternative possibilities. He explained that this experience helped him realise:

you could emancipate yourself…it de-junked you of psychiatry…to realise that there was another perspective out there…your experience wasn’t something that was chemically imbalanced in your brain…(Owen)

66 Anam Cara was a peer-run crisis house, one of several ‘run-away houses’ established in the UK during the 1990s.
He reported seeing people come in crisis and leave after six weeks: “...having gotten through the crisis...able to...soldier on.” He also referred to his later experience visiting the Soteria\textsuperscript{67} project in New York, where he witnessed the enormous difference in ethos from mainstream MHS: “it was a community of people being together with their own distress and crisis and finding solutions for themselves and with others around them...it was the process of healing actually before your eyes.” Owen’s experience of alternative care models provided him an opportunity to re-think his previous experiences and to question the medical explanations of psychosocial distress that he had previously accepted uncritically. Liam and Thomas referred to another example of alternative care being reported from Finland, the Open-DIALOGUE\textsuperscript{68} process.

Niall explained his understanding of \emph{Recovery} as a process of re-discovering the joy and mystery of life. He was very committed to the idea of \emph{Recovery} as a challenge to bio-psychiatry, and on understanding the processes of how people overcome emotional/cognitive distress apart from, or in spite of, the MHS. He understood the way people are treated by the MHS to be highly damaging and was very pessimistic of service-users’ life chances within the MHS. He was convinced that emotional distress needs a different intervention than a medical response, and his experience was that peer-support groups provided the supportive space that allowed healing to occur.

Jack raised a serious reservation about the concept of \emph{Recovery} as understood and uncritically articulated by many in the user-movement. He argued that the focus on the individual, rather than on social relationships and networks, was supporting the individualised biological model:

we’ve shot ourselves in the foot...people don’t recover in isolation, there’s always [others] involved but if you look at Recovery and Recovery stories, it’s more or less like the Frank Sinatra thing, ‘I did it my way’, you basically find that all the time. (Jack)

\begin{flushright}
\textsuperscript{67}Soteria was a therapeutic project established by Dr Lauren Mosher in the USA to provide an alternative model of care to the traditional psychiatric hospital settings he worked in. It provided a ‘therapeutic milieu’ which supported the individual in distress without coercive interventions, as they worked through the emotional crisis. (Aderhold et al 2007).
\end{flushright}

\begin{flushright}
\textsuperscript{68}Open-dialogue is a very early intervention treatment approach which works with the whole family system, through dialogue, to explore the meaning behind the ‘psychotic’ state. Medication is only considered as a last resort and not until at least six weeks of intensive family work. (Seikkula and Alakare 2007)
\end{flushright}
Some participants also contested how the rhetoric of Recovery is being used within the MHS. Two participants in particular protested at how the articulation of Recovery as an alternative vision for the care and treatment of psycho-social distress, developed by the user-movement, has been assimilated into a biomedical approach by the MHS. Owen expressed his fear about this appropriation: “what they’re actually talking about is the medical model redressed.” Given his close contacts with many local services around the country, he had a good idea of what was happening as services introduced care planning and so-called Recovery: “I am totally frightened by the process and there’s times I’m actually afraid that we should never have…[introduced] the Recovery concept…they’ve captured it…they’ve turned it back into their own concept.” Jack corroborated this view in his observation that the MHS: “have definitely…usurped, taken it on themselves and made it into what they want”, giving the example of the Royal College of Psychiatry: “if you go onto the UK Royal College [website] you’ll see Recovery on one of their main pages.” He also highlighted how Recovery and WRAP discourses are appearing in MHS care plans.

Patricia had a different opinion and was positive about the dissemination of Recovery language within the MHS: “some people have…realised that Recovery/discovery, whatever you want to call it, is better for all.” She remarked on how a nurse welcomed the fact that she had developed her own WRAP because it meant the service-provider did not have to take responsibility for the service-user. Siobhan, on the other hand, described betrayal of the fragile hope of people who believed a MHS offered Recovery: “I’ve seen people going in and they’re full of hope…and they’re getting bitterer and bitterer by the day.”

A politicised collective identity developed through the process of sharing common narratives among service-users. Many participants were involved in

69 Wellness Recovery Action Planning (WRAP) is a programme, developed by an American survivor (Copeland 2002), as a self-management tool that offers a practical framework for managing one’s life to understand, anticipate and ameliorate the stresses and triggers that may lead to mental health problems. It is currently the most widely used self-management strategy (Higgins et al 2012, p.2). A recent large Irish education programme on WRAP was evaluated by Higgins et al (2012) who, while reporting the positive attitudes of the service-users, carers and practitioners who undertook the training, observe the potential for WRAP to be assimilated into the current MHS ethos and become just another tool for a ‘benign, paternalistic, and illness-orientated paradigm of mental health care.’ (Higgins et al 2012, p.9).
such work, as Patricia reported: “We’re talking out…in front of loads of people.” Niall explained: “if one service-user stands up and [tells their story] it’s a magnet for other people to come in and say well ‘I’m in the same boat.’” He maintained that the user-movement has developed a more coherent, unified voice, particularly in relation to alternatives to the medical model, through listening to each others’ experiences. He believed that this collective voice could evolve into a powerful alternative narrative to psychiatric hegemony:

you start empowering a story…giving it space…giving it different mouths to speak through, so it becomes a collective…
So gradually you get this voice where it’s being spoken by lots of people which gives it power. (Niall)

Participants were cognisant of a need to bring more grassroots service-users into the movement. Some participants were actively disseminating the ideas and examples from international peer-run initiatives and non-coercive, dialogic forms of treatment to other service-users, for instance through the Leadership Initiative at DCU. Liam wondered, though, if these ideas might be too radical for some service-users. He commented on a group to whom he had given articles about Soteria, Open-Dialogue, Recovery, but: “whether they are actually taking that on board, I don’t know.” Other participants commented on a lack of awareness among grassroots service-users that things could be different, and that they did not have to be grateful for paternalistic care.

Two key findings emerge here. The first is how core concepts of the user/survivor movement (peer-support and Recovery, developed and articulated as a resistance strategy), have been appropriated and assimilated into institutionalised practice. However, conflicting perspectives emerged in response to this development. Some participants protested at, and feared, this appropriation because the transformative potential has been lost, whereas a wider recognition for Recovery within the MHS was welcomed by others as an indication of change. This conflict points to tensions around differing objectives for SUI within the user-movement. The second key finding is the development of a collectivised, politicised identity as a user-movement, emerging from sharing common narratives around Recovery and resistance and dissemination of alternative approaches developed internationally.
**Strategy Tensions**

Given the collectivised identity present among participants mobilising the movement’s resistance to bio-psychiatry and the expert-led ethos, this theme considers the differing strategies adopted by user/survivor movement actors. The spectrum of opinions on outsider versus insider strategies emerges as a source of tension within the movement. Participants discussed the effectiveness of outsider strategies (such as public protest) and insider strategies (such as participation in committees) in pursuing their objectives to improve conditions within the MHS for people experiencing psycho-social distress and, ultimately, to develop peer-run services. The participants’ experiences of insider strategies presented tensions in terms of dealing with inequities of power, the political dimension of payment, and denials of recognition. The final issue of contention is the question of assimilation, whether the movement can remain independent while pursuing a strategy of engagement with the MHS. This theme and its sub-themes are illustrated in Figure 12 below.

**Figure 12: Strategy Tensions**

"Chain Ourselves to Hospital Gates"

A tension emerged about strategies available to the user-movement to contest abuses of human rights within the MHS. This sub-theme presents participants’ views on external strategies, such as protest and public demonstration against the MHS. Owen recalled protesting against ECT in the UK:

We used…to chain ourselves to…gates outside hospitals on the day of ECT. ...You can argue the rights and wrongs of it, or whether it made any difference or not, but it did focus people onto thinking…why were people chaining themselves? (Owen)
Both he and Liam reminisced about the heady days of street protest in the eighties. Liam compared current activity of the movement with the earlier civil rights activism: “maybe we need to actually reclaim our activism.”

Ruairi and Thomas were committed to public acts of protest to highlight the abuses of care within the MHS. Patricia and Kate, on the other hand, believed that protest activism was counter-productive: “If you start mouthing off and shouting, they shut the doors rapid” (Patricia). Several participants were uncomfortable with aggressive tactics, referring to a disruption staged by a movement actor at a recent public campaign meeting as unacceptable because of the personalised nature of the tactic.

Most participants occupied positions in the middle of the spectrum, exemplified by Martin, who had struggled with the dilemma of whether to: “be a completely independent voice on mental health issues or…integrate to a degree to be able to influence services?” He reported that at times he had been very angry and wanted to protest whereas other times he thought that: “communication…some degree of partnership also improves things.” His conclusion was that both strategies were contributing to the: “great big melting pot” of the user-movement.

Jack discussed a common ambivalence about radical action and its effectiveness: “there’s a place for all of this…I think you still need people outside throwing stones in, but I don’t think leaving committees will make any difference either.” He recognised a need for public action to draw attention to service-users’ concerns and spoke about the need for strategies within the user-movement, but was unclear how the movement might strategise, or even if it was possible. Most participants believed engagement with the MHS was critical to their aims of reforming the MHS, as expressed by Owen, who argued, albeit reluctantly, that SUI is imperative: “unfortunately one part…is always going to be tied up in the long-stay committee rooms…one of the first processes of engagement is statutory services, we have to take it as a given this is going to happen.”

The findings reveal tensions due to a spectrum of opinions about public action as a strategy for the user-movement. A few participants endorsed strategies such as public protest while some others completely rejected outsider
strategies. Most participants accepted that a collaborative strategy of SUI was the best option currently available for achieving their goal of reforming the MHS, while not rejecting the option of outsider strategies.

“I Ended Up Being on Committees”

Participants discussed their understanding of SUI on committees as a movement strategy as committee work within the MHS featured prominently in the SUI activities of participants. The title comes from a comment by Owen who encapsulated the current state of SUI as committee membership, paraphrasing an activist who stated: “I wanted to be in the service-user community and ended up being on committees.” Jack explained that committee work ranged from the level of being active in local services at an operational level, right up to strategic involvement on national committees in the HSE and DoHC. He identified participation on the boards of user-movement organisations such as IAN or NSUE as another form of strategic committee work. Vinne discussed committee work at the operational level in his local service, but in his experience it was a token exercise: “I can’t say that…it’s done anything other than try to change the name of the acute unit and even that was rejected…by the providers.” He believed the MHS were just going through the motions of SUI because they had to in response to top-down policy.

SUI on several statutory and/or high level advisory bodies was discussed by three participants. The fact that two of the thirteen places on the Mental Health Commission (MHC) are reserved for service-users by legislation was heralded as a significant recognition of SUI by some participants. Accounts of how SUI operated on the MHC specifically were necessarily limited due to confidentiality restrictions on anyone sitting on the MHC. There was mention of the Official Secrets Act (1963) being invoked to cover the proceedings of the MHC. However, service-users were involved in promoting a Recovery agenda on the MHC, including the production of a discussion document on Recovery.70

70 This document was the first official policy on Recovery in Ireland, and was produced by a subcommittee of the MHC, chaired by a service-user. Mental Health Commission (2005) *A Vision for a Recovery Model in Irish Mental Health Services*. Dublin: Mental Health Commission.
Service-users were also involved in lobbying for a service-user inspector on the multi-disciplinary Inspectorate of Mental Health Services.  

Some participants discussed specific objectives for engaging with the MHS. Owen outlined a strategic vision around SUI as an essential means to achieve peer-run services. He considered that the ultimate objective is for service-users to: “design, create, run their own type of peer-driven services.” Independent peer-run services, he believed, would lead to greater personal autonomy and sharing of expertise among peers: “actually getting to the stage that we take control of our own lives again through our own shared experience and… understanding of what it is we need to help ourselves.” Three peer-run services in Ireland (IAN, GROW and Suicide or Survive) were cited by several participants as examples of independent support for service-users.

Some participants discussed the aspiration of peer-provided services within the MHS. Jack and Liam observed that some MHS are beginning to explore the employment of service-users on community teams: “peer-mentoring or Recovery workers…working with the services to develop peer-involvement within the delivery of services.” (Jack)

Several participants discussed potential benefits for the user-movement in operating on committees. For instance, Owen believed that when the conditions for participation are right: “service-users could use their power and influence to make things happen.” He also observed that the skills learnt by movement leaders through this “apprenticeship” were disseminated throughout the movement. Other participants also discussed their learning experiences through being engaged in this form of SUI. However, they were cognisant of the odds against one service-user sitting on high powered committees making significant changes to the ethos of the MHS.

Ruairi dismissed current SUI practices because he believed the user/survivor movement needed to strategise rather than wait for invitations to consult on

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71 The Inspector of MHS is a statutory role under the Mental Health Act (2001), which has a remit to inspect all approved centres where people are involuntarily detained at least once a year. It submits a report annually. Unlike the old Inspector of Mental Hospitals, established under the 1945 legislation, the Inspectorate consists of a multi-disciplinary team under the direction of the Inspector, who remains a consultant psychiatrist. The position of a service-user Assistant Inspector was advertised and filled in 2008. However, the identity of this individual is a closely kept secret, including within the service-user/survivor movement, quite an unusual situation in a small country like Ireland.
committees, where the positions of power are held by professionals. He proposed a reversal of the usual power dynamic by inviting the key agents in the MHS field into survivor-created spaces. He advocated that the user-movement should take control of the consultation process: “to create the tables, to invite people to the table and be selective in who they’re going to invite.” He maintained that all it took was the determined will of service-users to make this happen and that respect would come from exercising power in this way: “...if you have enough respect, then you get the power and influence. …We should refuse to be going to any of the tables, in my opinion, until [they] come to us and we chair it.”

The findings reveal that some participants consider the user-movement’s ultimate goal for SUI to be autonomous peer-run services. Meanwhile a few MHS around the country are beginning to develop peer-involvement in their model of service delivery. There was another finding that the user-movement derived benefit from the dissemination of the experience of seasoned activists, as knowledge and skills filtered throughout the movement. There were occasions when service-users, under favourable conditions, could influence decisions and policy, but more commonly the ability of service-users to leverage influence was limited in professionally-controlled spaces. Hence a reversal of power through the creation of user-controlled consultation spaces was advocated by one participant.

“Going into the Lion’s Den”

Given the acceptance by the majority of participants that a strategy of engagement with the MHS was the only current option available to achieve their objectives, this sub-theme presents their experiences of SUI. The accounts reveal the emotional costs of participation: fear and intimidation, frustration and anger at denials of recognition and tokenistic involvement. Owen used the title metaphor when describing his first meeting:

…it was like going into the lions’ den…It still conjures up that sense of fear and panic…a demeaning feeling that I was…the least educated to sit in that room…I had no concept of what they were talking about, they were using language I had never heard of…it was a frightful experience. (Owen)

All the other participants shared similar accounts: feeling “intimidated”, “like David and Goliath”, “tongue-tied”, “under-gunned” in terms of language,
knowledge, education and insider knowledge of how the system worked. Many felt their education and knowledge to be inadequate in these settings. Liam described how a display of epistemological authority overwhelmed him:

where people are so...certain of their own knowledge base...to know all about their...specialism and they have this...rant going on and you're saying to yourself sure they know it all, what could I as a service-user possibly contribute to this... (Liam)

He regarded this as a deliberate form of exclusion: “it’s a...bullying...aggressive way of excluding the service-user voice.” Many participants commented that they received little or no training and support when they initially became involved. Participants had overcome their initial sense of inadequacy, but they still had to manage such feelings. Patricia described the personal strength required to overcome feelings of intimidation: “…you have to be bloody strong, persistent, resilient because it’s tough, it’s really tough.”

Another common experience of these invited spaces was anger and frustration. Participants were generally frustrated and disappointed with the pace of change. There was a common sense of initial optimism followed by frustration, illustrated by Jack: “you do get very frustrated to have all of these great ideas and excitement but it’s deflated...things move very slowly if they move at all.” Tokenistic attitudes were also a source of frustration for many. Liam described frustration at the resistance to SUI: “…ten years of peer-advocacy, of people who’ve proved themselves on the ground...and yet there is still that resistance.” He reported his observations of service-users on high-powered boards feeling totally silenced and powerless: “I think a lot were disappointed...they became more and more silent, more and more voiceless.”

Kate discussed an experience, which is particularly illustrative of the emotional challenges and power imbalances faced by service-users. She was present at a high powered meeting where a Clinical Director, unaware there was a service-user present, made highly disparaging comments about SUI, citing a particular incident she was unaware of: “…he slated service-users, and...everybody except this guy knew that I was there.” She described the position she was in: “…I thought my job was to represent service-users...to

72 This would be a consultant psychiatrist by default.
make sure that people respected service-users. I couldn’t answer this guy.” So she left the meeting and phoned colleagues who dictated a statement for her providing the service-user perspective on what had happened. The conversation paused when she walked back in, yet: “…this guy was still going on about [how] he thought it was fairly good to include [service-users] but…that they should be included in their place and…told what to do.” She described the trepidation she felt waiting for an opportunity to read out her statement: “Oh God, I’ll never forget it, I’m telling you, I shook and I was sick and I could feel the tears coming and everything, but I did it.”

Another dimension to experiences at meetings included accounts of exclusionary decision-making processes. Martin observed that although there was much rhetoric about partnership: “...if you just organise meetings to make decisions that are all rubber stamped … that have already been made, it wouldn’t work.” Kate reported her early naivety that decision-making was a transparent process: “I used to be rattling my brains trying to think when we made the decisions because I didn’t know they were made outside the meeting.” She also experienced times when the decision was included in the paperwork sent before a meeting, which required work to uncover. She observed that sometimes decisions can be an acceptable compromise between what different groups want, but that decisions made prior to meetings are difficult to challenge.

Other participants also commented on behind the scenes negotiations. For instance, Ruairi described collusion to allocate powerful positions, such as the Chair, before a committee is established and how he was excluded when he objected to decisions taken outside meetings. Owen also discussed: “how things can be manufactured…pre-ordained” at strategic meetings before the main one to determine strategy or to influence the outcome desired: “Oh there’s no question about it…there’s organisations that actually have their meeting with a small core group of people, have…an agenda…sold to the larger group in a certain way that it’s a done deal.” He spoke of having acquired a honed ability to understand and deal with covert and hidden power operating to exclude the interests of service-users.

73 Shortly afterwards, a meeting was arranged between herself and the Clinical Director by two senior managers in the HSE, where they discussed the issue and reached a resolution so that both felt they could work together in future.
The findings (that participants were unprepared, lacked training, felt like outsiders, excluded by jargon) are similar to those of local participants in Chapter Five. Displays of epistemological authority provoked fear and intimidation. Resistance to power sharing and tokenistic involvement provoked anger and frustration. These unequal conditions of participation extract high emotional costs but participants here, like in Chapter Five, had developed coping strategies over time and with experience. The common factor in all accounts was the impact of engaging in highly unequal settings, where hidden power shapes decision-making, resulting in the frustration of tokenistic SUI.

"Asking for Payment is a Political Request"

The penultimate sub-theme about tensions inherent in SUI explores the issue of payment and recognition of service-users for their involvement activities. This was a political issue for participants as Martin explained: “[SUI] is a personal and political activity…it’s motivated by experience, I suppose that’s what I mean by political…it is about human rights…on principle asking for a payment is a political request of acknowledgement.”

Most participants regarded payment in terms of recognition and validation of their contribution to improving the MHS. Vinnie illustrated a recurring demand for parity: “you are asking me for my expertise...why shouldn’t I be afforded the same...as you get in terms of equality...of financial reimbursement?” Participants felt payment would demonstrate the MHS took their contribution seriously. For many participants the issue of payment was contextualised by stigma and the devalued position of service-users in the institutions, but also “compromised citizenship” (Martin), for instance in discrimination around issues like car or house insurance. Paying for decent meals or accommodation for service-users was explained as a political gesture, to demonstrate that service-users were just as valued as any other member of society.

Some participants were angry about tokenistic expenses that did not cover the real costs of SUI, and about lack of clarity on how expenses were calculated. Siobhan discussed the difficulty that lack of clarity about remuneration and budget allocations caused, especially for people affected by poverty: “I find it is
quite difficult for people who have come from a poverty perspective to be able to
stand up [and discuss money].”

Some practical obstacles to payments, such as benefit traps, were
acknowledged, but the notion there was no budget was dismissed. Participants
responded angrily to the suggestion by a service-provider participant that SUI
could be considered voluntary activity akin to school parents’ committees or
coaching a local football team. Sean saw: “no element of volunteering…of
altruism, no going the extra mile amongst the professionals” when their travel
expenses were cut. Owen dismissed the volunteering proposition, arguing for
recognition of the value of service-users’ experiential knowledge, and concluded
that the volunteering argument was: “a way of avoiding affording the dignity,
respect [for] those people’s experiences.”

There was a contrasting view. Niall argued in favour of altruistic
involvement, and took the view that SUI should not become unionised. Jack
spoke of occasions when service-users refused payment, because that was not
why they got involved. Martin discussed a project he was involved with where
the participants also rejected payment. The group of service-users, with one or
two social workers, collaborated to develop teaching materials for both student
and qualified social workers on the service-user perspective; he described it as a
“brilliant project” which continued for about six years, due to the commitment of
all involved. There was frequent honest communication and good relationships
between workers and service-users. The service-users believed their involvement
was worthwhile because they: “were talking about important ideas and reaching
their target audience…social workers and care workers,…[and] making a
difference.” The service-users chose to invest the funds generated by their work
in weekends away: “to review activities and eat nice lunches” rather than taking
a payment.

The findings around payment indicate that recognition and validation of the
contribution of service-users is a political issue, and that receiving payment, or
being offered payment which some may choose to decline, is significant in terms
of respect for the contribution of service-users. Recognition of their contribution
was found to be intrinsically associated with the historical context of the
powerless and stigmatised position of service-users, which made validation by
payment important. A minority view proposed the value of the altruistic contribution of volunteering but this position was rejected by the majority who demanded payment as a mark of parity of esteem with professionals.

“Does Activism Become Dampened Down?”

Given that most participants were engaging with the MHS in different forms of SUI, the dynamics of assimilation, and the loss of critical focus that collaboration with MHS may entail were discussed. Liam articulated the inherent tensions of collaboration: “if we do become part of the system…does activism become dampened down or does it reform itself within the system, changing the system from within?” Many participants had given serious consideration to the question of co-option. Jack questioned whether all the activity of service-users on committees was making any difference at all despite more and more committees being established:

Has the ethos, the culture of the service changed? And if you look at things like suicide rates…recovery rates, and you match that against…the activity…there’s something wrong…we’re involved, but there doesn’t seem to be improvement in care…So what is it we’re doing at these committees and what difference is it making? We need to be honest with ourselves.

(Jack)

He went on to reflect on the user-movement: “[We have] lost our way…we did start off…a human rights movement…I think we’ve become assimilated.” Owen described the achievement of the user-movement as: “committeeship…we’ve been assimilated into that sort of service provision.” Liam discussed the issue of assimilation in terms of the ethical dilemma about participation without seeing results.

Although Patricia was aware of the potential for assimilation, she believed it was important to be at the table regardless of how difficult it was: “you have to have the balls to sit at these tables…to sit in the horrible tension…but stay authentic yourself. So if you call that being sucked into a system, I don’t.” Kate believed SUI was the only option to change the realities of life for people caught within the MHS.

Two participants spoke of their disillusioning experience of SUI with local services and had concerns about being used. Vinnie believed that SUI was all about appearances and reputation for being progressive and as a result he had lost
faith in the motivation and integrity of the service-providers involved. He described feeling manipulated to participate in some projects, even though he did not want to work with a specific service-provider also involved because he felt bullied by this individual: “There’s fierce manipulation and pressure put on you to be part of the team, and if you do not want to be part of the team…they blank you…it’s like you don’t exist.” He has since refused to communicate with this local service, concluding: “they just trample all over your rights.” Likewise, Siobhan felt very disillusioned with SUI because of similar experiences. She had resigned from her local consumer panel because service-users did not receive adequate support or expenses, and she felt that it had been established by professionals for their own ends.

Ruairi emphatically rejected the idea of SUI within the MHS, because of its failure to acknowledge and address human rights concerns. Under current conditions, he equated SUI with silent collusion. He argued that, unless human rights abuses are acknowledged and acted upon by those with the power to do so, SUI risks being part of the masking of such problems and stymieing the efforts of the survivor movement to bring these issues into the public domain.

The findings in this sub-theme reveal further tensions around SUI for activists. A spectrum of opinion emerged again, this time on the issue of assimilation. At one end was a rejection of SUI as collusion, until human rights abuses are acknowledged and addressed. Others reluctantly acknowledged that the energy of the user-movement has been subsumed into service-provision and serial membership of MHS-controlled committees and had concerns about assimilation and tokenistic involvement. Some were disillusioned by their experiences of SUI. Opinion at the other end of the spectrum rejected the idea of abstention from SUI because engagement was regarded as the only way to effect change.

**Structural Inhibitors and Facilitators of SUI**

The structural factors within the MHS which hinder or facilitate SUI are part of the context that shapes SUI. Participants contested the powerful position psychiatrists hold within the hierarchy on several grounds. Epistemological challenges have already been considered but they also contested the legislative
position which confers de facto authority on the role of psychiatrists. Other professionals were also identified as posing barriers to SUI, while allies can be seen playing a significant role in supporting the user/survivor movement in the achievement of their objectives for SUI.

“Psychiatrists don't Relinquish their Power”

There were many accounts of the dominant position of psychiatrists within the MHS hierarchy, and how they impacted on service-users and other disciplines. Several participants observed that psychiatrists do not share their power even with multi-disciplinary colleagues, as Kate explained: “they don’t relinquish their power…actually they don’t like anyone to have any power…the other disciplines find that as well with psychiatrists.” She reported that some local services had sought to extend team leadership roles to other disciplines, as occurs in the UK and elsewhere: “but the psychiatrists don’t allow it.” All participants referred to the dominance of consultant psychiatrists, including a few observations that nurses were often afraid to challenge a psychiatrist.

Kate also referred to the absolute power consultant psychiatrists have over any decisions made about the MHS, even though they often do not attend meetings. Owen elaborated on how this power manifests: “if the dominant player doesn’t want to play, well then, they don’t play…they’ve dictated the rules and regulations…and everything else.” Liam reported attitudes he had experienced from psychiatrists towards SUI, the employment of peer-workers in particular. He found some to be: “extremely prejudicial and arrogant…‘no, no we can’t have a service-user on a multidisciplinary team…no, no we have to have…right governance, right people’.” Liam demanded adequate explanations of their rationale for excluding service-users, not just a refusal to engage with the topic.

A significant factor underpinning the power of psychiatry is the statutory position of the profession, the legitimacy of which was contested by many participants. Many believed the law needed to change to remove the bias in favour of psychiatry, giving equal powers to other professions. Liam pointed out the weight given to psychiatry in the text of the Mental Health Act 2001: “85 citations upon consultant psychiatry…I mean it says it all.” Jack observed that psychiatrists are not in the position they are in as team leaders due to their
knowledge: “…they’re in a position of authority because all this legislation puts them in a place where they can say yes or no to a lot of the stuff.” Owen believed the user-movement needed to be strategic about the legislative situation. He questioned whether specific mental health legislation is required at all, but observed that, under the current framework, too much legislative power is vested in one profession which is not good for psychiatry itself because it prevents any delegation of responsibility: “…because they’ll always use the argument, ‘well the responsibilities…the risks are ours.” He saw the need for a shift within the wider public: “to realise it’s no longer acceptable for one single profession to be invested with all that legality and power.” He argued that the changes sought by service-users could be achieved without the co-operation of psychiatrists: “I don’t think we need them…either they engage or they don’t engage but the reality is that…I think we’ve given them too much power over the years…and then we’ve allowed them to use it.” Ruairi’s primary focus was on obtaining equal rights for service-users as citizens under the law. He maintained that the current law contravenes the Convention on the Rights of Persons with Disabilities (CRPD) and must be changed to remove the power to treat people against their will.

The findings here are challenges to the legitimacy of the dominant power of psychiatry. The dominance of one profession, underpinned by historic practice, hegemony and legislation, was challenged as open to corruption and unhealthy, not just for service-users and the other professions within the MHS, but also for psychiatry itself. Psychiatric power was found to be an impediment to reform of the MHS and to SUI in particular. Many participants believed legislative changes were necessary, primarily to remove the exclusive statutory privilege of psychiatry in Irish law, but also to protect service-users’ human rights and stop forced treatment.

“The Arrogance of Power”

This category considers participants’ evidence about the power and influence of other professionals, most especially nurses and managers but also social
workers, in the MHS. The title metaphor was used by Martin who referred to an article\(^{74}\) which resonated with his experience of nurses:

…I happened to come across a journal article by the…Professor of Nursing at [a local] University…This article was entitled ‘The Arrogance of Power’ and he actually proceeded to deconstruct his profession’s negative influence…because…nurses…have all this power over people and were to an extent institutionalised themselves, individually or as a profession…they were too powerful for the good of the service-user/Recovery so…he seemed to be putting into words clearly what I felt. (Martin)

Many participants referred to the power that nurses hold within the system: “on a day to day basis on the ground, [nurses have] the power” (Siobhan).

The power of an individual in a management position to facilitate or hinder SUI arose again with participants in this chapter. Fifteen years ago two participants were employed as SUI workers in a project established by a senior nursing manager, who promoted the development of SUI practices among staff in his area. These projects ran for a few years with his support. The first participant observed the manager had: “struggled to get staff interested and motivated in SUI….So even if you have a good leader…you can’t make staff interested.” There was often resistance by nurses to specific initiatives of service-user workers: “often it had to come from somebody else to tell them that this is the way you have to do it.” He acknowledged that there were individual practitioners with a genuine interest, but they attended meetings on their own behalf: “they’re not really representing their profession.” Once this manager moved on, the projects and the employment of the service-users ceased. The second participant summed up the significant role of the lead manager: “the influence of a key person…or the leader of that team…[everything] very much depends on her or his attitude and how that filters through to his team.”

The power of a manager to hinder SUI appeared in another account. Thomas spoke of an administrator (who was not from a nursing background) whose resistance really frustrated him. He described the administrator’s attitude as dismissive of his financial costs to attend a committee (a 120 mile round trip by car) and tokenistic in what was offered. The excuse offered was he couldn’t

\(^{74}\) It was not possible to locate this article, as searches for it in the literature yielded no results.
afford to pay his suppliers: “...when I heard that I said to myself, ‘we’re fighting a losing battle here.’”

Owen referred to obstructive attitudes from some social workers. He commented that, while he might have expected resistance to SUI from nurses, he had been surprised to encounter this from social workers who were: “one...profession that has handcuffed us more.” He observed there were supporters and detractors of SUI in all professions:

...But given that social work has a sort of particular background ... enabling people to empower themselves...I just found [some social workers] very entrenched in their views...not allowing people to make or take those risks or...decisions, they had a sense of being very paternalistic around them. (Owen)

The findings here support findings from earlier chapters about the power of individuals in key positions to facilitate or hinder SUI. Individual professionals have initiated projects, but without positive support from professional groupings for SUI, it will not gain traction across the system. Nurses have significant power within the system and therefore their cooperation or resistance has particular implications for the success of SUI.

“Allies with the Smaller Voice”

The final sub-theme presents accounts of professional allies who open up invited spaces for SUI within the MHS. Niall used the title phrase about a particular official who: “allies himself with the smaller voice.” He spoke of the great respect he had for certain individuals within powerful positions who had worked for reform of the MHS, including a senior HSE manager and a previous Junior Minister for Mental Health, but qualified the extent of their ability to influence change in the overall ethos of the MHS. Martin was aware of the potential for success of SUI if there is trust between powerful allies and service-users: “user involvement is more successful when trust develops, if certain key people in positions of power...have a moral commitment to the ideas, and are intrinsic allies.” Kate and Patricia reported leveraging allies to advance service-users’ objectives. They also referred to the emotional support they obtained from professional allies.
Owen had observed a significant shift in the past decade whereby the situation had moved from having no SUI within the Irish MHS to one of significant strategic involvement at national level. In fact, he believed that comparing the Irish experience with that in the UK: “we’re light years in front now…coming from a place of absolutely having [no voice, to where]…the National Office for Mental Health does nothing now unless there’s service-users at the core…that’s a major shift.” He reported there were a small number of key allies who made this possible, who remained loyal to the user-movement and had not tried to control them: “none of them have tried to…handcuff us…in any way, we have said things at times [publicly] that wouldn’t have been comfortable for them to listen to, but they’ve never had a backlash on us.” Indeed, he described a process of building and cultivating relationships with key people who in effect: “became the advocates for the advocates…they covered our backs” when problems arose. As a consequence he believed this loyalty had to be reciprocated: “we’ve had to support them when we knew it was right to support them.”

Several participants referred to psychiatrists who are allies of the user/survivor movement, and of SUI. Liam had encountered: “some really good professionals, psycho-analysts and psycho-therapists particularly, who are trained as psychiatrists as well, but who questioned everything or had a point of view that was different from the traditional view.” Owen discussed Dr. Laren Mosher, the founder of Soteria, who challenged the medical approach and resigned from the American Psychiatric Association because he believed: “his profession was doing harm to people…he had found another way of enabling people to be able to understand their experience and move on with it.” Niall also believed genuine friendships and goodwill with some psychiatrists offered the biggest possibility of change. He mentioned psychiatrists with whom he believed it was possible to have reasoned debate about their understandings of mental illness. Yet he also observed these encounters may only produce superficial effects on hegemonic thinking:

I can have wonderful conversations with psychiatrists about Recovery, and then at the end, they’ll say something that reveals that they’re on a totally different wavelength. [You can] …create good relationships, but whether that actually changes someone or not, I don’t know. (Niall)
However, a public alliance with the user/survivor movement had consequences for such allies. Niall commented that those psychiatrists who have more radical ideas: “…tend to be just as marginalised as anybody else” by their colleagues, and dismissed as eccentrics especially if they went public on counter-hegemonic ideas. Patricia recounted an incident addressing a group primarily comprised of junior doctors training to be psychiatrists with a senior psychiatrist present. She presented her insights into the changes needed in the MHS in order to respond in ways which service-users found helpful, and was very disappointed that none of the junior doctors would engage in discussion with her in the presence of their senior colleague.

The importance of developing good relationships with key professionals is once again found to be a key contributor to the success of SUI. Key people in powerful positions have advanced the cause of service-user access to significant decision-making forums at a national level. One participant spoke of alliances which required reciprocal loyalty from service-users. Some psychiatrists were regarded as allies of the user-movement, but this posed risks of marginalisation within their professional organisations, while the inhibitory effects of hegemony were evident in another account.

**Discussion of Findings**

**Contestation**

The first theme reveals how contestation is a key dynamic in the emergence of a politicised collective identity among participants. This is evident across all the areas of contestation: the spotlight on human rights abuses, the rejection of the dominant paradigm’s understanding of, and responses to, psychosocial distress, and finally in the espousal of Recovery and peer-run services as an alternative narrative to the biomedical paradigm.

“*Shuffling around the Streets with the Shakes*” highlights that the key challenge for these participants is naming routine practices within the MHS as human rights abuses, and placing these on the political agenda for reform of the MHS. There are many historical accounts in the literature of psychiatry’s search for biological causes for psycho-social distress resulting in horrific practices in the name of cure (Newnes 1999; Foucault 1971; Samson 1995; Scull 1993;
Ussher 1991). Niall was particularly well versed in the details of historical abuses, such as the eugenics movement and surgical interventions to cure madness. While the other participants may not have had the historical details to hand, most were well aware of the unethical practices that have continued to this day: forceful and coercive treatment, including the use of ECT on unwilling patients, the overuse of psychotropic medications and the consequent iatrogenic damage. The key challenge is to reframe coercive practice as human rights abuses, thereby forcing a re-examination of routine practice as unethical.

Participants were angry at other abuses that occur within the MHS: neglect, squalid living conditions, the consequences on patients of control and domination by the MHS and the emotional abuse of damaging people’s self-confidence and sense of self. Behaviour that is challenging of the ethos within the services is construed by professionals as symptoms of illness, often responded to in the manner Sean described. It is not uncommon to have difficult or challenging behaviour medicated (various in Read and Reynolds 1996). The experiences that led to the participants’ politicisation about the need for reform of the MHS resonate with the issues raised in the literature by both survivors and critical professionals and academics (Brandon 1995; Beresford 2010; Lindow 1995; McGruder 2001; Rogers and Pilgrim 2005; Samson 1995; Sayce 2000). Double trauma as described by Cresswell (2005, p.1675) was evident in the accounts of people being re-traumatised by their experiences within the MHS, after seeking help with earlier traumas. The abuse of people in the name of cure has mobilised participants to place contested practices under the moral spotlight of human rights abuses.

Language is a cultural product, as well as a means of communication, through which associated meanings and structures organise our understanding of the world, which Foucault (1972) called ‘discursive practices’. Whether one approaches an analysis of Ruairí’s comment about euphemisms for abusive practices from Foucault’s (1972, p.49) understanding of discourses as “practices that systematically form the objects of which they speak”, or Harper’s (1995, p.347) approach to understand “systematic ways of talking about a topic”, it is clear that there are operations of power manifesting. Firstly, in the attempt to disguise unpleasant practices by renaming them, power remains unchanged.
Words and expressions position us in relations of power, and so a phrase such as ‘assisted admission’ means something different depending on who is using it. This is Ruairi’s point, changing the language does not change the practice, but neither does it change the traumatising experience of forceful removal to an approved psychiatric treatment centre by the Gardai, as Sean pointed out. However, the point of contention for participants is that changing the language is an attempt to make the practice more palatable and the power less overt.

In “Need for a Paradigm Shift” participants contested how psycho-social distress is understood and responded to. They referred to rigid bureaucratic procedures for staff, nurses in particular, who are trained to record discrete incidents and behaviour in order to measure progress of treatment (thereby objectifying and labelling people) rather than listening and talking to them, which is the universal demand of service-users (Read and Reynolds 1996; Beresford 2010). All of the participants contest the rigidity of such thinking and beliefs about the nature of human beings. A key point of passion for survivor activists is the epistemological gulf between a reductionist, bio-medical view of psycho-social distress and how to treat it, and their framing of distress as life-crises, and the alternative responses service-users want to such distress.

The reference to authoritative power is resonant with accounts of how hegemony is created and becomes accepted as the given way to see the world through employing various discursive forms: appearing in policy framework, legislation, textbooks, speeches, lectures, etc, so that it appears common sense and taken-for-granted (Carey 2009, pp.181-182). The same process explains how psychiatric knowledge is proliferated, initially throughout medical education and subsequently to a wider audience within society, including the media, aided substantially by pharmaceutical company marketing ploys (Healy 2012; Frances 2012; Whitaker 2010). People experiencing distress accept this orthodoxy because it is so widespread and has the veneer of scientific knowledge and medical credibility; they are persuaded that the drugs on offer are the only solution to their distress rather than considering social, emotional or structural injuries caused by life circumstances (Beresford 2010; Healy 2012; Lynch 2001).

75 Ironically, Carey’s (2009) argument is that service-user and carer involvement in the UK has become hegemonic through New Labour’s marketisation agenda for the NHS.
There are accounts of an epistemological challenge to psychiatric orthodoxy, including references to academic research, journal publications, and book chapters by users/survivors, which privilege experiential knowledge. There is further evidence of an articulated challenge to the bio-medical model of the MHS, but a sense also of being disheartened by the imperviousness of mainstream psychiatry to any critique. Their challenges to psychiatric hegemony were suppressed by the epistemological authority claimed by psychiatrists, who dismiss all challenges to their knowledge. This is an example of psychiatric disqualification, of being dismissed and diminished when offering an opinion counter to an established medical authority. This resonates with the ever-present politics of non-recognition of service-users (Lindow 1995; Lewis 2009). Holmes et al (2001) discuss the personal impacts of speaking out against the status quo, but conclude the resistance movement to psychiatry must continue, as eventually it has to bear fruit, as more and more people join the chorus of critics.

Hess (2004) describes how the ‘lay’ knowledge of health social movement activists can be dismissed by the dominant knowledge paradigm. He names this as “epistemic politics”, suppression strategies that he describes as: “a blanket rejection of challenging knowledge claims” by the leading researchers and opinion shapers in a field (Hess 2004, p.704). This was evident in accounts of dismissal by psychiatrists to epistemic challenges to their authority and privilege across several sub-themes (e.g. employing service-users). Another resistance strategy Hess (2004) identifies is assimilation of the contesting ideology into the dominant paradigm, as was evident in some of the participants’ concerns about the co-option of Recovery.

Participants adopted different strategies to challenge the dominant paradigm, primarily by highlighting service-users’ experiential knowledge through their involvement in professional education and user-led research. Much of the extensive body of literature on this topic, particularly with social work and nursing students (Beresford and Campbell 1994; Repper and Breeze 2004; Tew et al 2004; Campbell 2006; Kemp 2012; Happell et al 2003; Happell and Roper 2009) suggests that SUI in education can highlight the human impact of taken-for-granted professional practice and norms. Education of mental health professionals in Ireland is an area in which there has been little systematic SUI,
apart from recent practices of inviting once-off guest lectures by service-users on
some courses. Two participants with more ongoing involvement with
professional education observed how, despite positive evaluations by students of
their courses, once the students were employed in the MHS they lost the
perspective they had demonstrated as students. It was disheartening to consider
the experience of losing even the best students to the more powerful effects of
hegemony and institutionalisation. This re-emphasises the power of the
institutionalised system to shape attitudes, even of those students considered to
have the potential to be more open-minded.

User-led research was another counter-hegemonic strategy that some
participants adopted to highlight the experiential knowledge of service-users
about how current service-provision is failing to meet their needs. Knowledge
can be determined by what is researched and the questions asked in the research
(Baker et al 2004; Gaventa and Cornwall 2008; Hess 2004). Participants
discussed the politics of the research question, and the significance of how
questions are framed, otherwise user-led research can also be assimilated into
support for the existing system. The significance of the researcher standpoint was
raised by some participants, pointing out that a researcher with life experience of
the area being studied is more likely to know the issues of concern, and to
understand what needs to be asked. The epistemological gulf means that
academic and health services research projects often miss the issues of most
concern to service-users.

Participants also reported a tendency by professionals to seek out service-
users with more positive experiences of care than to listen to service-users who
are angry. Participants observed that Recovery stories are heartening for service-
providers to listen to, but not accounts of how service-users feel abused by the
MHS. By selecting the narratives they will listen to, professionals can continue
to believe that what they are doing is therapeutic. Listening to positive accounts
is less threatening and less challenging to power than hearing the experiences of
people who are angry (Brandon 1995; Lindow 1995; Crepay-Kray 1996).

A key finding in “De-Junked of Psychiatry” is how core concepts of the
user/survivor movement (peer-support and Recovery) have been appropriated
and assimilated into institutionalised practice, so that that their critical and
transformative potential have been diluted. Recovery was developed by the user/survivor movement as a response to, and way of overcoming and resisting, institutionalized and oppressive psychiatric care (Beresford and Wallcraft 1997). Several participants emphasised the role of social factors, such as supportive relationships and community, as essential to regaining mental well-being, evident in the accounts of peer-support and peer-run alternatives. Recovery, as understood by the MHS, and indeed many service-users, ignores the social factors which shape the conditions many service-users experience. Issues such as discrimination and stigma, high levels of unemployment and social isolation are often omitted in discussions of Recovery (Harper and Speed 2012; Pilgrim 2008). This is one reason service-users, both within the literature (Costa et al 2012; Turner-Crowson and Wallcraft 2002; Beresford 2010) and some participants in this study, are concerned about the strategic appropriation of Recovery discourse.

The appropriation of Recovery discourse is evident in Irish national, and local, policy documents. WRAP (Copeland 2002) has been substituted for care planning within some services. Conflicting perspectives emerged in response to this development. Some participants protested at and feared this appropriation, and observed that mental health practice continues as usual, with the gloss of Recovery added. While these participants deplored this development and the loss of the critical focus on emancipation as a result, other participants were less critical of the appropriation of the discourse, indeed, welcoming the favourable reception of WRAP by staff. These conflicting viewpoints point to tensions around differing objectives for SUI among user-movement actors, a finding developed further below.

Several participants presented alternatives developed outside Ireland, which have been shown to be effective, albeit not supported by mainstream MHS. They named peer-support and crisis supports such as Anam Cara, Soteria and the

76 Despite some initial meetings in 2006/2007 with user-movement actors, interested professionals and academics to discuss the possibility of setting up an alternative crisis support model in Ireland, with links to one or more mainstream services, the idea had been shelved as unlikely to gain any support from the current mental health establishment, even before the recession had begun to take effect on funding possibilities. The idea is still alive and perhaps even still being discussed among service-users, as some participants certainly displayed enthusiasm for the idea.
Open-Dialogue process as spaces for people to overcome psychosocial distress. These alternative approaches, described by various writers (Faulkner 2002; Hartmann and Braunling 2007; Johnstone 2000; Read et al 2004; Whitaker 2010), share a common ethos of non-coercion, especially in relation to medication, thereby respecting and supporting the existential journey of the person experiencing distress. Most importantly, the prominent role of survivors in such centres offers hope and inspiration to people experiencing distress that they too can survive and thrive. Faulkner (2002, p.3) reported on the benefits of independent peer-run crisis services, which included greater opportunities for interaction with staff, a focus on practical problems and links with other services, and an ethos of more positive expectations because of the supportive environment created. These approaches provided epistemic challenges but also allowed for counter-hegemonic ideas in claimed spaces, a point of analysis followed in the next chapter.

A key finding across the theme of Contestation is how sharing common knowledge and narratives around service-users’ experiences contributed to the development of a collectivised, politicised identity. Framing psychosocial distress as an existential reaction to social and emotional trauma can occur within the spaces where service-users gather to listen to stories of ill-treatment, fear, abuse, and survival, and to create awareness of alternatives, and challenge psychiatric hegemony. Participants recognised the need to create a greater awareness among the general body of service-users and the public about such alternative discourses, and were engaged in dissemination of ideas, materials and narratives of resistance, which was contributing to the development of a collective politicised identity.

**Strategy Tensions**

The second theme, *Strategy Tensions*, revealed the tensions emerging among the movement activists over the most appropriate strategies to achieve their objectives. Participants occupied different positions across a spectrum of opinion

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77 The Critical Voices Network is one such group active nationally to create a space where movement discourses can be rehearsed and formulated by wider groups of interested parties, as it includes professional allies, academics and family and friends of people affected by emotional distress (Sapouna 2012).
on insider/outsider strategies. Tensions emerged about public action as a strategy for the user-movement. A few participants were in favour of developing direct forms of protest while others favoured an exclusively insider strategy. Most participants, however, considered a collaborative strategy of SUI as being the only option currently available in pursuing their goals, while not rejecting the option of public protest as a strategy to highlight human rights abuses within the MHS.

Within the literature on social movements and insider/outsider status, Grant (1978) defines strategies as: “the combination of modes of action used by an interest group to attain its goals” (cited in Maloney et al. 1994, p.18). Dunleavy (1991) categorises strategies available to interest groups as 'low cost actions' (responding to routine consultations, petitions, lobbying elected representatives), as opposed to 'high cost actions' (non co-operation with government, boycotts or non-compliance, strikes/industrial action, civil disobedience) (cited in Maloney et al. 1994, p.26). Chaining oneself to gates may be somewhere between low and high cost action, but the resultant publicity would be uncomfortable for policymakers, and likely to be unwelcome, as was evident in Chapter Six. Yet strategies such as media campaigns, street protest, civil rights actions and other symbolic actions provide opportunities for the user-movement, not just to highlight human rights abuses, but to build esprit de corps and recruit members into the movement (Crossley 2006).

Craig et al. (2004), in their study of voluntary and community sector organisations across the UK, found that different strategies are adopted by different sections of movements depending on the policy environment and the opportunities available to achieve their goals. Rather than finding a dichotomy between insider and outsider approaches, Craig et al. (2004) identify that many movement organisations used both tactics as opportunities arose. They report that: “insider strategies can open channels for information and understanding of the policy context while outsider strategies can use that material for pressurizing, naming and shaming, and so on.” (Craig et al. 2004, p.237). In this study, while most of the contestation strategies of participants were focused on insider strategies of collaboration with the MHS, they recognised the place of outsider strategies, albeit the majority of participants were not engaged with such tactics.
Indeed, some were concerned with a potential hostile reaction of senior management to outsider strategies. Craig et al (2004) refer to the creative tension that exists between groups pursuing different strategies, which nevertheless move towards the common goals of movements. For example, it can be useful for insiders in their negotiations to adopt to point to the banners on the street.

However, this tension can be problematic if some groups are perceived as too aggressive or provocative, and can lead to splits and factions within the movement (Craig et al 2004). For instance, some participants were uncomfortable with the aggressive tactics of one movement activist. Jasper (1998) comments on the risk of schisms within the movement if the emotions aroused are divisive. Several participants were cognisant of the need to raise public awareness and build alliances around unacceptable practices of the MHS, and were active in strategies of awareness raising and education of ‘grassroots’ service-users in order to mobilise more recruits for the user/survivor movement.

In the sub-theme, “I Ended Up Being on Committees”, most participants were focused on strategic involvement as a way to achieve change, demonstrating a pragmatic attitude towards committee membership. The focus of the service-users on statutory bodies was to prioritise issues of concern, such as a different vision for how the MHS could operate. Given the statutory role of the MHC in monitoring the MHS, producing a discussion document such as A Vision for a Recovery Model in Irish Mental Health Services (2006) created quite a lot of debate generally within the MHS and prompted the up-take of the concept by a number of progressive professionals. This has had mixed results as some participants felt the concept had been ‘captured’ by the MHS. However, other achievements have resulted from SUI on committees, some individuals were said to have acquired a certain amount of influence, and the skills acquired through this work were returning to benefit the user-movement. It is a feature of social movements that skills acquired by seasoned activists can percolate down to novices, thus building capacity for action and SUI (Crossley 2005).

One participant identified that the ultimate goal of SUI was the achievement of autonomous peer-run services as an alternative to the current treatment model. Peer-run MHS have been established in the USA and Australia (Doughty and Tse 2011; Meade 2007; Millet 2007; Solomon 2004) since the 1990s. There has
been no success in advancing autonomous peer-run direct care projects in Ireland but there has been some advance on peer-involvement in MHS delivery.

Peer-involvement in service delivery is far less threatening to the current paradigm. For example, peer-support workers have been a feature of some MHS internationally for some time (Owen et al 2012) but have not yet appeared in Irish statutory services, although a few pilot projects employing service-users as peer-workers are appearing, albeit hosted within a voluntary sector organisation (Rehabcare). Thus, SUI in service delivery is tentatively being incorporated into some outlier MHS in an Irish context. This form of peer-delivered care within mainstream MHS is a strategy that the Irish user-movement has been pursuing through the opportunities that SUI on committees offers, as there is evidence that it leads to increased service-user satisfaction and better outcomes for all, service-users, carers and the MHS (McLean et al 2009; Solomon 2004) or at least no worse outcomes than traditional care (Simpson and House 2002). The peer-support worker development is an example of how insider strategies are used by participants to advance movement objectives to reform how the MHS operate, as well as contesting failures of current service provision. By campaigning for direct employment of service-users in providing care, participants seek to affect changes in the system and the dominant paradigm.

The findings in “Going into the Lion’s Den” reveal the high emotional cost of unequal conditions of participation. Fear and intimidation were experienced due to displays of epistemological authority, but also anger and frustration at tokenistic involvement and resistance to change. The common factor in all accounts was the impact of engaging in highly unequal settings, with hidden power shaping decision-making resulting in the frustration of tokenistic SUI.

Participants felt ill-prepared due to lack of training, but also inadequate, fearful and diminished by their initial experiences in these forums. Fear is a normal reaction in situations where one is outnumbered, ‘out-gunned’, with one’s sense of security threatened (Pilgrim 2009, p.28). It may also be a response to unequal power, the uncomfortable sense of being a marginalised

78 IAN is the only solely peer-run service providing support in conjunction with the MHS (albeit limited to a peer-advocacy role, rather than providing direct care as in peer-led MHS). GROW run peer-support groups within some MHS facilities: they too operate independently from the MHS. However both organisations, as voluntary peer-led services, are dependent on funding from the HSE for their staff.
outsider. The characterisation of themselves as inadequate is an example of the subtle processes of power working to displace structural deficits and inequalities onto the Other, thereby bolstering the power of the dominant by blaming the victim for not being more resourceful or efficient (Gaventa and Cornwall 2008). Participants were resisting these processes and power games, by supporting each other and developing a collective politicised identity through their challenge to psychiatric hegemony.

Participants reported initial optimism and excitement about engaging; they had high expectations of having opportunities to make some changes in the MHS. Instead they experienced frustration at the lack of progress. Participants need to do constant emotional work to counter the feelings engendered in the business-like spaces which allow no emotional expression. Church (1996, p.39) wrote about the ethos of consultative processes in which the hidden, implicit agenda was: “a code of professional etiquette which implicitly defines emotionality as irrationality.” Within such forums service-users learn to play by the unspoken rules of non-emotional expression. Anger can be understood as an expression of a claim that injustice has been done to the speaker, and silencing this anger is a political tactic of power (Lyman 2004). So not only are service-users silenced by the inequalities and non-recognition they experience in the meetings, and the lack of preparation or training, but the subsequent anger and frustration had no place for legitimate expression especially in dispassionate forums. This is another instance of denial of recognition (Lewis 2009). The resultant anger and frustration can be understood as ultimately rational, and a source of motivation for the user-movement, as pointed out by Jasper (1998).

The incident described by Kate at a top-level meeting illustrates many of the power and recognition dynamics occurring when service-users are invited into the previously closed spaces of decision-making. Schwartzman (1987) maintains that meetings are worthy of study in their own right, as they in effect constitute and construct the reality of organisations. This account corroborates evidence of the power dynamics and emotional work of SUI. The power dynamics are discussed more fully in the next chapter as an example of the explanatory potential of the power cube. The support of peers was crucial to a resolution of the situation, providing Kate with a strategy to respond. In awaiting her chance to
read the prepared statement, she would have been aware of the emotional tension building, and her description of her feelings as she read it out are evocative of both terror and courage, as she defended the maligned right of service-users to be involved, and to be capable and professional when offered an opportunity to participate.

Participants’ accounts also reveal decision-making processes that are far from transparent and easy to follow. The description of the work that service-users needed to do, firstly to understand what is going on at meetings and then to follow the decision-making process, indicates the difficulties inherent in dealing with the power dynamic at meetings. It requires constant attention, reading and tracking what has been said and recorded in accompanying documents. Church and Reville (1988) describe the work overload and burnout that occurred among leaders in the Canadian service-user/survivor movement because of the administrative and procedural demands that were placed on those who got involved in committee work. Hidden power and uneven access to resources were operating as barriers to SUI, given the administrative support and back-up available to management and professionals, who will have assistants who can track and highlight the relevant and most important parts of documents to focus on.

In addition, participants suggested that many decisions are taken outside meetings with specific references to decision-takers as distinct from those attending the meetings. Kate also referred to compromises. Making compromises are a necessary part of collaboration, but there is a fine balance between compromising and being assimilated. A feature of a good compromise is when nobody is happy with the outcome, because each side has had to accept less than they wanted. Each party needs equal negotiating power in order to leverage an acceptable compromise from everyone. It is rare for those in power to be forced to compromise, except they choose to offer concessions, in order to appear more benign. The issue of decision-making as an exercise of power will be followed up further in the next chapter.

The findings in “Asking for Payment is a Political Request” indicate that recognition and validation of the contribution of service-users is a political issue, and that receiving payment, or being offered payment which some may choose to
decline, is significant in terms of respect for the contribution of service-users. Re-distribution of money is a highly political topic, although it is often reduced to economics or accounting (Ryan and Bamber 2002). For these participants, payment clearly was an issue of justice and recognition of their work within the MHS. They argued that non-payment could not be excused on grounds of inadequate budgets; this was seen as a feeble rationale which demonstrated a lack of parity of esteem with service-providers.

Most participants angrily rejected the suggestion put to them that, because volunteering is a worthwhile endeavour, payment is less important. The double standards made some angry; it was considered inconceivable that professionals would be expected to contribute their expertise on a voluntary basis or travel to meetings without full reimbursement. Participants also pointed out that their contribution to the MHS is substantially different to volunteering at a community level: they contribute their expertise into professional forums. Not to recognise the demand for payment and to obstruct progression of the issue is indicative of professional/bureaucratic resistance or intransigence (Church 1996). Dismissal or trivialisation of the issue reflects a resistance to acknowledging the contribution of SUI in providing an expertise which can help inform the direction of change in the MHS.

The evidence about the project Martin worked on for six years suggests that service-users and service-providers can experience working together in fulfilling ways given the right conditions. In this case, the experience was positive and worthwhile, so receiving money was of lesser importance; all the other conditions were right in terms of respect, pride in their work and other positive benefits. It was also their own decision not to accept money, choosing other rewards and team-building social activities instead. The political principle of payment is more pressing in challenging and unequal conditions of participation, where the discrepancies in power and status between professionals and service-users made payment a political demand and a strategy for recognition.

Concerns that SUI provides legitimacy to the MHS while service-users have no control over the agenda appear in “Does Activism become Dampened

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79 However frequent non-payment did not dent their commitment to the principle that SUI is vital to make a difference; indeed the majority were not in paid positions.
There was a wide spectrum of opinion about the value of SUI, but collaboration did not appear as a major point of contention. Several areas of concern emerged around the issue of co-option. The first issue concerns whether SUI has made any impact in achieving change for service-users in the MHS? Some believed it has, others do not and some are unsure, acknowledging that it is difficult to find hard evidence that SUI is making any difference. This raises the question about whether developing outcome measurements for SUI activities would be beneficial. This is one strategy that the user-movement is pursuing in the UK, both in terms of quality assessments and measuring impact in relation to SUI in research (Faulkner 2012; Morrow et al. 2010; Staniszewska et al. 2011). However, given the limited SUI initiatives in the Irish MHS, quantitative measurement of outcomes is not yet feasible.

For most participants assimilation of the user-movement, as well as of individual service-users, is a concern. Following the acceptance of any new trend in policy or the emergence of any new sphere of interest, those who have been raising awareness of the issues are seen as having something to contribute to the new developments, thus social movement actors can become absorbed in the practicalities of governance (Cox 2010; 2011; Murphy 2002; 2011). Several participants acknowledged this was occurring. A different risk, expressed by one participant, is that SUI is about a MHS building its reputation as a progressive service, regardless of the cost to the service-users involved. In his case, he felt used by his involvement.

The position taken by Ruairi, an outright rejection of SUI until abusive practice is addressed, is one end of the spectrum or continuum of SUI noted by Pilgrim (2008, p.299). Ruairi was emphatic about the abusive nature of the MHS, and the lack of influence of service-users within the system. Campbell (2001) noted the lack of influence service-users had achieved over 20 years of SUI in the UK. Ruairi, however, went a step further; in his opinion collaboration was collusion. Other survivors who advocate a separatist stance share similar reasons to resist collaboration (Chamberlin 1977; Lindow 1995; Oaks 2007; Meade
There are many examples of separatist or resistance survivor groups internationally who refuse to engage with mainstream MHS (various in Stastny and Lehmann 2007; Read et al 2004). Naturally such outsider strategies exist in spaces outside the influence of MHS, distant from service-providers who can feel very threatened or react angrily to such attacks (Church 1996). The goal of such strategies is for internal objectors to remove themselves from systems such as the MHS, which would then collapse from lack of personnel to carry on the work. Such is the argument of radical separatists, groups such as Mad Pride or MindFreedom. This argument would work if sufficient numbers were to leave, but without a critical mass of people refusing to work in it, the system continues and is self-perpetuating as is the nature of all organisations, particularly institutions such as the Irish MHS (Molloy 2010). In the meanwhile, well-intentioned professionals remain, and seek to reduce the dehumanising impact of the MHS for those they work with (Johnstone 2000; Repper and Perkins 2003; Townsend 1998).

The MHS worldwide is such a massive globalising industry (Thomas et al 2005; Watters 2010) that it cannot realistically be ignored, because that does not ultimately change the reality of the current treatment of individuals caught up in it at present or for future generations. In fact this is a distinguishing feature of Health Social Movements, as distinct from other social movements such as the environmental or Occupy movements; because the movement actors (or their friends or families) are usually dependent for their healthcare needs on the very system they contest (Brown et al 2004). Hence many psychiatric system survivors are pragmatic and work with reformers within the MHS in different ways, and on their own terms, while they also seek to create alternative ways to work with people experiencing psychosocial distress.

**Structural Inhibitors and/or Facilitators**

The final theme considers the structural context of the MHS which either inhibits and/or facilitates SUI. The power structures occupied by the professions, especially psychiatry and nursing, are features of the context which shapes SUI.

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80 Groups such as Mind Freedom and Mad Pride, World Network of (ex)Users and Survivors of Psychiatry (WNUSP) and the European Network of (ex)Users and Survivors of Psychiatry (ENUSP)
It is often from these groups that individual allies emerge to support SUI initiatives against the resistance of their colleagues. The first profession considered are psychiatrists.

The findings in “Psychiatrists don’t Relinquish their Power” concern the legitimacy of the dominant power of psychiatry. The dominance of psychiatry, underpinned by historic privilege, hegemony and legislation, was challenged as open to corruption and unhealthy, not just for service-users and other professions within the MHS, but also for the profession itself. The domination of the clinical multidisciplinary teams by consultant psychiatrists mirrors the control over physical healthcare by the medical profession (Brown et al 2004; Hess 2004; Rogers and Pilgrim 2010; Turner 1995) and is especially pronounced in the Irish MHS (Hyde et al 2004). Within the hierarchy of the MHS, the dominance of the psychiatric profession permeates every aspect of the services, even in their frequent absence from meetings. Any decisions made will have to be approved later by consultant psychiatrists. They do not have to explain or justify any of their decisions, especially not to service-users. Giving absolute power to one profession leads to a domination which prevents mutual understanding with other professionals, and indeed service-users, a point argued by critical psychiatrists (Bracken 2012; Double 2001). The underlying objections to service-user workers on multi-disciplinary teams do not need to be spelt out; if the psychiatrist is opposed to SUI then it just will not happen. The reason offered, needing the “right people, right governance” suggests a multi-layered set of prejudices towards the competence of service-users. The implication of course is that service-users are not the right people and that they could never be acceptable under current governance structures. Stigmatising attitudes of professionals towards service-users are not new and they still present barriers to significant roles developing for service-users (Beresford 2010; Happell 2008; Solomon 2004). These attitudes are all the more formidable given the power of consultant psychiatrists to block any change not in their interests.

The question of whether separate mental health legislation is necessary to regulate the MHS and protect human rights, as opposed to requiring the MHS to
be compliant with the CRPD\textsuperscript{81}, is currently being debated (Mégret 2008; O’Mahoney and Quinn, forthcoming). Under international human rights instruments, governments are obliged to ensure equal access of all people to adequate, appropriate and timely health care (Amnesty 2011). Some argue that robust mental health laws provide some protection against, or offer hope of remedy for, the abuse of human rights of people detained in psychiatric institutions (Perlin 2007). The High Commissioner of Human Rights has interpreted the CRPD to mean that involuntary detention and forced treatment with psychotropic drugs and ECT is discriminatory and therefore unlawful (Bartlett 2009; Dhanda and Narayan 2007). Survivors argue that mental health laws should be abolished because they are inherently discriminatory, and legitimise involuntary detention (Kovary 2008; Minkowitz 2007). However, while legislation does confer enormous additional powers on psychiatry, removing these statutory powers alone will not significantly reduce the power of psychiatry, as it is still a branch of medicine situated at the apex of the healthcare hierarchy. Psychiatry will not relinquish its claim to hold special expertise over the control of ‘unreason’ and emotional distress, given the entrenched power of psychiatric hegemony.

The findings in “The Arrogance of Power” support findings from earlier chapters about the power of individuals in key positions to facilitate or hinder SUI. Individual professionals have initiated projects, but without positive support from all professional groupings for SUI, it will not gain traction across the system. Another finding supports earlier evidence (Chapters Five and Six) that mental health nurses hold considerable power over service-users within the system and can support or hinder SUI. The “arrogance of power” comment resonates with frequent accounts from service-users of unhelpful attitudes from many nurses (Campbell 1996; Chamberlin 1977; Read 1996), who are often experienced as controlling and coercive in their interactions with service-users (Breeze and Repper 1998; Cutcliff and Happell 2009; Walsh \textit{et al} 2008).

There was also evidence about paternalistic attitudes from some social workers. Beresford (2000) observes that social work theories have traditionally been based on individualised medical models of both disability, and madness and

\textsuperscript{81} UN Convention on the Rights of Persons with Disabilities
distress. Wilson and Beresford (2000) critiqued some of the power dynamics between service-users and ‘anti-oppressive practice’ in social work. They point out how ‘anti-oppressive practice’ can perpetuate the oppression it aims to alleviate, by failing to address the social worker’s situated practice vis-à-vis service-users’ positioning in coercive MHS structures. Additionally, appropriating service-user knowledge for career progression replicates oppressive constructions and definitions of service-users (Wilson and Beresford 2000).

In “Allies with the Smaller Voice” the role of allies is once again found to be a key contributor to the success of SUI. Allies use their power and influence within the system to invite the service-user to join those sitting in the “seats of power”. Key people in powerful positions have advanced the cause of service-user access to significant decision-making forums at a national level. Some psychiatrists were regarded as allies of the survivor/user movement, but this posed risks of marginalisation within their professional organisations, especially if they went public on counter-hegemonic ideas. This is resonant with much of the literature reporting the responses to criticisms of a dominant orthodoxy (Double 2001; Hess 2004; Holloway 2009; Johnstone 2000; Rogers and Pilgrim 2005; Whitaker 2010). Defence strategies deployed against critics of the biomedical paradigm fall into three broad areas: firstly, denial and suppression of evidence counter to the dominant paradigm; secondly, attacking and undermining the credibility of the critic, threatening and blocking careers of internal critics, etc; and thirdly, assimilating aspects of different approaches without changing the basic medical model (Johnstone 2000). Denial and assimilation strategies of defence against survivor epistemology have been evident across the various sub-themes above. The discrediting strategy, especially in relation to career development, is highly effective in maintaining conformance with discipline orthodoxy and silencing any dissent, especially within a small demographic such as the Irish MHS field. Therefore, to publicly identify as an ally of the user/survivor movement, or even as a social psychiatrist, risks marginalisation within the biologically orientated profession (Bracken et al 2012; McLaren 2010a). However, there is a major difference between aligning with the more critical views of opponents to bio-medical psychiatry and
espousing SUI. Most of the allies of SUI referred to or encountered in this study were firmly established within the statutory MHS, and while welcoming and supporting SUI, did not express any counter-hegemonic views.

Chamberlin (1988) in the introduction to the UK edition of her book (based on her experience in the USA), speaks of the collaboration she saw between British service-users and service-providers as distinct from the drive in the USA to establish independent consumer-led services. Owen claimed that collaboration and alliance building was even more pronounced in the Irish context, and that SUI has made considerable strides at a strategic level in Ireland, because of the support of powerful allies. Forming alliances with powerful insiders is a strategy which has furthered the cause of SUI in Ireland, although not without inherent risks of assimilation. The strategy of naming and resisting coercive practices within the MHS, informing the collectivised political identity of the user-movement, is a mitigating factor against assimilation.

**Summary**

This chapter presents data from interviews with twelve participants who are national activists in the emergent Irish user/survivor movement. They have a significant amount of experience of SUI between them, and represent the range of opinion amongst user/survivor activists. As with local service-user participants in Chapter Five, these participants’ understandings of the shortcomings of the MHS inform the dominant theme of contestation. They presented a systematic analysis of the inherent power structures within a hierarchical, medically dominated mental health system that privileges psychiatric expertise. The participants question the assumptions about power, knowledge and best practice underlying a rationale that fails to address structural inequities. As a group they are more politicised and with more pronounced counter-hegemonic discourse than most participants in Chapter Five. The key finding in this chapter is again around the inherent tensions between contestation and collaboration, but here a significant additional tension emerges among the user/survivor movement participants about the appropriateness of insider/outsider strategies.
All participants present a robust contestation of the biomedical/technological paradigm, including an articulation of the consequences for service-users of both the over-reliance on pharmacological interventions and the controlling, coercive ethos within the MHS. Most articulated passionately the social injustices and human rights abuses occurring within the current practices of the MHS. Serious historical abuses, such as the eugenics legacy of psychiatry and current abuses such as contentious, coercive practice against non-compliant patients, including forced ECT, force-feeding and forced-administration of medication, were named specifically by two participants. The over-reliance on, and/or the iatrogenic affects of psychotropic medication were contentious issues discussed by many participants, three of whom specifically referred to Whitaker’s (2010) research on the rise in reported disability amongst service-users associated with the increased use of psychotropic medication. Several other participants referred to issues such as sub-standard living conditions within MHS facilities, loss of custody of children, bullying and fear of speaking up amongst service-users. Naming of abusive practise within the MHS was more explicit among participants in this chapter than most participants in Chapter Five.

Among participants in this chapter, the concept and ethos of Recovery emerged as a contentious issue. They associated Recovery concepts with strategies for living that require community supports rather than medical interventions. For those who saw Recovery as a new site of contestation, the MHS were deemed to have appropriated the concept while failing to embrace its core principles - a rejection of the coercive ethos and bio-medical expert-led approach to dealing with psycho-social distress. Some participants claimed that the critical focus on emancipation, both cognitive as well as structural, represented in the user-articulated concept of Recovery was lost in mainstream bio-medical discourse.

Most participants see their engagement in SUI as a political and epistemological challenge to the current MHS and the prevailing paradigm that it operates under. Some discussed specific, non-coercive, alternative approaches to dealing with psychosocial distress, including initiatives developed outside Ireland by mental health professionals (Soteria and Open-dialogue), and by survivors (Anam Cara). These were described by participants who had
experienced them as sanctuaries of healing and refuges in crisis as well as emancipatory challenges to the current paradigm. Other participants contested the current focus on objective diagnostic criteria and the micro-recording of discrete behaviours in order to classify symptoms, as objectification of people, which is not how service-users want to be treated. Indeed service-users want to be listened to, a serious failure of care (as well as SUI), noted in both chapters with service-user participants. Peer-run and peer-involved crisis centres were also presented as challenges to the current expert-led paradigm, and formed part of the counter-hegemonic discourses employed by many participants. The issue of both peer-support workers within current MHS and alternative autonomous user-run crisis centres (involving experienced service-users offering direct care to other service-users) were discussed by some participants as strategies for reform.

These discourses of contention contribute to the emergence of a collectivised politicised identity, a core feature of an EHM. The politics of recognition (Fraser 2000) familiar from Chapter Five, once again emerged in accounts of the experiences of SUI: disrespect, non-recognition and mis-recognition from more powerful service-providers were reported by all participants. These participants, however, display a stronger challenge to denials of recognition by virtue of their collective identity as social movement actors.

Some participants were ambivalent towards committee membership at strategic and operational levels. One participant acknowledged the influence some service-users can leverage on some committees, but suggested that unless service-users gain more influence, SUI could be considered a tokenistic exercise. Others raised questions about the impact of SUI to date; they questioned if it has made any difference to suicide or admission rates, or made an impact in terms of reforming care. Individual involvement, even at the level of care planning, was found to be lacking or inconsistently implemented across the MHS, or provided through inappropriate appropriation of Recovery concepts such as WRAP.

A new finding in this chapter is tension about SUI itself. Most participants consider SUI as an essential strategy in achieving a core objective of the user-movement, i.e. improved client-centred care. However, two participants were disillusioned about SUI, while another rejected it outright under current
conditions. The tensions around potential assimilation into a MHS agenda were much more pronounced among participants in this chapter. Many had seriously reflected on the issue of whether they should remain involved, but the majority view was that SUI was the best available option for the user-movement because of their commitment to the principle that the MHS require reform, and this must be informed by the perspective of those who have experience of using MHS.

The challenge to the legitimacy of psychiatric power enshrined in legislation is another key finding in this chapter. A point of convergence from Chapters Five and Six are the power structures occupied by professionals in a hierarchical MHS. Several participants challenged the legitimacy of the authority conferred on consultants by legislation and whether it is legitimate to give so much power to one profession, due to the potential for corruption that domination offers. Participants were cognisant of how knowledge is constructed by the dominant interests to filter out contesting knowledge claims. Many in this chapter were well-versed in the politics of research and how the formulation of questions, and by whom, support current knowledge paradigms. Several spoke of challenging psychiatric hegemony only to be intimidated by the epistemological authority claimed by psychiatry, which dismisses all challenges to their orthodoxy.

As in Chapters Five and Six, mental health nurses were reported by participants to hold considerable power over service-users within the MHS and can support or hinder SUI initiatives. Individual managers were again reported by some to be highly influential regarding SUI projects, either in a positive or obstructive manner.

The emotional work of SUI again emerged as a finding, with accounts of hostile and challenging experiences at meetings. The procedural and bureaucratic tone of meetings, concerns about governance and the operations of hidden power to manipulate decision-making, make SUI challenging, especially for newcomers, as many accounts revealed. Initial enthusiasm was damped by the realities of lack of progress. This resulted in anger and frustration over time, at the sense that nothing could change given the inequities of power, recognition and resources available to service-users. Participants revealed practices of hidden power in pre-arranging outcomes, burying important information in copious material, pre-selecting the powerful positions, and pre-deciding strategies
between more powerful, established professionals to get issues resolved in their favour. This is in accordance with findings in Chapter Six, where meetings were reported to be dysfunctional even without the presence of service-users.

Participants explicitly identified payment as a political issue in the struggle for recognition of SUI initiatives. The fact that not all service-users want payment does not detract from the argument that the political principle of payment is a recognition issue. Developing alliances between professional allies and the user-movement once again emerges as a significant strategy of participation for activists within the user-movement, and was found to have advanced the cause of SUI at a national level.

An additional finding to emerge in this chapter points to the inherent tensions among movement activists on the appropriateness of SUI as a movement strategy. Most are in favour of pursuing SUI as an insider strategy to contest the current provision of care and to position themselves to affect changes (such as direct SUI in delivery of MHS) and ultimately the provision of independent services. Regardless of concerns about assimilation and co-option expressed by some, and rejection of SUI as collusion by one participant; the unifying drive for participants is the collectivised political identity which arises from their challenge to the bio-psychiatric, expert-led paradigm of care, and passion for reform of the MHS, the ultimate motivator for their activism and SUI work.
Chapter Eight:

Theoretical Analysis of

Power Dynamics
Chapter Eight: Theoretical Analysis of Power Dynamics

Introduction

The power cube (discussed in Chapter Three) is a framework for examining how power operates in citizen participation (Gaventa 2006) and can be usefully applied to SUI to illuminate the conditions of participation. The model illustrates the power dynamics operating across three different domains: forms, spaces and levels. The three forms of power are: visible (overt and explicit manifestation), hidden (the power to determine the agenda, to define what is included or excluded for discussion) and invisible (ideological boundaries which shape and limit what is permissible to discuss). The spaces of power in the MHS field are: closed (not accessible or available to SUI), invited (MHS-led initiatives around SUI) and created/claimed spaces (user-controlled groups and user-led initiatives). The final dimension considers three levels of power: strategic (SUI in overall service planning, policy development and implementation, and reform initiatives, including user-led training, research and/or peer-led services), operational (SUI concerned with day-to-day issues of how the MHS organise their services) and individual (a service-user’s clinical or therapeutic relationship with service-providers). All these are ideal domains in the sense that they are fluid and moveable dimensions, rather than fixed and contained. Gaventa (2006) explains that the power cube is not static but interactive as power acquired in one area can be used or applied in other domains. Using the conceptual lens of the power cube offers both service-users and service-providers, developing SUI initiatives, a potential framework for understanding the hidden and invisible dimensions of hegemony and the politics of power and participation.

The overall themes from the preceding three chapters highlight the different tensions inherent in the practice of SUI operating under the terms of the MHS. To recap, Chapter Five contains the local service-user participants’ accounts, Chapter Six the service-providers’ and Chapter Seven the accounts from national service-user activists. The tension identified by service-user participants arises when their contesting of the expert-led, bio-psychiatric paradigm is by necessity accompanied with their collaboration with the MHS to reform it. A few
participants in Chapter Seven aspire to ultimately achieve peer-controlled services and spaces, whereas others seek institutional support for a more alternative system of service delivery. The service-providers, on the other hand, initiate SUI in line with top-down policy to pursue their agendas of reform, which includes how the individual service-user experiences their care. But they also seek to align with service-users to manage and protect services against budget cuts, and for top management, to achieve institutional structural and governance reform. Among the tensions experienced by service-provider proponents of SUI are those caused by the power disparities between themselves and service-users, and from the difficulties that arise in supporting them without unduly influencing their critical perspective on how the system fails service-users. These are the overarching themes that the power cube framework can illuminate. The power cube, adapted for SUI by the author, is re-presented in Figure 13.

Figure 13: The ‘power cube’ for SUI: adapted from Gaventa (2006, p.25)

Forms of Power

All three forms of power (visible, hidden and invisible) influence how service-users experience mental health professionals as either facilitators of, or obstacles to, SUI. The findings in relation to the power of psychiatrists and nurses and the hegemony of bio-psychiatry are examined in this dimension of the
power cube. The primary means professionals use to retain control are the forms of power that shape the boundaries of what is permissible in the spaces of participation and the tacit rules of engagement. Both service-user and service-provider participants alike identified that the most powerful professional groups, psychiatry and mental health nursing, were the main agents acting either as facilitators or obstacles to SUI and reform of the MHS: a point of analysis developed in relation to this dimension of power.

Visible Power

Visible power refers to the overt power operating within the MHS. The key findings about visible power were the structural obstacles that some professional groups presented for SUI. Psychiatrists and mental health nurses were found to be most resistant to sharing power with service-users. This is visible power, because the position they hold confers authority within the hierarchical processes and structures of the MHS, and individuals in powerful positions choose to use their positional power to either hinder or facilitate SUI. This is resonant with international literature describing the MHS as hierarchically structured and dominated by professions who adhere to the medical model (Beecher 2009; Lewis 2009; Masterson and Owen 2006; Rogers and Pilgrim 2010; Stickley 2006). This structure is especially prevalent in Ireland, where the dominance of psychiatry over the MHS is more pronounced than in other countries because psychiatrists are the sole holders of clinical leadership (Hyde et al 2004; Mental Health Commission 2011, p.89). Given the dominance of psychiatry, SUI initiatives are not likely to succeed or even get off the ground without the active support of consultant psychiatrists. All participants were aware that this was the case. Likewise, given nurses superior numbers in the system and predominance in the ranks of management, their resistance to sharing power with service-users was identified as another significant barrier to SUI.

Service-provider participants were cognisant of the visible power attached to professional roles within the hierarchy because this impacts on their own roles. The findings revealed that medically-aligned participants underwent a personal journey of attitudinal change as a result of their experiences of SUI and learnt to value the perspective of service-users, sometimes through training and/or
through their involvement with service-user initiatives in other jurisdictions. Many had let go, to some extent, of their professional certainty that they had all the answers. In spite of the overall resistance to SUI within the MHS, and an initial sense of being threatened by SUI, the service-provider participants regarded SUI as valuable. They had moved beyond the position where they regarded service-users solely as recipients of care and now viewed them as agents in their own right with a contribution to make in changing the ethos of the MHS.

All service-user participants sought strategies to counter visible power by speaking up for service-users’ right to be consulted, most especially at the individual level of involvement, the therapeutic partnership. Most contested the dominance of the medical model of care, and problematised psychiatric power as the norm. This power was considered unproblematic by a few service-users (Chapter Five) based on their personal experiences with individual psychiatrists. These participants were comparing their current situation with past experiences when total authority was invested in the psychiatrist. However, several service-user activists (Chapter Seven) pointed out that the structural dominance by one profession is an obstacle to change because of their power to veto or obstruct any developments they perceive to be contrary to their interests.

**Hidden Power**

Hidden power is covert in how it operates to control who is invited to participate, and in managing the scope of the influence of SUI. Most service-user participants were aware of hidden power, especially in relation to how psychiatry frames public debate as the authoritative body of expertise. However, many were also critical of the control that nurses (within the administrative, management structures of the MHS) have over the agenda of SUI, in terms of setting the parameters of what is up for discussion. Hidden power also emerged strongly as a feature in the culture of domination and fear within the MHS identified by service-user participants. The covert power of psychiatrists and nurses permeates the culture of the MHS, for instance, several participants in Chapter Five reported that service-users were fearful to raise complaints against their conditions. When service-users have no effective means of reporting their
grievances and seeking redress: fear is de-facto a mechanism of control. In Chapter Seven, participants emphasised the hidden power of psychiatrists to control all decisions made at meetings without any need to justify their decisions, especially to service-users. Indeed, participants in this chapter noted that psychiatrists do not need to be present at meetings to exercise power since strategic decisions are either made prior to consultation, or they can be vetoed afterwards because of the authority psychiatrists hold in the hierarchical system. Hidden power also operates within professional groups, for instance in how the status of nurses and social workers can be bolstered by their assimilation into the medical model (Walsh et al 2009) and alignment with the dominant profession of psychiatry.

Several of the service-provider participants revealed some reflexive consideration of the visible and hidden powers held by those at the top of the hierarchy. There was an evident openness on the part of some service-providers to consider the challenges that the power of psychiatry and the resistance to change within the ranks of nursing poses to SUI. Indeed, SUI was used as a means to unsettle current power structures, and had the effect of troubling the routine power of nurses over service-users, especially in relation to service-users entering clinical settings to interview other service-users. This point will be discussed further later in this chapter.

As noted in the preceding three chapters, participants highlighted the potential of individual managers to be highly influential, either in a positive or obstructive manner. SUI was flourishing at the local site because of the backing of a middle manager and the local consultant. As can be seen in Chapter Seven, visible and hidden power was also evident in one senior nurse manager’s ability to secure sufficient funds to establish a project employing service-users while another middle manager failed to provide appropriate travel expenses. In the latter instance, hidden power was operating in the excuses that were made on the grounds that the budget was insufficient; the manager had the ability to make choices over what discretionary funds were available, yet insisted he could not. He was in fact using his power to undermine SUI, while denying the discretionary power associated with authority. That this was discretionary power is apparent from the ability of his counterpart in an adjoining MHS to support
SUI initiatives (Chapters Five and Six). This was a manifestation of hidden power, because of the ability to covertly influence who was financially supported to attend meetings and, therefore, who was able to participate.

Decision-making within meetings is another definitive example of the operation of hidden power as described by Gaventa (2006). Hidden power manifested in the practices of pre-arranging outcomes, by burying important information in copious material, pre-selecting the personnel to fill the powerful positions, or pre-deciding strategies with core power-brokers to get issues resolved in their favour. While service-user participants sought to challenge these practices, there is no evidence that they managed to get decisions over-turned. The mechanisms of power are evidently stacked against service-users (and less powerful allied-health professionals) at these meetings. Some service-provider participants suggested that if SUI is to be an effective tool of change, as opposed to tokenistic rhetoric, service-users need to be involved in the senior management teams, but even then the politics of hidden power will control decision-making processes.

**Invisible Power**

Invisible power operates through ideology that perpetuates inequality by defining what is the norm and results in the acceptance of subjugated and minority groups of their powerless position. It is most successful when people do not even realise that the current system is not in their interest (Gaventa 2006). Within the MHS invisible power lies in the control of the hegemonic bio-psychiatric model that the MHS operates under. All participants in Chapter Seven, and several in Chapter Five, contested the epistemological, legislative and institutional powers of psychiatry. Many national service-user activists presented service-user alternatives developed internationally as contestation against the expert-led, bio-psychiatric model of treatment available in the Irish MHS. Indeed a key finding in Chapter Seven is how this contestation of the epistemological paradigm of psychiatry contributed to the politicised collective identity of participants as social movement actors. Strategies of contestation included user-led research which problematised current service provision and SUI in education
of professionals. Both these initiatives are, however, subject to epistemic politics and resistance from the dominant paradigm.

Epistemic politics were at play in the resistance strategies of psychiatrists reported by some participants in Chapters Five and Seven, illustrating the invisible power of psychiatric hegemony. Dismissal of counter-evidence and ridicule of alternative models of service-delivery, such as limited or no medication, employing service-users within the current system or peer-led services, are the first form of resistance deployed against challenges to hegemonic medical authority. Appropriation and assimilation of contesting ideas into the existing hegemony, without any change to the underlying assumptions of the bio-psychiatric approach was evident in the findings on Recovery in Chapter Seven. The assumption that consulting with service-users will result in change was implicit in Chapter Six, yet without an explicit commitment to make the culture of professional expertise more responsive to service-user critiques, hegemonic power is both reproduced and masked. In terms of invisible power, the hegemony was so successful that most participants in Chapter Six did not address this form of power although several revealed themselves to be constrained and disaffected in their roles given the hierarchical culture within the MHS. The overarching conceptual framework of the bio-psychiatric model was not raised by most of these service-providers when discussing barriers to SUI or its effectiveness. The exceptions were the allied professionals who themselves were subject to the power of psychiatric privilege in their own roles. While they felt that their ethos of holistic, humanistic values is difficult to implement and compromised, they nevertheless did not articulate any doubt that the MHS were best placed to provide care and support to people experiencing psycho-social distress. However, a point of optimism in the findings from this chapter was an acknowledgement by several participants that expert-led services are not infallible, hence their enthusiasm for SUI as a way to utilise service-users’ experiential knowledge to shape better services. SUI is occurring within spaces of power, the next domain to be discussed.
Spaces of Power

Spaces of power are arenas where SUI can occur within the MHS. Spaces in this context are not necessarily physical but they can be and they may occur within the MHS or in user-claimed arenas. In this sense the user-movement is a space of power. Closed spaces are inaccessible to service-users, as by definition these are spaces behind closed doors, or where service-users are excluded by procedural closure. Invited spaces are those opened up to SUI, and hence remain in the gift of those opening them up, and subject to their use of hidden power to control the conditions of participation. Invited spaces, therefore, are where all the dynamics of power around SUI are playing out, including tensions around legitimacy. This raises issues about control of SUI via representational versus participatory forums, and whether a constituency base is a condition of SUI for service-users.

Other issues arise within invited spaces. These issues include the role of professional allies, and the dynamics of participation under unequal conditions, including the ‘mal-distribution’ (Fraser 2000) of resources to service-users. The rules of bureaucratic engagement are those of the powerful professionals. Finally, created/claimed spaces are those where the survivor/user movement can develop its own counter-hegemonic discourses and strategies that help counter the assimilatory potential of invited spaces.

Each of these spaces will now be discussed in further detail, beginning with closed spaces.

Closed spaces

Closed spaces abound in the MHS: from legislators who legalise the detention of people against their will; the offices and rooms where the decision-takers and policy makers meet behind closed doors; the committees at the highest level nationally where decisions about budget allocation and future service provision are made; to professional membership. One type of closed space discussed by several service-user participants was that of decision-takers in middle and top management. The power within these spaces was inaccessible

82 The professions are closed to SUI in the sense that membership requires long years of study and significant resources.
because it is institutionalised and remote from service-users. ‘Power-to’ is a useful way to understand the power of this level of management: these people generally have power-to implement policy decisions, for example, close facilities or re-allocate staff and, in the case of nursing professionals, carry out the ‘power-over’ directives of psychiatry, such as detention and supervision of service-users, administration of medication and care planning. There was little evidence of SUI making any impact in these spaces, in fact, political decisions on the implementation of policy decisions, such as the closure of local services, are made prior to consultation with service-users.

Gaventa (2006) highlights that those within closed decision-taking spaces can seek to increase their legitimacy by opening up invited spaces for people to participate in some aspects of their decision-making. This endorsement of SUI to advance the agenda of the MHS has been identified in the literature and is certainly noted to be a significant motivator behind the drive for SUI in the UK (Beresford 2002; 2010a; Carey 2009; Cowden and Singh 2007; Forbes and Sashidharan 1997). A drive for legitimacy may also explain the increasing enthusiasm for SUI in the Irish MHS at policy and senior management levels; indeed this is borne out by the findings of participants in management roles discussed in Chapter Six. Controversial decisions taken about the closure of local services due to resource issues were somehow believed to be more palatable to service-users when such closures were discussed with them. These are some of the issues discussed in developing the concept of invited spaces.

**Invited Spaces**

Invited spaces are: “those into which people (as users, citizens or beneficiaries) are invited to participate by various kinds of authorities” (Cornwall 2002 cited by Gaventa 2006, p.26). There are increasing numbers of invited spaces in the Irish MHS, where all the dynamics of involvement and collaboration are occurring while at the same time power is firmly retained by those who invite marginalised groups into their spaces (Gaventa 2006). Service-users are generally invited into these “consultative” or “deliberative” spaces.

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83 Beresford (2010a) distinguishes between once-off ‘consultative’ events such as town hall meetings and ‘deliberative’ structures, which are set up by the state to provide ongoing consumer
(Beresford 2010a), either by allies seeking to develop new structures and models of service delivery, which will reform current practices, or by senior management in response to top-down policy drivers, and as a legitimising exercise for the MHS agendas. Both rationales for SUI were evident in the interviews with service providers in Chapter Six. Local service-provider participants aligned service-users as allies in the struggles against funding cuts, whereas some participants at local and middle management leverage SUI to soften the impact of decisions already taken. At a top management level the rationale for SUI was for institutional and structural reform, with a strong emphasis on governance processes.

Power remains with those who create the invited spaces (Gaventa 2006) and from the findings detailed in Chapters Five, Six and Seven this was certainly the case in this study. Various manifestations of power were reported by the participants. The risk of assimilation was discussed by some participants in Chapter Six; service-users could become acclimatised to accepting excuses for poor practice, and non reform, thereby losing their critical focus. Other service-provider participants were cognisant of the risk of tokenistic SUI, whereby service-users were out of their depth at meetings and SUI was seen as little more than a box ticking exercise. Both these areas of risk are heightened by the power inequities in invited spaces, where all the forms of power play out. Although service-users are invited to attend, they are not invited to partake as equal partners. One participant in Chapter Seven proposed the creation of user-controlled invited spaces to which service-providers would be invited to participate on service-users’ terms. He advocated this strategy as an inversion of the power imbalance occurring in provider-controlled spaces, claiming that power and respect would accrue to service-users as a result of claiming their own spaces.

In Chapter Five reports about displays of power included the use of physical space (such as seating arrangements), embodied gestures (such as eye contact) and forms of expression (exclusionary language/jargon) by powerful input into policy-making. These second, semi-permanent structures proliferate in the UK PPI landscape, and can be said to provide members some opportunities for discussion (hence the name). Consumer panels in the Irish MHS can be characterised as deliberative processes, as they are established with the purpose of informing policy and include the widest possible definition of service-user. For more detail refer to Chapter Two.
professionals to maintain their power within the invited spaces of SUI. Participants experienced exclusion dynamics as painful and demoralising, and which furthermore, undermined their confidence and efficacy. Acts of resistance occurred both by the service-users’ recognition of the dynamics of exclusion at play, and by being strategic about where they chose to sit, thereby, upsetting the power play. Although a few participants had learnt that by changing seating arrangements and interspersing themselves among the service-providers they could interrupt the power dynamic, this action required a high level of confidence as the service-users lost the comfort of proximity with each other. Thus invited spaces are the arenas where the embodied, emotional work of SUI occurs, and the disparities of power, status and authority are negotiated by the participants. Some health professionals were more aware of the emotional and personal challenges of SUI because they were personally invested and directly involved in supporting service-users.

Emotional expression, especially anger, is discouraged in SUI forums, which are governed by the tacit rules of bureaucratic engagement (Church 1998). There are no forums in the current system for the expression of the righteous anger of service-users. Lyman (2004) claims that listening to the justified anger of oppressed people provides an opportunity for those in power to reduce social suffering, open up political dialogue and redress the injustices done. Instead, the powerful more often use tactics to silence anger, interpreting righteous anger as a loss of emotional control (Lyman 2004). Anger is framed as a form of irrationality by ‘psychological hegemony’ and a threat to order, whereas for the oppressed, anger is a legitimate expression of the social injustices they experience, which if listened to could provide some resolution to injustice (Lyman 2004, p.133). Therefore, the rejection of legitimate anger about past and current injustices and abuses within the MHS can be understood as another expression of invisible power to control the parameters of discussion and acceptable forms of expression within invited spaces.

Another key issue for invited spaces concerns the conditions of participation and the politicisation of payment for SUI evident in all empirical chapters, but especially so in Chapter Seven. Payment is articulated as a political demand, a question of equal status and recognition for their work in SUI. Service-users are
invited into unequal spaces, as abundantly evident in the empirical accounts, to work for the MHS. There are no structures in place to recognise this work. Failure to recognise this requirement for parity is an exercise of hidden power, as explained above. Local ad hoc practice has developed in a policy lacuna, and remains at the discretion of middle and top managers, which is not just precarious and unsustainable, it also causes frustration about variations in local practice, as was particularly evident from a participant in Chapter Five.

Positive relationships with the professional allies of SUI allowed for closer collaboration, and the development of a sense of common purpose in reforming the MHS. These allies were highly appreciated by all service-user participants, not only because they created opportunities for SUI, but because without them the task of representing the voices of service-users in MHS forums would have been even more daunting. These allies offered support and solidarity to service-users, especially the local service-user participants who engaged with the MDT as discussed in Chapter Five. This rapport explains the difference in attitudes among this group of participants towards service-providers and SUI: those with the least social contact with supportive allies tended to have more adversarial experiences of SUI. However, professionals’ attitudes towards service-users also shifted as a result of their contact in invited spaces; they began to regard involved service-users as competent individuals rather than recipients of care. SUI activities, such as meetings, targeted training, and the informal social contact around such activities, provided opportunities for positive attitudinal change on the part of service-users and service-providers.

Right of access to invited spaces is an issue of power. The differing expectations of service-users with regard to representing a constituency are a significant finding in Chapter Six. This resonates with other literature, which has identified how professionals seek to control and manage SUI. Access to invited spaces is restricted by questioning the legitimacy of involved service-users by demanding a formal mandate to their presence, and/or questioning their representativeness. This issue has bedevilled service-user activists since SUI became established as official policy in other countries (Beresford 2010a; Bennetts et al 2011; Campbell 2001; Crepaz-Keay 1996; Forrest et al 2004; Lindow 1995, 1999). Townsend et al (2008) argue that professionals at meetings
are not expected to represent their entire profession, yet this double standard is often applied to involved service-users who are deemed to be unrepresentative of ‘ordinary’ service-users. The experiences of using MHS shape the opinions of those who become involved, and indeed are the drivers for SUI as was evident with the participants in this study. Rose et al (2010) demonstrated a commonality between opinions and experiences of activists and ‘ordinary’ service-users. Similarity of opinions and experiences were present among both local service-users and national activist participants in this study. Indeed, the commonality of shared experiences of failures of the MHS resulted in the emergence of a politicised collective identity among service-user participants, one united in contesting coercive and counter-therapeutic practices, in spite of differences of opinion between them about what strategies to pursue, or the risks of assimilation.

Insisting on a constituency base, without adequate resources and structures to develop an engaged, active and motivated membership, is a tactic of power used to discredit both speaker and their message. The user-movement in Ireland does not have organic structures which can lend themselves to election of formal representatives, except where these have been created to meet MHS needs, as pointed out by a participant in Chapter Six. The imposition of premature representative structures undermines participatory democracy. Beresford (2010a, p.498) discussed the potential that invited spaces, established by policy-makers, heighten the risk of: “extending existing exclusions, prejudices and unequal power relationships.” His concerns mirror those of scholars such as Young (2000) who argues that representational democracy creates a culture of elites, as distinct from participatory processes of democracy, which encourage equal participation of all in small, local, accessible forums where voices can be heard equally. In the UK, policy-makers have poured money into creating deliberative service-user forums that can provide them with information for their decision-making (Beresford 2010a). This consumerist rationale is the logic of the constituency base discussed by a participant in top management; a manufactured constituency such as has emerged in the form of the NSUE. The NSUE is not an organic, user-movement membership-based organisation (quite apart from the
managerialist amalgam of carers and service-users): at best the NSUE is an artificial construct in the deliberative mode identified by Beresford (2010a). Such a structure is prone to the problems identified in the UK context, (replication of hierarchical structures, losing critical perspective and connection with grassroots service-users), as a result of creating user-groups to meet the needs of policy-makers, rather than the user-movement (Lakeman et al. 2007). Beresford (2010a) argues that service-user created organisations are more democratic, emerge from identified needs within the movement and are less likely to fall prey to the hegemony in service-provider created spaces.

Claimed/Created spaces

A claimed/created space is one which emerges informally or organically in response to the structures imposed on invited spaces. Again it may occur in a physical space such as a tearoom, or be as temporary and fleeting in nature as a phone call to peers (or a debrief with supportive professionals), or it may be a collective social space such as the user-movement. These are spaces that provide opportunities for resistance to the hegemony encountered with officialdom (Gaventa 2006). Feminists (e.g. Veneklasen and Miller 2002) writing on power as resilience, explain how people can develop personal power (power-within) as result of the processes that can occur in claimed spaces. A key finding among local service-user participants is the solidarity created amongst themselves, and also with professional allies, through pre- and post-briefing sessions around difficult meetings. This solidarity produces an increased resilience and determination to persist with SUI. Solidarity was an important issue for all the participants in Chapter Five, it could take the form of mutual support outside formal meetings, helping to overcome the challenges of involvement, and contributing to a growing sense of ‘power-within’. This is in contrast to service-provider participants where there was little evidence of engagement in user-created spaces: they volunteered nothing about personal relationships with service-users. During fieldwork, I did, however, observe the camaraderie amongst some local service-user and service-provider participants at several social celebrations to mark milestones, and in the informal banter which took

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84 Service-users and carers have quite separate needs and agendas, as outlined in Chapter Two.
place around meetings, indeed sometimes within meetings. These occasions were created spaces as distinct from work-focused meetings, and played a large part in the development of an inclusive team spirit that the service-providers wished to create for involved service-users.

This solidarity building was also occurring at a more politicised level among the national activists who demonstrated a collectivised identity based on shared narratives of contestation and resistance, informed by international developments in the survivor and critical mental health communities. Counter-hegemonic ideas are disseminating among the critical mental health community in Ireland (Sapouna 2012), and offering fresh impetus to those seeking viable alternatives to the bio-medical paradigm in Irish MHS. Such information provides ammunition for the growing number of activists with an alternative vision to contest and assert that a different way is possible, and to highlight the gulf between the two different worlds - the expert-led, bio-medical paradigm and the survivor vision of peer-run, non-coercive therapeutic communities. Such approaches also provided epistemological space to the participants, who experienced (or read) about them, and emancipated their thinking and helped them to regain the hope that an alternative to the current treatment regime is possible.

The national service-user participants emphasised the significance of the user-movement as a counter-hegenomic space, demonstrating an awareness of the need to inform other service-users of possible alternatives to mainstream MHS. There was awareness among most participants of the need to engage ‘grassroots service-users’ in learning about different ways of responding to psycho-social distress. Some participants discussed the importance of spaces where service-users could come together to hear stories of overcoming and recovering from distress. This is resonant with much of the literature by pioneers of the user-movement, which discusses conciousness-raising in order to spark emancipated thinking (Chamberlin 1977; Costa et al 2012; Deegan 1988; Brandon 1995). Chamberlin (1977, pp.68-92) describes as emancipatory the process of sharing stories and strategies, to overcome personal distress, with other people who had experienced similar difficulties. People are able to free themselves from the lack of self-belief and self-stigma that follows from
internalising difficulties which are structural and external to themselves. For instance, not coping well with oppressive societal structures, such as poverty, trauma, discrimination and the consequent lack of opportunities is not due to personal failures nor is it caused by bio-chemical malfunctions in the brain (Chamberlin 1977). This experience is in marked contrast with the emotional work required from service-users in invited spaces, which is about coping with tacit rules to suppress passionate expression (Barnes 2008; Church 1998; Lewis 2010). The process of sharing stories and articulating narratives of counter-hegemonic resistance amongst service-users forges a politicised, collective identity among Irish mental health movement activists, despite their differences. This identity building work is a core feature of a health social movement, most likely to occur in user-controlled claimed/created spaces (Beresford 2010a; Brown et al 2004; Nelson et al 1998).

Literature on health social movements (Brown and Zavestoski 2004; Brown et al 2004; Hess 2004) state that these movements are more likely to engage directly with policy forums and health professionals because individuals in these movements (or their family and friends) are dependent on the healthcare system. The user/survivor movement is classified by Brown and Zavestoski (2004) as an Embodied Health Movement because individuals are motivated by their lived experience of psychosocial distress and discontent with the failures of the MHS. All service-user participants, even those who had grave concerns about collaboration under the current situation, were motivated by the vulnerabilities of those currently “captive” within the system, and sought to leverage opportunities to reform current structures.

However, a key finding in Chapter Seven, of the spectrum of opinion on insider/outside strategies, revealed tensions around the movement’s strategies. Movement strategies, especially outsider ones, create spaces of power. Literature on social movements (Craig et al 2004; Crossley 2006; Maloney et al 1994) indicate that outsider strategies can play a significant role in raising the public profile of issues of concern and in the recruitment and retention of a broad membership base, as members can observe and engage with such strategies, whereas insider strategies are confined to a far smaller number of individuals and the broad membership may see little or no result from strategies such as SUI.
Thus, it is an issue for the user-movement what types of claimed spaces they seek to occupy to contest psychiatric hegemony.

The tension among the user-movement activists about what contestation strategies to adopt co-exists with the tensions of engaging with the MHS and their concerns about assimilation discussed above in the section on invited spaces. The creation and dissemination of counter-hegemonic discourse is a significant feature of the potential of created spaces to assist movement actors to resist capture by officialdom (Gaventa 2006). The strategy of engagement is less likely to result in assimilation of these participants because emergent created/claimed spaces are mobilising critiques of psychiatric hegemony.

Levels of Power

Power occurs at different levels, strategic, operational and individual. The levels domain is a useful framework to consider the various levels of influence SUI may wield. As these are ideal levels, there is considerable movement across the levels, and they flow into each other, as do the skills, knowledge and benefits acquired at different levels. At a strategic level there is a national focus on the service-user perspective informing and advising the HSE’s national MHS planning office, and the MHC. There was evidence from service-users of knowledge acquired at the strategic, national level, which impacted on participation at operational levels and vice versa. Operational level involvement focuses on the day to day operation of service delivery, while the individual level of involvement concerns clinical/care decisions and relationships with treating professionals.

Strategic level

Strategic level SUI is understood to be concerned with macro-level policy issues (Baggotts 2009), which have the potential to affect wider changes in the national or international MHS field. Strategic forms of SUI include many of those listed by Rose et al (2010): campaigning and lobbying; user-led or controlled research; SUI in professional training; and user-run services such as IAN. All of these forms of strategic SUI emerged in the accounts of the national service-users, while this level featured to a lesser extent among the local service-user and service-provider participants, as all but one participant (a top manager)
operated primarily at a local level. It was the belief of some service-provider participants that until SUI occurs at a strategic national level there will not be any significant change in service-provision. These participants saw a need for SUI in strategic decisions on budget allocations and policy decisions implemented at a national level.

There was significant activity among national service-user participants at strategic level meetings, especially with the national office for policy implementation and the MHC. One participant claimed that SUI in Ireland was more influential over policy directions than in the UK because service-users have access to the national level policy-makers and statutory regulators. Several national service-user participants (and one local) spoke highly of the respect and recognition afforded their views at meetings in the national policy implementation office. This was corroborated by a top manager, who rejected tokenistic involvement, expecting service-users to align with his efforts to reform institutional power and governance structures, and to robustly defend their opinions and beliefs and be able to negotiate for their constituency. Indeed, it was suggested that service-users had equal responsibility for decisions made at these strategic planning meetings. However, this position fails to consider the power inequities and the other underlying assumptions that surround the official policy rationale for SUI. Within these forums, all the forms of power discussed above are operating to disadvantage participating service-users, the recognition of which is central to improving the conditions of participation, especially at strategic level.

A significant finding in Chapter Seven was an ambivalent attitude by some participants towards committee membership at strategic (and operational) levels of SUI. One participant did acknowledge the influence some service-users can leverage on some committees, but suggested that if service-users did not gain more influence then SUI could be considered a tokenistic exercise. Some questioned whether SUI has had any impact on reforming questionable practices in the MHS. One participant asserted the need for users to have control over their own organisations and provide peer-run services. Peer-operated MHS are a feature of the mental health field in other jurisdictions, primarily USA, Canada, 85 Mental Health Commission
and Australia (Campbell 2009; Doughty and Tse 2011; Solomon 2004). A less autonomous form of SUI, increasingly evident in the UK, especially Scotland (McLean et al 2009), is peer-involvement in service delivery. Peer-employment on Irish mental health teams is, however, unlikely to affect strategic changes to power structures in the current system, as all strategic decision-making is likely to remain with the current power structures.

Transfer of information from macro-level strategic meetings and training courses back to SUI at the local operational level illustrates how ‘information as power’ (Gaventa and Cornwall 2008) can move across the different levels of involvement. Participants in Chapter Five developed networks with people in other regions through the DCU Leadership Initiative (MacGabhann et al 2010), whereby they gained more status and collective power locally as a result. Comparisons between their experiences of SUI with service-users from other areas were often favourable, which increased participants’ sense of power and agency in relation to SUI in their region. Knowledge (and thus negotiating power (Gaventa and Cornwall 2008)) and increased agency was transferred from national forums to local groups as a result of SUI in wider forums. This is a similar process to knowledge dissemination among members of health social movements discussed as a finding in Chapter Seven.

**Operational level of SUI**

The operational level is a functional level of involvement concerned with more micro-level issues such as how a local MHS organises its systems and procedures for care delivery and what decisions are made about local resource allocation. Much of the SUI activity among participants in Chapters Five and Six occurred at an operational level in terms of overseeing service-delivery under the remit of the MDT, and in the Consumer Panel activities in the area. A finding from Chapter Six is that SUI led to improved policy, which service-provider participants believed was more client-focused. The local MDT routinely sought out the views of service-users on their policy documents. Developing local responses to implement official policy through SUI, rather than adopting ready-made national policy, was perceived to give staff ownership over the changes to
be implemented. As a result policy implementation was said to be better across the entire team.

Policy development may be considered in light of evidence reported by Rutter et al (2004) in their study that revealed poor implementation of the policies drawn up with SUI. They also noted that the development or revision of policies around issues of most concern for service-users, such as ECT or compulsory and forced treatment, did not have input from service-users. The policies of the MDT in this study did not address issues such as ECT or compulsory and forced treatment, instead policies developed by the team were ‘customer care’ issues such as the physical environment, service-user access to their premises and use of facilities, as well as care-planning documents. Therefore, while SUI in policy development at an operational level was an important strategy for the MDT to improve care within the wider team and to address institutionalised paternalism, it had no bearing on the core areas of contestation for service-users. There was little reference to local operational involvement in Chapter Seven except for one participant who reported his experience of tokenistic practice with his local MHS and questioned the integrity of the process. It is easy to adopt the rhetoric and appearance of changing practice but unless the underlying power structures are addressed, service-users are quick to spot what are, in effect, tokenistic gestures and empty rhetoric.

The power of middle management to allocate resources to support SUI is another aspect of operational power. Research on service-users perspectives on SUI (Chapter Two) reveals the importance of material and financial supports for service-users if it is to be anything more than a paper exercise (Beresford 2010a; Chamberlin 2005; Jones et al 2004; Repper and Breeze 2007; Rogers et al 1997; Rutter et al 2004; Wallcraft et al 2003). The availability or absence of expenses, payment of gratuities and the use of personal IT equipment came up repeatedly among the participants in Chapter Five. At this level of power the middle manager at the research site used his operational power over the allocation of budgets to facilitate various SUI initiatives. This is a feature of hidden power operating at a functional, operational level to support SUI in invited spaces and is a critical feature of services where SUI has been successful.
Individual level of SUI

This level of involvement is the relationship of the individual with their care-providers. For all participants the most important goal of SUI is to change how individuals experience their relationships with treating professionals. All the forms of power operating in the field of MHS interact at this level to determine the experiences of individual service-users. Therapeutic relationships are micro-level interactions; the cumulative experiences of individual encounters shape the overall field. Service-user participants, especially in Chapter Five, reported relationships with treating professionals that were very much shaped by the expressions of power-over used in controlling or limiting ways. Apart from how an individual practitioner chooses to manifest their power-over with a service-user, whether they act in a kind, respectful, empathic way or not, the relationship always occurs within a system which is unequal, controlling and potentially coercive (Cresswell 2005; Masterson and Owen 2006; McGruder 2001; Rogers and Pilgrim 2010).

The key finding at the individual level is the power imbalance in the therapeutic relationship. The most obvious influences on individual relationships have to do with how the systemic power of the MHS operates to constrain the parameters of possible choices at the individual level of treatment. Participants in Chapter Five argued for more choice and control, and made a link between empowerment resulting from SUI and individual level involvement, in that people were observed to be more assertive about their own care relationships following SUI. Some local service-user participants experienced that their advocacy for others had affected their own relationships with treating professionals; on occasion encountering the same professionals as activists and as service-users. Most participants in Chapter Seven did not discuss their personal involvement at this level, but there were some similar accounts of coercive and controlling experiences, and lack of personal autonomy in relation to treatment within the MHS.

For the service-provider participants, the individual relationship was also the most important aspect of SUI; indeed many of them conflated the individual level of involvement with SUI generally, requiring prompting to consider operational or strategic levels, especially those few who were not engaged with
service-users in these different levels of SUI. Care planning appeared synonymous with individual level SUI. Some of this group reported greater awareness among their nursing colleagues of the need to work in client-focused ways, to consult service-users about their care plan and not to make decisions on their behalf as an outcome of SUI. This was reported to be the biggest change in their practice, albeit no evidence was available from service-users receiving care from this MDT, as they were not included in this study. However, the accounts in Chapter Seven of the reported failures of local MHS to implement meaningful care-planning in spite of extensive resources being put into a pilot project at eleven local services by the MHC were disappointing. As reported, SUI at this level is not occurring on the ground. It is evident that implementation of top-down policy does not easily translate into changes in practice. More importantly, care planning is a paper based exercise that can be conducted in the same old paternalistic fashion, whereas what service-users want is meaningful engagement and a sense of agency in their relationships with treating professionals.

As can be seen from the discussion above, the power cube is a useful framework for examining the politics, positioning and levels of influence participants experienced in SUI. It offers an accessible and intuitive conceptual model for the highly complex dynamics of participation. This applicability is further illustrated by a selection of particular instances from participants’ accounts which can be examined by applying the power cube as a cross-sectional point of analysis.

**Cross-sectional application of power cube**

Evidence of resistance by nursing staff to SUI in research was reported in Chapters Five and Six. Two incidents provide examples of how the power cube can explain the dynamics of power that were present. In the first incidence, nurses sought to obstruct a service-user conducting research for the MDT. The nurses’ resistance was mitigated by a lower status staff member, the cleaner, who helped the service-user circumvent the obstacles placed in her way by nurses. The situation was dealt with later by the consultant psychiatrist who communicated with all staff that co-operation was expected with the research. The operation of forms of power is clear in the hierarchical nature of how the
incident played out, resonant with the literature (e.g Masterson and Owen 2006). The resistance was acted out by staff with the expectation (hidden power) they could get away with disrespect (visible power) because of their position within the system vis-à-vis the service-user. The subsequent communication by the consultant psychiatrist, (embodying all three forms of power) re-established the power hierarchy, and affirmed the status of the service-user researcher. It is a feature of this research site that the power of the psychiatrist was allied with the position of the service-users, otherwise such resistance from frontline staff would render the service-user position completely ineffectual. His positional power opened doors into closed spaces, thereby creating an invited space for the service-user researcher. This sharing of power with service-users was within the gift of an individual consultant psychiatrist.

A similar dynamic was at play in the second account of service-user-led research in the chapter. In this account, the MHC replaces the consultant psychiatrist as the power broker in the hierarchy of the MHS. Service-user researchers moved into the previously closed spaces reserved for professional experts, invited in by the MHC to carry out a user-led evaluation of the Care Planning Initiative (strategic level involvement). Senior nursing management attempted to control the research by exercising hidden power, as their presence in the room was likely to have a constraining effect on the research, bearing in mind the finding of a fearful captive audience in the first sub-theme of Chapter Five. The service-user researchers were able to leverage hidden power given the associated authority of the MHC to both gain access to service-users, and to demand privacy for research participants, thereby creating (albeit temporary) claimed space with service-users.

Another incident of power recounted in Chapter Five (the Clap on the Back) can further illustrate the explanatory potential of the model. The consultant psychiatrist had both visible and hidden power in his position as team director to open invited space to the service-users to present to the professionals, which may be considered either strategic or operational level involvement (or indeed both,

86 The National Mental Health Services Collaborative on Individual Care Planning (NMHSC) established by the Mental Health Commission to promote care planning at eleven MHS sites. Service-user researchers conducted an evaluation of service-users experiences of care planning flowing the six-month intervention. (Discussed by three participants, Jack, Kate and Elaine).
depending on the content and purpose of SUI in that case). The power dynamics were further highlighted by the participant in her illustrative reversal of the gesture, the incongruity of a service-user clapping a consultant on the back to congratulate him on a job well done reveals the hegemonic power in the status assigned to psychiatry.

The final incident to be examined is Kate’s dramatic account in Chapter Seven of the high-level meeting where she had to defend the disparaged right of service-users to be involved at any level of influence in the MHS against the voiced opinion of a very highly ranked consultant psychiatrist, a Clinical Director. All the domains of the power-cube are evident in the account; visible and hidden forms of power at strategic level SUI in what were previously closed spaces. The initiative of inviting service-users to attend was a new departure and certainly not expected by the Clinical Director who acted as if he was in a closed space, and therefore spoke his mind freely about SUI, displaying stereotyping and dismissive attitudes towards service-users (mis-recognition), expressing the desire to contain SUI within limits (hidden power), all the while unchallenged by the other professionals in the room (invisible power). The support of Kate’s peers was crucial to a resolution of the situation. She claimed space by leaving the meeting to confer with them by phone, which provided her with a strategy to respond and challenge the hegemonic view that service-users were incapable of contributing to reform of the MHS. Her account, describing the emotional tension, corroborates findings about the emotional work entailed in negotiating the power dynamics of SUI.

The above accounts of participants’ experiences go some way to demonstrate the explanatory potential of the power cube to illuminate some of the complexity of the dynamics of participation for activists and neophytes to SUI This conceptual model is more complex and dynamic than a two by two matrix, yet intuitively easy to grasp, if not to resolve. Like its real-world physical counterpart, adjusting different alignments of power forms, negotiating improved conditions for equal participation in different spaces, or moving from different levels of involvement results in a dimensional shift in other domains. To solve the puzzle of how power operates in SUI one needs to view the entirety of the complexity and tensions inherent of SUI.
Summary

This chapter has outlined how the tensions inherent in SUI can be examined using the power cube as an explanatory model. Data and findings from the three empirical chapters were discussed in relation to the three domains of the power cube. Each of the three domains has components that interact together in dynamic ways; a shift in one area will have ramifications in other parts of the system. In the same way, introducing the concept of SUI has the potential to shift and unsettle power in other areas of the system. Introducing service-users as nominally equal players will affect existing powerful vested interests, such as psychiatric and nursing professional groups, provoking a response, which in turn affects other structures of power. However, the odds are stacked against service-users because, given the cumulative effects of visible, hidden and invisible power vested in the two primary holders of power within the system, the psychiatry and nursing professions, their resistance to sharing power with service-users is a serious obstacle to meaningful SUI in spite of efforts by allies. The overall findings indicate service-providers have much to learn from service-users about the conditions of participation. Unless the various dimensions of power that maintain and reproduce unequal conditions are acknowledged, the risk of tokenistic SUI is ever present and likely to impede any of the potential of SUI to shift power relations within MHS.
Chapter Nine:

Conclusion
Chapter Nine: Conclusion

Introduction

This study problematises service-user involvement (SUI), a recent policy development in the context of Irish MHS. I have questioned whether the policy rhetoric about partnership with service-users actually serves to gloss over the challenges of including such a previously marginalised and devalued perspective. The contribution of this study lies in its attention to the Irish case and evidence about the politics of participation and power dynamics within recent initiatives of SUI in Ireland.

The research question sought to understand how service-user and service-provider participants experience SUI. Overarching themes in the data are the inherent tensions around SUI between contestation of the legitimacy of current practice and collaboration with the MHS, and the consequent risk of co-option from the perspectives of service-users. The second theme considers the dynamics of participation, from the perspectives of service-providers, allies of SUI, who experience different tensions around SUI. The points of convergence and difference within these themes across all three data sets are linked to the current literature. I reflect on the overall research process before considering the strengths and contributions of this research, as well as its limitations. The implications of the research and suggestions for further research are outlined. Finally, my overall thesis statement is presented in my concluding comments.

Purpose, Rationale and Framework

This study proposed to explore the tensions and dynamics of SUI in an Irish context. The aim was to examine a local experience, from both service-user and service-provider perspectives, and triangulate and compare that with the wider national perspective of service-user/survivor movement activists, and a top manager in the HSE, to provide broader contextualisation to SUI in the local case. The research question sought to explore participants’ experiences and
understandings of SUI, in order to identify the tensions inherent in SUI and the power dynamics operating within spaces where SUI occurs.

I initially approached the analytical process with a lens informed by my own experience and knowledge of the issues, without applying a specific theoretical or methodological lens, in order to allow emergent issues to appear. I wanted to give voice to the concerns of the service-user participants in Chapters Five and Seven, the local and national service-user participants respectively. This process is described in Chapter Four, as is the development of survivor epistemology underpinning the research methodology. As SUI is a collaborative process, it is important to also hear the experiences of the professionals within the MHS who seek to implement a top-down policy of SUI. The perspectives of local service-provider participants are contextualised by a perspective from a top manager in Chapter Six. These themes were further elaborated on in a cross-sectional analysis of the data, which developed Gaventa’s (2006) power cube as an accessible framework for understanding how power operates in relation to SUI. Examining the levels, spaces and forms of the power-cube facilitates the unpacking of complex dynamics of participation, as demonstrated in Chapter Eight. This attention to the dynamics of participation is necessary to problematise SUI, which is becoming a buzzword in Irish policy discourse.

**Key Findings**

The points of comparison and divergence between the key findings constituting the theme on the inherent tensions of SUI will be outlined firstly for service-user participants, followed by consideration of the findings from the service-provider participants. This synopsis will be followed by a synthesis of key findings on the dynamics of participation, outlined in Chapter Eight. The key empirical findings from Chapters Five, Six and Seven are summarised in Tables 8, 9 and 10 on the following pages.
<table>
<thead>
<tr>
<th>Main Themes</th>
<th>Subthemes</th>
<th>Finding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contestation of Service-users (SUs) Position</td>
<td>“A Fearful, Captive Audience”</td>
<td>Dependency and learnt helplessness of SUs locked into the MHS by fear of speaking out against their position.</td>
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<tr>
<td></td>
<td>Injustice as Motivation and Leverage</td>
<td>Human Rights and Social Justice discourse function both as motivator and leverage.</td>
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<td></td>
<td>Struggles for Recognition</td>
<td>Participants contest the assumptions of professionals about mental illness, which lead to discrimination (participants embody the stigmatised SU identity), lack of equal recognition and tokenistic involvement.</td>
</tr>
<tr>
<td></td>
<td>“Providers in your corner”</td>
<td>Participants who developed a rapport with professional allies experienced more positive conditions of participation. Positive role played by allies of SUI in improving the conditions for collaboration and reducing the fear of tokenistic SUI. Increased proximity provided opportunities for attitudinal change, and less of an ‘us and them’ on the part of both SUs and service-providers.</td>
</tr>
<tr>
<td></td>
<td>“Sometimes my Head goes into a Spin”</td>
<td>Participants did not feel listened to or heard by many professionals, both in therapeutic encounters and in SUI work. Improved listening skills by younger professionals were linked to SUI in professional training. Participants’ acceptance of the tactic rules of engagement signalled the transition from contestation to collaboration.</td>
</tr>
<tr>
<td></td>
<td>“I felt Belittled and It Bloody Well Hurt”</td>
<td>Emotional impact of failures of communication. Communication is a condition of collaboration to be addressed.</td>
</tr>
<tr>
<td>Coping strategies</td>
<td></td>
<td>Significant emotional burdens to the work of SUI. SUs engaging have to be strong, courageous and committed in order to deal with isolation, discrimination and exclusion at meetings. Participants’ deployed personal strength, supports such as pre-and de-briefing before meetings and supportive relationships.</td>
</tr>
</tbody>
</table>

Table 6: Key Findings from Chapter Five (Local Service-users) summarised.
<table>
<thead>
<tr>
<th>Navigating Structural Barriers to SUI</th>
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</thead>
<tbody>
<tr>
<td><strong>“Somebody Else Can Pay”</strong></td>
<td>Funding at the discretion of local allies - SUs effectively subsidising MHS reform efforts. Those who volunteered time and personal resources felt taken for granted, over-burdened with lots of work and with no office-hour boundaries.</td>
</tr>
<tr>
<td><strong>Administrators</strong></td>
<td>Marked difference in commitment to SUI from two administrators</td>
</tr>
<tr>
<td><strong>“The Doctor was the Boss”</strong></td>
<td>Challenge to lack of alternatives to the bio-medical approach and the unassailable orthodoxy of the expert whose perspective determines best practice. Hidden power was challenged by naming gatekeepers who hinder SUI. Visible power was challenged at the level of therapeutic relationships. Some participants normalise visible power as benign, and thus unproblematic. Others more cognisant of psychiatric power constraining choices for SUs and SUI.</td>
</tr>
<tr>
<td><strong>Nursing Power and Resistance</strong></td>
<td>Nursing professionals use their power within the MHS hierarchy to hinder SUI. Legacy of institutional practice underpinning resistance to SUI, - some nurses seeking to co-opt SUs to maintain the status quo, non-cooperation with research conducted by SUs, professional boundaries and policies and procedures used as a strategy to emotionally distance themselves from SUs. Given their predominance in the ranks of management, and resistance to sharing power with SUs, the nursing profession was found to constitute another structural barrier to SUI.</td>
</tr>
</tbody>
</table>
Table 7: Key findings from Chapter Six (Service-providers) summarised.

<table>
<thead>
<tr>
<th>Main Themes</th>
<th>Subthemes</th>
<th>Finding</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Structural Context</strong></td>
<td><strong>SUI</strong></td>
<td>Participants experienced MHS as being hierarchical and institutionally resistant to change. As a result many felt disaffected and constrained by an inflexible and stigmatising work environment.</td>
</tr>
<tr>
<td><strong>Institutional Resistance to Change</strong></td>
<td></td>
<td>Some participants acknowledged past abusive practices about which SUs have legitimate anger. Different responses – a few acknowledged anger as legitimate but currently unrecognised within the MHS, whereas others more defensive and regarded emotional expression as a barrier to change and to SUI.</td>
</tr>
<tr>
<td><strong>Drivers of SUI</strong></td>
<td><strong>“How Far Up the Ladder?”</strong></td>
<td>SUs regarded as allies and SUI leveraged to support differing agendas. Local – sought to align with SUs in resisting service cuts and reallocating resources to community initiatives. National - institutional reforms and governance structures Top manager regarded SUs as equally accountable with all other parties for decisions made without acknowledgement of the inequitable conditions for participation.</td>
</tr>
<tr>
<td></td>
<td><strong>“That’s the Way the Flag is Blowing”</strong></td>
<td>SUI a top-down policy encouraged by the MHS, implemented at the discretion of local leaders, rather than a SU-led initiative. Rewards from initiating SUI: improved working conditions and job satisfaction, recognition for better practice, reduced stigma towards mental health in their workplace, more positive perceptions of SUs.</td>
</tr>
<tr>
<td></td>
<td><strong>Professionals have “Travelled a Journey”</strong></td>
<td>Medically-aligned participants underwent a personal journey of attitudinal change - through training and/or working in other jurisdictions. Many let go, to some extent, of their professional certainty that they had all the answers. All participants regard SUI as valuable and see SUs as agents in their own right with a contribution to changing the ethos of the MHS.</td>
</tr>
</tbody>
</table>
Drivers of SUI (continued) Validating the SU Role in SUI

No nationally recognised roles for SUs engaged in new SUI developments, such as peer-support or peer-education work - roles developed through local practice. Different expectations placed on SUs; can expect to be dismissed as a tokenistic requirement; yet be able for the rigors of adversarial meetings, and be prepared to defend their arguments against more powerful actors. Participants believed involved SUs should be paid for SUI, yet no national policy and the user-movement not independently funded to support SUI.

“SUs own the Care Plan”

SUI at the individual level, synonymous with care-planning, considered most important form of SUI. All local participants referred to better care-planning with SUI as a result of inviting SUs to their meetings. Power dynamics and decision-making autonomy remain issues in care-planning for nurses especially, but overall staff attitudes towards care-planning were positively influenced by SUI.

Tensions of SUI

“It’s a Big Ask for SUs”

Challenges of SUI for SUs recognised, and their ability to meet challenges respected. Participants were cognisant of the tension between supporting SUs, yet not overly influencing their voice. Lack of consensus about the representativeness of involved SUs: whether constituency base required or advising on the basis of their own experience. Top manager considered SUs derived their legitimacy from a constituency

“A minefield of power”

Participants experienced SUI as a means to unsettle and subvert existing power relations. Psychiatric power not identified as an obstacle within the context of the MDT, given the local consultant’s efforts to develop SUI.

Nurses were the professional group that were most resistant to SUI.

Moving from less coercive relationships with SUs and adopting positive risk-taking strategies recognised as of benefit to professionals as well as SUs.
Tensions of SUI (continued)  “Domestication of the SU Perspective”

Differing levels of awareness and concern among participants about risks of co-option and/or tokenistic SUI.
Risks identified- that SUs could become acclimatised and accepting of excuses for poor practice thereby losing their critical focus. -SUs out of their depth at meetings and SUI was a box ticking exercise.
SUI was considered the only strategy available for SUs seeking reform by two participants. Others reported that SUs were consulted to make implementing difficult decisions more palatable.

Some participants believed in selecting SUs who would not be overly assertive or upset the bureaucratic rules of engagement.
Top manager considered SUI restricts SUs’ options to engage in public protest activity against the MHS.
Table 8: Key findings from Chapter Seven (National Service-user Activists) summarised.

<table>
<thead>
<tr>
<th>Main Theme</th>
<th>Subthemes</th>
<th>Finding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contestation</td>
<td>“Shuffling round the Streets with the Shakes”</td>
<td>Participants frame taken-for-granted practices within the MHS (over-use of medication, ECT, forceful and coercive treatment) as human rights abuses and place these on the political agenda of reform of the MHS. Articulation of these abuses forged a politicised collective identity among participants.</td>
</tr>
<tr>
<td>“Need for a Paradigm Shift”</td>
<td></td>
<td>Strategies of contestation included research which problematises current service provision, and SUI in education of professionals. Challenges subject to epistemic politics and resistance from the dominant paradigm. Contestation of the epistemological paradigm of psychiatry contributed to the politicised collective identity of participants as social movement actors.</td>
</tr>
<tr>
<td>“De-Junked of Psychiatry”</td>
<td></td>
<td>Core concepts of the user/survivor-movement (peer-support, Recovery) assimilated into institutionalised practice, and transformative potential lost. Conflicting perspectives - some protested and feared appropriation of Recovery discourse - others welcomed it as an indication of change. Sharing common narratives around SUs’ experiences and dissemination of alternatives to bio-psychiatry contributes to the development of a collectivised, politicised identity.</td>
</tr>
<tr>
<td>Strategy Tensions</td>
<td>“Chain Ourselves to Hospital Gates”</td>
<td>Tensions due to a spectrum of opinions about public action as a strategy for the user-movement. - A few endorsed strategies such as public protest while others completely rejected outsider strategies. - Most adopted a collaborative strategy of SUI as only option currently available in achieving their goal of reforming the MHS, while not rejecting the option of public protest against the MHS.</td>
</tr>
<tr>
<td>“I Ended Up Being on Committees”</td>
<td></td>
<td>Developing autonomous peer-run services identified as the user-movement’s ultimate goal for SUI. -a few MHS are developing peer-involvement in service delivery. User movement derived benefit from the dissemination of the experience of seasoned activists, as knowledge and skills filtered throughout the movement.</td>
</tr>
</tbody>
</table>
**Strategy Tensions (Continued)**

“I Ended Up Being on Committees” (continued)

SUs, under favourable conditions, could influence decisions and policy, but more commonly the ability of SUs to leverage influence was limited in professionally-controlled spaces.

Reversal of power through the creation of user-controlled consultation spaces was advocated by one participant.

“Going into the Lion’s Den”

Participants were unprepared, lacked training, felt like outsiders, excluded by jargon. Displays of epistemological authority provoked fear and intimidation. Resistance to power sharing and tokenistic involvement provoked anger and frustration.

Unequal conditions of participation extract high emotional costs but coping strategies developed.

Engaging in highly unequal settings, with no control of decision-making led to frustration with tokenistic SUI.

“Asking for Payment is a Political Request”

Recognition and validation of SUI is a political issue - payment is significant in terms of respect for the contribution of SUs.

Recognition and payment associated with historical context of powerless and stigmatised position of SUs.

A minority view proposed the value of the altruistic contribution of volunteering, a position rejected by the majority who demanded payment as a mark of parity of esteem with professionals.

“Does Activism Become Dampened Down?”

A spectrum of opinion on issue of assimilation.
- rejection of SUI as collusion, until human rights abuses are acknowledged and addressed.
- energy of the user-movement subsumed into service-provision and serial membership of MHS-controlled committees with concerns about assimilation and tokenistic involvement.
- rejection of abstention from SUI because engagement was regarded as the only way to effect change.

**Structural Inhibitors and Facilitators of SUI**

“Psychiatrists don’t Relinquish their Power”

Psychiatric power an impediment to reform of the MHS and to SUI in particular.

Legitimacy of the dominant power of psychiatry contested - dominance of psychiatry unhealthy, not just for SUs and other professions, but also for psychiatry.

Many believed legislative change is necessary.
- to remove the exclusive statutory privilege of psychiatry and,
- to protect SUs’ human rights and stop forced treatment.
Individual professionals in key positions have initiated projects, but without positive support from professional groupings for SUI, it will not gain traction across the system. Nurses have significant power and their cooperation or resistance has implications for the success of SUI.

Relationships with allies key contributor to the success of SUI. Key people in powerful positions have advanced the cause of SU access to significant decision-making forums at a national level. Alliance of psychiatrists with user-movement posed risks of marginalisation within their profession.
Inherent Tensions of SUI: Contestations

The tensions around SUI for service-user participants, between contestation and collaboration, are a dominant theme in the findings. These participants contest the cultural ethos of the MHS, the epistemological framework of biopsychiatry and the conditions of participation as they engage in SUI with mental health professionals. Service-provider participants are also disaffected by the hierarchical structures of the MHS and institutionalised practice (especially within the nursing profession who are strongly resistant to change) and seek to align with service-users to effect reform towards more person-centred care. A constant tension for service-user participants is the question of whether the strategy of collaboration with the MHS is achieving their aim of influencing change to the current power structures and treatment paradigm. This is a core consideration given the potential for assimilation and the risk that SUI lends legitimacy to a MHS agenda.

Cultural Ethos of the MHS

Chapter Five described the stigmatised, powerless and fearful position service-users occupy in the MHS. Local participants’ prior experiences and personal history of engagement with MHS very evidently motivated them to challenge the system. Most national service-user participants demonstrated a radicalised awareness of the wider context of the institutionalised history of the MHS, both international and Irish, framed explicitly by human rights and social justice discourses. Many of the service-provider participants were also disaffected by the MHS cultural ethos, described as hierarchical, dominated by a medical model and resistant to change, again reflecting the literature describing both the Irish and international MHS (Hyde et al 2004; Newnes 1999; Rogers and Pilgrim 2010; Sapouna 2012). In the Irish context however, this is more pronounced due to the legislative control over the system solely held by psychiatry, mirroring the resistance of the medical profession in Ireland to cede autonomy to other health professionals, and the legacy of a significantly higher rate of institutionalisation in an Irish context than occurred internationally (Brennan 2012; Byrne and Onyett 2010; Walsh and Daly 2004).
Service-user participants seek to make visible practices that undermine the human rights of service-users. Many used social justice and human rights discourse to critique practices normalised within the MHS as ‘therapeutic’. One finding about such discourse was its potential as a means of contesting quality of service issues, but also to highlight the lack of recognition for those service-users engaged in SUI and to demand an equal place at the table. Social justice and human rights discourses add powerful moral weight to contestation of the MHS, as well as leverage for inclusion, influence and recognition in decision-making forums.

Several of the service-provider participants acknowledged past harms perpetrated by the MHS and service-users’ righteous anger, suggesting that it should be heard by those in power. Yet, the suggestion that service-user anger is related to past, rather than current practice is a defensive mechanism which allows professionals to avoid confronting the moral tension around coercive and iatrogenically harmful practice within the MHS (Bracken et al 2012; Breeze and Repper 1998; Happell et al 2003; Newnes et al 1999; Sapouna 2012). The refusal to allow space for expressions of anger is a tactic of invisible power used by those in authority over service-users (Lyman 2004). Pilgrim (2009) suggests that SUI provides a potential forum for service-user disaffection to be brought to the table, while the claimed spaces of the user-movement create a public space for expression of this anger.

**Epistemological Challenge**

A key finding around contestation for service-user participants is the presence of a moral, political and epistemological challenge to the current MHS. They presented a strong critique of the individualising, pathologising, biological model of mainstream psychiatry, leveraging human rights discourse to contest the harms and trauma that result from this treatment and to demand a place at the table as equals. This is not SUI per say, but potentially creates the conditions by which SUI might become more meaningful. Participants in Chapter Seven framed psycho-social distress as a response to life-crisis or trauma, positing alternative approaches to supportive non-coercive care to people in crisis as a paradigm shift. The challenge to the legitimacy of psychiatric authority is more
pronounced among the national service-user participants. Several challenged the authority conferred on consultant psychiatrists by legislation and were also cognisant of how knowledge is constructed by the dominant interests and filters out contesting knowledge claims. Several spoke of challenging psychiatric hegemony only to experience ‘epistemic politics’ (Hess 2004) in the form of dismissal of their challenge without any pretence of debate. These experiences of epistemic politics or ‘cognitive injustice’ (Gaventa and Cornwall 2008) can also be understood as a form of cultural domination (Fraser 1997), a dimension of mis-recognition. Such cultural domination underpins the dynamics of participation all service-user participants experience as they seek to create epistemological space for a paradigm shift in MHS.

Some national service-user participants explicitly argued for a paradigm shift in the MHS, demonstrating a sophisticated understanding of the damage and limitations of the bio-medical model and its failure as a model of care to address service-users’ expressed needs. These findings also resonate with the international literature highlighting the need for reform within the MHS towards a model of care that is client-centred and Recovery-focused (McGruder 2001; Ralph 2000; Stickley and Wright 2011; Walsh et al 2008). Peer-run MHS and crisis alternatives discussed by participants in Chapter Seven have been successfully operating in other countries for years (Doughty and Tse 2011; Faulkner 2002; Johnson et al 2004; Killaspy 2000; Segal et al 2011; Solomon 2004) and provide safe, supportive spaces for people in crisis. Although such services have yet to be established in Ireland, nevertheless these alternatives provide fodder for service-users’ epistemological challenges to the entrenched bio-psychiatric model of care.

Some service-users and service-providers believe that achieving greater inclusion of service-users through employment as peer-support workers on community mental health teams will result in change to the ethos of the MHS. These positions are also well-established in MHS in countries such as Scotland, USA and Australia (Bennetts et al 2011; McLean et al 2009; Solomon 2004), where there have been benefits reported for both service-users and the MHS. Steps taken to minimise risk of co-option for these workers include strong links to user-led groups, and oversight of the employing project by a steering group

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which is user-controlled and maintains equal partnership relations between user and professional members (Happell and Roper 2009). Establishing such posts in Ireland would be a significant shift towards both more acceptance of SUI and reform of how some service-users experience their care from the MHS. All the challenges inherent in SUI in terms of the politics of recognition and participation described by service-user participants can be expected to reappear and be magnified in such innovations. Meanwhile, the vision of alternative crisis centres remains just that, a vision. The tension around holding a vision for an independent, non-coercive, respectful, peer-led service and pragmatic decisions to collaborate in order to nudge reform of the current system was evident for many participants. This is a significant component of the inherent tensions of SUI that participants must hold as they engage with the MHS.

Recovery was another site of contention among national service-user participants, some of whom were very critical of the appropriation of user-initiated discourses of Recovery into a MHS agenda. They highlighted how practice could be re-classified as Recovery-focused without changing the power structures, the ethos or treatments on offer, with detrimental consequences to the integrity of the original concept. Recovery discourse was prominent among the service-provider participants in Chapter Six, for whom it signified their aspiration to provide more person-centred care. Some local service-user participants also adopted Recovery discourse to refer to the person-centred focus they advocated for, but were critical of services providing access solely to a psychiatrist and medication claiming to be Recovery-focused. All participants were cognisant of the need for service-providers to listen to service-users, and some service-provider participants reported that SUI had changed practice, in that attitudes of nurses within their team had become more favourable towards SUI, especially at an individual level of involvement, a core objective of the service-provider rationale for SUI. Practice around care planning was the key focus of reform for these participants, as well as promoting an ethos of more respectful engagement between staff and service-users generally. One significant finding was an acknowledgement from several service-provider participants that they do not have all the answers as to how to provide care that meets service-users needs or wishes, nor on how to reform the MHS, and therefore they
welcome the input from service-users. This opens up a potential space for
dialogue with service-users in the practices of SUI.

The Politics of Recognition

A key finding across all groups was the emergence of the politics of
recognition (Fraser 1997; Lewis 2009), in service-user participants’ accounts of
the stigmatising and dismissive attitudes they experienced from many service-
providers in the spaces of SUI. All service-user participants described denials of
recognition:

- disrespect (e.g. hearing service-users disparaged at meetings);
- psychiatric disqualification (being dismissed because of their service-user
  status, governance procedures presented as excuses for not employing
  service-users);
- non-recognition and cultural domination (feeling ignored and silenced at
  meetings or the concept of peer-run services dismissed).

Several service-provider participants report that they themselves experience
non-recognition in relation to their own professional roles, so they understand the
denials of recognitions service-users experience. Many spoke of a journey of
over-coming previously held attitudes and coming to recognise involved service-
users as competent individuals who enriched their meetings and professional
practice. For the local service-users, the primary exception to disrespectful
attitudes was in the meetings with the MDT. The struggle for recognition among
local service-user participants involved reframing their self-identity: a process
that moves from internalising the marginalised, stigmatised, de-valourised identity
of a recipient of care, to becoming an ‘expert by experience’ with a valuable
contribution to make. This process was aided by the support of both other
service-users and their professional allies. The counter-point to this experience is
when SUI is implemented as a tick-box exercise.

Service-user participants’ (local and national) emotional work to overcome
denials of recognition included learning to manage feelings of intimidation and
fear, learning to be dispassionate because it was a more effective strategy in
meetings with professionals, and the solidarity and support obtained from each
other. This is resonant with the literature describing how the rules of engagement
in bureaucratic organisational settings privilege rational objectivity and reason, thereby devaluing and constraining the expression of emotion or affective discourse (Barnes 2008; Lewis 2010; McDaid 2009). The rules of engagement discourage acknowledgement of the anger of service-users and the emotional cost of participation in inequitable settings. Service-user participants reported their experiences of meetings, especially as novices, as traumatic. Building on accounts of double trauma in the literature (service-users’ experiences being mis-recognised and minimised in written reports after consultation (Church 1996), and of failures of institutional care in the MHS (Cresswell 2009)), it is arguable that the double trauma of failures of care reported by participants can be compounded by a third trauma of painful experiences of mis-recognition or symbolic violence (Lewis 2009) when engaging in SUI. The possibility for such trauma is largely unacknowledged in most SUI literature, but it is a dynamic of participation which requires attention from those initiating SUI.

**Tensions between Collaboration and Co-option**

The second significant tension around SUI for service-user participants is that between collaboration and co-option. Collaboration is understood to be the space service-users occupy once they accept the invitation of the MHS to engage in SUI activities. By confining SUI to MHS planning and delivery, there is little debate about how SUI will, or if it can, affect a shift in how psycho-social distress is responded to and how the MHS can be re-organised. These were issues of strategic importance for the national service-user participants. As the literature on SUI in the UK demonstrates, the political focus of the user-movement can be consumed by the demands of SUI in the MHS (Campbell 2005; Pilgrim 2005; Stickley 2006). This is evident in the interviews with local service-user participants, whose focus was on improving local services, and negotiating more favourable conditions of participation, especially around recognition and power dynamics at meetings. This requires considerable investment from service-users and support from their professional allies in order to improve their chances to effect change. For these participants, fears about co-option stemmed from being taken-for-granted, and losing a critical perspective as a result of excessive demands on under-resourced volunteers.
An area of tension around SUI for service-provider participants is achieving a balance between supporting involved service-users, but without influencing their critical perspective and/or respecting their autonomy. Some participants are more cognisant than others of tensions around co-option, that involved service-users could become socialised into a MHS culture and lose their critical perspective as an unintended consequence of close collaboration with service-providers. Several believed that strong links with the user-movement could prevent this, yet one participant observed that the Irish user-movement was created to serve the needs of the MHS, that there was no organic grassroots user-movement prior to the official policy of SUI. This may be the case locally, although training in peer-advocacy has resulted in local user-groups forming for periods, only to dissipate for lack of focus and unsustainable numbers. The experiences of some national service-user participants would refute the assertion that the user-movement was created by the MHS, given the struggle to develop IAN. However, almost all the energy of IAN is devoted to service-provision within the MHS, acknowledged by a national service-user participant.

There are differing levels of awareness among the service-provider participants about the ambiguity of occupying powerful positions within the MHS and aligning with those subject to a coercive system. Such tensions emerged in relation to issues such as how best to wield positional power to support service-users engaging in new activities. For example service-user research promoted by the team leader threatened existing power structures of nursing practice, already threatened by new roles of responsibility for service-users. Although SUI is national policy, the MDT struggled to implement SUI without additional resources, which had implications for wider staff buy-in, because of the requirement for staff training and redeployment to support SUI. In the absence of adequate resources to support local involved service-users, the service-users were found to be effectively subsidising the MHS reform efforts, an example of ‘mal-distribution’ (Fraser 1997); a failure to re-distribute resources towards marginalised groups. This issue became politicised in Chapter Seven, as payment was framed as a political demand for equal recognition of service-users’ contribution to the MHS. Service-provider participants also recognised the need for parity of esteem of time contribution with professionals.
A key tension among national service-user participants concerns the appropriateness of SUI as a movement strategy. Most are in favour of pursuing insider strategies such as SUI, as a means to contest the current treatment regimen and to position themselves to affect changes, such as direct involvement in service delivery and ultimately, the provision of independent services. Regardless of concerns about assimilation expressed by some, and rejection of SUI as collusion (until human rights abuses are addressed) by one participant, the unifying drive is the collectivised political identity which arises from their contestation of the bio-psychiatric, expert-led paradigm of care, and their passion for reform of the MHS, the ultimate motivator for their activism and SUI work. Most service-user participants reject the idea that they could be co-opted, but are pragmatic about what they can achieve at this early stage of SUI. They spoke of the benefits of good working relationships within the MHS established through persistence with SUI in the face of initial resistance. Most concluded that there are no alternatives for the user-movement but to engage in the ‘long-stay committee’ rooms, because of the plight of those who have no alternatives or choices about MHS use, described as a ‘captive audience’ by one local service-user participant. The strength of the epistemological challenge articulated conveys a sense of resilience and resolve to persevere among service-user participants, local and national alike. They are clearly committed to the principle that the MHS require reform and that this must be informed by the perspective of those who have used the MHS.

All of the above tensions, between contesting the bio-medical paradigm and coercive care in the MHS, and collaborating to effect change, the struggles for recognition of a de-valorised service-user identity, and the risk of SUI providing a legitimising strategy to a MHS, resonate with the critical literature on SUI discussed in Chapter Two. These tensions inform the experience of service-users who engage with the MHS, and have provoked debate from user-movement intellectuals (Beresford 2010a; Campbell 2005; Chamberlin 2005). These writers recognise the potential for co-option, given the epistemic, legal and financial power and resource inequities that service-users experience, and highlight that the optimal form of involvement is that emerging from a base of self-defined organisation in user-run SMOs which have the potential to provide counter-
hegemonic space. Such user-controlled structures are more likely to prevent the socialisation and assimilation of users into MHS agendas (Beresford 2010a), a point elaborated on in the discussion of claimed/created spaces in Chapter Eight.

**Dynamics of Power**

Chapter Eight outlined how the power cube can be applied as an explanatory framework to illuminate how SUI operates in unequal conditions. The findings from the three empirical chapters were elaborated on and cross-sectionally analysed across all three domains of the power-cube, forms, levels and spaces of power. That analysis demonstrates the potential of the power-cube to isolate, illuminate and synthesise the cumulative impact of forms of power on SUI practices, highlighting the complexity of dynamics of participation for service-user activists and novices to SUI, as well as service-providers. This conceptual model is more complex and dynamic than a two by two matrix, yet intuitively easy to grasp, if not to resolve. Like its real-world physical counterpart, exposing and adjusting different alignments of forms of power, negotiating improved conditions for equal participation in different spaces, or moving from different levels of involvement results in dimensional shifts on interconnected domains.

This cross-chapter analysis revealed that invisible power, in the guise of hegemonic thinking, eliminates any debate within invited spaces that MHS are best placed to deal with psycho-social distress. Hegemonic agents, i.e. powerful actors within the system, control who is invited to the table and how decisions are arrived at, indeed often pre-determined before meetings. Given hidden and invisible forms of power constraining progress of SUI, positive leverage of visible power, in the guise of a consultant psychiatrist or senior manager supporting SUI, is to be welcomed. But if SUI occurs, when it does, at the discretion and direction of powerful individuals, in an ad hoc fashion, it does not change the structural and ideological impediments to SUI playing a significant role in reforming the MHS.

When professional allies open up invited spaces to SUI, they seek to align themselves with service-users in reforming the MHS towards more client-focused care, as occurred at the study site. Many movement activists engage with them because of the ongoing dependence of most service-users on the MHS, in
itself a distinguishing feature of health social movements (Brown et al 2004). SUI is a source of tension for some within the user/survivor movement as outlined earlier. Most start off optimistic and impatient for change because of the relative novelty of SUI in an Irish context; there is far more wariness about being incorporated into MHS agendas among movement activists in other jurisdictions after decades of experience of officially initiated SUI (Campbell 2005; Pilgrim 2005). Therefore, as a potential tool to unpack the complexities of power dynamics of SUI, the power cube model may be welcomed as an addition to the user-movement’s resources. The power cube, by explaining the interactions of power in different spaces, can counter the ideology that simply bringing service-users into MHS meetings will result in change. The level of access and influence over decision-taking, policy direction and service delivery that service-users are granted can be analysed to determine whether SUI is meaningful or not.

The power cube is particularly useful in understanding how the power structures interact with SUI, as the forms of power underpinning the hierarchical nature of psychiatry and the nursing professions are exposed. The findings were consistent across all three groups that these two professional groups posed the greatest structural challenge to SUI, and resistance to change. Yet reports in Chapter Six indicated that SUI was shifting attitudes among those professionals with closest proximity to SUI; they learnt to appreciate what SUI brings to the MHS in terms of fresh insight into jaded and institutionalised systems and ways of working.

The power cube can also be used as an educational tool for professionals. By highlighting the conditions of participation for service-users in relation to forms, spaces and levels of power, service-providers can improve conditions through reflective analysis of the dynamics of participation they create or help maintain in invited spaces. Reflective analysis must lead to increased awareness and action to address what has been learnt, otherwise the exercise is worse than pointless, it is insulting to service-users. The service-provider participants will, no doubt, welcome opportunities to reflect on the conditions and dynamics of participation for service-users, as learning how to improve their practises around SUI was one of their motivations for granting me access to their meetings and
forums for SUI. As a team, they have demonstrated willingness to examine and address conditions of participation under their control.

The levels of involvement domain prompts consideration of what level of influence over the system the SUI is focused on. SUI occurs across all levels, from strategic, through operational to individual level of SUI. Strategic level of involvement is significant in that, until there is meaningful influence by service-users over national policy and service development, then SUI is unlikely to deliver on service-users aspiration for institutional reforms, such as changes to treatment regimes across the system. Operational level SUI, such as the activities around SUI at the local site, seeks to influence service-delivery on the ground, and was the focus of most participants in Chapters Five and Six. The significance of the power-cube as a cross-domain analytical tool was evident in how it can explain local differences in SUI. The variation in local supports for SUI, between administrators’ use of hidden power to operationalise resources for SUI, and the extent to which invited spaces opened for SUI, is an illustration of how the model can explain the dynamics of participation. Increasing an individual control’s over their own involvement with the MHS is a core goal of SUI for both service-provider and service-user participants. The cumulative effect of individual, micro-level interactions shapes meso- and macro-level issues such as the culture of the MDT and the wider MHS. SUI seeks to effect change across all three levels, and a shift at one level of influence can impact on other levels. Evidence is presented of a shift in attitudes among both service-user and service-provider participants as a result of engaging with SUI.

The dimension of spaces, in particular invited and claimed/created spaces, offers new ways to think about what is being proposed in SUI. Bringing service-users into service-provider controlled spaces reveals that the power remains firmly in the hands of the MHS, evidenced in the empirical chapters. Beresford’s (2010a) analysis of the situation of PPI in the UK, especially in consultative and deliberative structures created to feed policy-makers’ need for consumer feedback, indicates that hegemony remains intact, whereas in created/claimed spaces, such as user-controlled organisations, there is scope for counter-hegemonic discourses to be developed. There were findings that this process is occurring among participants in their development of a politicised collective
identity, and in the solidarity that developed in de-briefing and social connections amongst service-user participants. These are the claimed spaces which provide possibility for resistance and broadening the base of epistemological contestation of the MHS, which in turn motivates others to engage in SUI processes. It is in these spaces that movement discourse moves out among members to widen the base of potential contestation and those willing to engage with SUI into the future. Of course, other movement discourses and resistances can develop in these spaces, which are not focused simply on SUI, but incorporate the wider dreams and visions of the user/survivor movement for better and more humane responses to psycho-social distress. These visions can support those engaging in SUI within the MHS and provide substance and hope for their struggles to make the MHS more responsive to service-users needs.

**Contributions of the Study**

This study makes many new contributions to the research field. It adds to the developing literature on survivor standpoint epistemology (Rose 2009; Sweeney *et al* 2009; Wallcraft *et al* 2009), by defending the proposition that those who experience both the effects of psychosocial distress, and use of the MHS, have vital contributions to make to research on the MHS, and SUI in particular. It is the first study of SUI practice in the Irish MHS incorporating both service-user and professional perspectives, building on the work of McDaid (2009). It also offers a theoretical account of recognition politics operating in relation to SUI, developing on the work of Fraser (2004) and Lewis (2009). Gaventa’s (2006) power-cube offers a framework to inform those engaging with SUI in the invited and claimed spaces of the MHS. As an explanatory framework, the power cube can illuminate the forms, spaces and levels of power operating in a rigidly hierarchical, unequal field such as the MHS, especially unpacking the hidden and invisible power of psychiatric hegemony. Additionally, this research updates the empirical picture (McDaid 2009; Speed 2002) of the Irish mental health service-user/survivor movement, given the spectrum of opinion across user/survivor participants in both chapters. It has a contribution to make to the international literature by adding further depth to our understanding of the dynamics of participation in SUI. Finally, through dissemination of the findings, in
publications and at conferences, it can create spaces for debate and discussion about the necessary conditions for meaningful SUI.

**Implications of the Study**

**Practice Implications**

By disseminating the findings to the local participants, service-users and service-providers, they can deepen the process of dialogue and debate already occurring. The service-provider allies can learn much about the conditions of participation experienced by service-users and vice versa. The unquestioned presuppositions about SUI are unpacked; presuppositions that assume that simply bringing service-users into meeting rooms of the MHS, without addressing the underlying power inequalities, will result in necessary reforms. The power cube is a tool that can illuminate the operations of visible, hidden and invisible power and poses questions for those developing policy on SUI as to how these power structures will be addressed to improve conditions for participation.

Another assumption, that the vested interests within the current system are willing or interested in change, or in divesting of some of their power, is exposed by evidence that reveals resistance to change within the system. This resistance to change primarily arises from the benefits accruing to psychiatrists, given their hierarchical position underpinned by hegemony, and the institutionalised practice of nurses. System change is required because it is not meeting service-users needs, and nor arguably those of service-providers. Thus SUI is proposed by its proponents within the MHS as a top-down reform strategy. However the underlying issue of power, especially hidden and invisible forms of power, must be addressed.

Training and support for those engaged in SUI, both service-users and service-providers, was identified as a requirement by participants. Training for professionals must include detailed attention to the conditions of participation for service-users and ideally be delivered by well-resourced and autonomous service-users and/or user-led SMOs with experience of SUI, or at minimum be co-delivered by service-users with professionals who understand the conditions and dynamics of participation. Meaningful SUI practice within the MHS could constitute stand-alone modules for incorporation into all professional third-level
education and training. Service-users also require preparation and capacity building before being expected to engage as equal partners in SUI initiatives developed by MHS. Adequate funding and resources must be ring-fenced to support service-users within budgets negotiated to support SUI initiatives.

**Policy Implications**

The elaboration of how the politics of recognition play out for service-users within the MHS can help to find ways to ensure that increased and favourable conditions of participation are created. Another feature of procedural justice includes resolving the issue of payment for time and expertise, and personal resources contributed by service-users.

The lack of national policy guidelines was highlighted. New policy guidelines on all aspects of improved conditions of participation need to be developed, especially the re-distribution of resources for payment to reward time and cover expenses (including provision of childcare/sitter payments) for service-users engaging with the MHS. These should be set at a reasonable rate so that they are not tokenistic or derisory. Service-users themselves must be involved in developing these policies, so they address the concerns identified by this research.

Different forms of SUI, including service-user participation on planning and delivery-oversight committees, need to be differentiated by policy planners, with service-users contributing to the development of defined, recognised roles for SUI within the MHS, and within policies on how SUI is to be operationalised. These should include SUI in education of professionals, MHS research, employment on community mental health teams and independent peer-advocacy services.

**Future Research Recommendations**

As SUI is a new development in the Irish MHS, further research is necessary to determine how it is being rolled out. One immediate need is a survey of the extent to which SUI initiatives are being developed across the country, including some measure of how such roll-out is addressing the dynamics and conditions of participation. Tools which could be adapted for a mixed methods study of the national context for SUI are PPPI or other quality measures developed by
survivor researchers in the UK (McKinley and Yiannoullou 2012; Morrow et al 2010; Rose 2001).

The development of peer-support workers, SUI in the education of mental health professionals in Ireland, user-led research and peer advocacy are areas of practice requiring detailed scrutiny. A similar methodology to that of this study, derived from survivor epistemology, would help uncover the dynamics and conditions service-users, and professionals, encounter operationalising these roles (some new, others established over a decade) for service-users in an Irish context.

The dynamics between service-users and family/carers, and the professional NGO sector which purports to represent service-user interests, particularly in the officially sanctioned NSUE, are topics worthy of other PhD studies.

The Irish user/survivor movement has not been researched in depth since Speed’s (2002) analysis of the Irish mental health field, during which time many developments have occurred, notably the establishment of IAN, Mad Pride Ireland and MindFreedom Ireland.

**Thesis Summary**

My thesis is that the politics of recognition and participation are overlooked or minimised by top-down proponents of SUI within the MHS. SUI always occurs at the discretion and direction of the MHS. If SUI is adopted as a top-down reform strategy but fails to critically examine the presupposition that service-users can leverage influence over reform of the MHS, without addressing the conditions for participation, then injustices of recognition and abuses of power will occur. The conditions which hinder SUI include bio-psychiatry hegemony which de-valorises the epistemological standpoint of service-users/survivors, and the existing power structures of psychiatry and institutionalised practices of nursing.

The findings from service-user participants reveal how complex tensions between contestation, collaboration and resistance are held and navigated. They adopt different positions as to the efficacy of SUI and the strategic import of SUI for the user-movement. All are fully committed to the principle that the MHS need to be reformed and that reform must be influenced and shaped by their
experience. The findings of this study reveal how the politics of recognition operate in the de-valorised identity associated with being a service-user, and service-users’ struggles for validation of their contribution. The service-provider participants, generally more positive about SUI, also believe that SUI is necessary to inform change. They accept and are working to implement top-down policy drivers of SUI as a reformist strategy to achieve more person-centred services. Without supportive space for self-determined reflection and action by adequately resourced user-controlled groups, on the movement’s own terms, the risk is that the SUI agenda is always determined and limited by the MHS.

This study examined the power structures inherent in the MHS through the lens of the power cube, to illuminate the forms, spaces and levels of power operating in SUI. This framework has the potential to become a useful social movement tool, given the energy invested by user-movement actors in SUI within the Irish MHS to achieve their agenda of person-centred care.
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Appendixes

Appendix A: Topic Guides

Topic guide for interviews with local service users

Preamble

Thanks for agreeing to do this interview. I am interested in hearing about your experiences in relation to service user involvement. As you know it is the central issue discussed in Chapter 3 of Vision for Change, which talks about Partnership with services users. It suggests that service users need to be consulted and represented at local, regional and national level levels, including at HSE management level. I am interested in your views and hearing about your experience today. You have read about my study and the measures I outline in the ethical protocols I attached to my information letter, and read the informed consent form attached. I will proceed with my questions and our discussion if you are ready to sign the consent form? When you have done so I’ll start the recording.

I’d like to hear as much as you can tell me about what service user involvement means to you in the widest possible way and in as much detail as possible.

Question 1  Let us start with your own experiences of getting involved. **How did you initially get involved** in representing service users, speaking on behalf of other service users?

<table>
<thead>
<tr>
<th>KEY TOPIC</th>
<th>SUB QUESTIONS AND PROMPTS</th>
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</table>
| personal experiences of being involved as a service user representative? | **1 How did you initially get involved** in representing service users, speaking on behalf of other service users, can you explain that more to me? **How long** have you been involved in this way?  
Do you remember the **first time you spoke up at a meeting**? Can you tell me more about that?  
Did you have **someone to talk over the experience** with?  
A mentor?  
What other measures were in place to help you in the beginning?  
Did you get training to help you prepare for getting involved if so what type of training?  
Did you get sufficient support coming to understand the complicated health service organisations? |
| General Understanding of SUI.? |  |
| Motivation for Involvement? |  |
| Question 1 |  
|-----------------|-----------------|-----------------|-----------------|
| **Sub question 1:** Recovery | What is your understanding of recovery? | Would you believe that a MHS that is seeking to develop user involvement is a Recovery focused service? In what way? Or why? | What is a recovery focused service in your opinion? |
| **Sub question 2:** Research | Have you been involved in research as more than simply a participant answering questions | If so can you tell me about it? Was it started by service users themselves or was it mental health services driven? |  
| **Sub question 3:** HRBA | Have you used Human Rights based approaches in your work? | If so what way specifically? | How do you see Human rights in relation to Mental Health? |
| **Question 2** | Let us look at how you see the policies that promote user involvement? |  
| **2 a Understanding of the MHS** | How do you understand this new development within mental health services of listening to the service user | What have you learnt about the mental health services from your experiences of going to meetings? | How do you Understand the policies underpinning SUI? |
| | | For instance? |  
| | | What does Vision for Change, Chapter 3 mean to you? Can you give me an example of when you might have looked at it, or referred to it in training or a meeting? |
| 2 b policies that promote user involvement | Are you aware of the Mental Health Commission Quality Framework document? If so Can you give me an example of when you might have looked at it, or referred to it in training or a meeting?  
Are you aware of the HSE Guide to User Involvement policy document? If so Can you give me an example of when you might have looked at it, or referred to it in training or a meeting?  
Are these documents useful to your work? In what way, can you give me an example?  
Have you been involved in drawing up any policies for the Mental Health Services yourself? If so what types of polices? Can you tell me more about that process? What did you do? Who was involved? |
|---|---|
| Question 3  
Level and type of representation  
In what ways have you been involved? For instance what types of committees, meetings do you attend?  
Sub-question a What makes involvement difficult?  
3 subquestion b) Payments?  
3 subquestion c) | Are you a member of the X Mental Health Services Consumer Panel? Do you believe that Consumer Panel has an influence on decisions about the way MHS are delivered? How so? Can you give me specific examples?  
Are there other ways for service users to get involved in your experience?  
What do you know about other levels of service user involvement, Locally, Regionally or Nationally?  
NSUE/ DCU course?  
Some people have talked about poor information before meetings, decisions already been made before meetings, not knowing what was expected of you at meetings, not being aware who has decision making power, or how decisions are made, who to influence, how to get your concerns onto the agenda, jargon being used all the time.  
Have you experienced power imbalances? If so, what form does this take? Can you explain, give me some examples?  
Other people have talked about the importance of being |
Impact of SUI on your life?

rewarded for involvement, getting paid for time or expenses? Has that been your experience? How has it been arranged to reward you if it was seen as important by the Mental Health Service? Was the arrangement satisfactory? What is your overall opinion of this issue? How does being a service user represent impact on your life? Has it made any difference to how you see mental health services? Especially in relation to your own relationship with MHS, if you still use them, that is?

Some writers have raised the issue of service users having to accept the label of being a service user in order to be involved and they can feel they lose out by this, either in terms of status or creditability, what’s your opinion of this issue?

Thank you so much for being so generous with your time and sharing so much knowledge and experience with me. Have you any questions for me? Is there anything you’d like to add? Do you want a copy of the transcript of this interview? Of the way I write up the results of my research?
Preamble

Thanks for agreeing to do this interview. I am interested in hearing about your experiences in relation to service user involvement. As you know it is the central issue discussed in Chapter 3 of Vision for Change, which talks about Partnership with services users. It suggests that service users need to be consulted and represented at local, regional and national level levels, including at HSE management level. I am interested in your views and hearing about your experience today. You have read about my study and the measures I outline in the ethical protocols I attached to my information letter, and read the informed consent form attached. I will proceed with my questions and our discussion if you are ready to sign the consent form? When you have done so I’ll start the recording.

I’d like to hear as much as you can tell me about what service user involvement means to you in the widest possible way and in as much detail as possible. Let us start with your own experiences.

<table>
<thead>
<tr>
<th>KEY TOPIC</th>
<th>SUB QUESTIONS AND PROMPTS</th>
<th>Notes/Rationale</th>
</tr>
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<tbody>
<tr>
<td>Personal experiences of promoting the involvement of service users? General Understanding of SUI?</td>
<td>Do you support service user involvement? Why? What do you understand by service user involvement? Do you remember the first time you were at a meeting with service users present? Can you tell me more about that? What was that like? What measures, if any, were in place to help everyone in the beginning? How long have you been working in this way? What has changed over this time? For instance do you remember what it was like working before the idea of including the service user voice was a common policy? How are things different since then? Or have they changed? In what ways?</td>
<td>Warm up Observations from their experience</td>
</tr>
<tr>
<td>Professional perspectives</td>
<td>Do you think your professional training helps or hinders you in listening to the service user perspectives? What values in your professional training support service user involvement? Do you observe differences between your profession &amp; other professional groups you work alongside?</td>
<td>Professional dimension</td>
</tr>
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<td>---------------------------</td>
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<td>------------------------</td>
</tr>
<tr>
<td>Communicating with colleagues about SUI</td>
<td>Do you communicate with colleagues about SUI? What ways do you speak about it? Do you need to convince others to adopt it? If so how? Why? What do you say?</td>
<td>Communication among team</td>
</tr>
<tr>
<td>Status in local service</td>
<td>How do you think your professional position or status helps you in promoting SUI?</td>
<td>Influence on others?</td>
</tr>
<tr>
<td>Sub topic 1: <strong>Recovery</strong>? Why is there this interest in SUI?</td>
<td>Why, do you believe, the MHS are promoting SUI? Do you see a link with SUI and Recovery focused practice? If so how do you see it?</td>
<td>(look for conceptual link?)</td>
</tr>
<tr>
<td>Sub topic 2: <strong>Research</strong> Are you aware of service users doing research as in more than simply a participant answering questions?</td>
<td>If so, can you tell me about it? Was it started by service users themselves or was it mental health services driven? What are the issues that come up in promoting service user research projects? Co-operation from staff? Resources? Support?</td>
<td>Research is a specific aspect of SUI (look for conceptual link?)</td>
</tr>
<tr>
<td>Let us look at the policies that promote user involvement?</td>
<td>For instance? What does Vision for Change, Chapter 3 mean to you? Can you give me an example of when you might have looked at it, or referred to it in training or a meeting?</td>
<td>References to specific policies?</td>
</tr>
<tr>
<td>Question</td>
<td>Answer</td>
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<tr>
<td>Are you aware of the Mental Health Commission Quality Framework document? If so Can you give me an example of when you might have looked at it, or referred to it in training or a meeting?</td>
<td>2 b policies that promote user involvement</td>
<td></td>
</tr>
<tr>
<td>Are you aware of the HSE Guide to User Involvement policy document? If so Can you give me an example of when you might have looked at it, or referred to it in training or a meeting?</td>
<td>Specific statement from local Service Plan?</td>
<td></td>
</tr>
<tr>
<td>Are these policies useful to your work? In what way, can you give me an example?</td>
<td>‘People who use mental health services need the authority to choose from a range of options and participate in all decisions-including the allocation of resources-that will affect their lives. They may need to be supported in making these choices not just by mental health workers, but by other service users and to learn as individuals and collectively how to influence the way organisations and people respond to them’. (page 8 of the Service Plan on a template on introducing recovery concepts into a Model of Care: No 3 of 10, (Wolfson and Cupitt)). What is your opinion of this aspiration?/How can it be achieved? / What are the steps in moving closer to this goal? /How do you see the role of other service users as</td>
<td></td>
</tr>
<tr>
<td>Have you been involved in drawing up any policies for the Mental Health Services yourself? If so what types of polices? Can you tell me more about that process? / What did you contribute? / Who else was involved in developing these?</td>
<td>Use of local policy statement to elicit comments</td>
<td></td>
</tr>
</tbody>
</table>

355
<table>
<thead>
<tr>
<th>Level and type of representation/ Mechanics of involvement?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>In what ways have SU been involved in your area?</strong> For instance <strong>what types of committees, meetings do SUs attend?</strong></td>
</tr>
<tr>
<td>Tell me about the level of representation of service users, and carers, at your team level. How does it work? Are you familiar with the work of the X Mental Health Services Consumer Panel? Do you believe that the Consumer Panel has an influence on decisions about the way MHS are delivered? How so? Can you give me specific examples? Are there other ways for service users to get involved in your experience? What do you know about other levels of service user involvement, Locally, Regionally or Nationally? For instance NSUE/DCU triologue course? What about SUI in training staff?</td>
</tr>
<tr>
<td><strong>What kinds of issues influence the dynamics between SU and professionals at meetings?</strong></td>
</tr>
<tr>
<td>From your experiences, what have you learnt about the practicalities of including service users at planning meetings? How are SU introduced at meetings? Do you feel a person’s identity as a service user matters at meetings? How might that influence the dynamics of meetings? Are people more careful how they speak when SU are present?</td>
</tr>
<tr>
<td><strong>Sub-question a)What makes SU participation at meetings work well?</strong></td>
</tr>
<tr>
<td>What makes these meetings work well? If they are good experiences, what makes them good experiences? What have you learnt about the process of making the meetings go well?</td>
</tr>
<tr>
<td>subquestion b) What makes participation difficult?</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>Power imbalances</td>
</tr>
<tr>
<td>Mentoring</td>
</tr>
<tr>
<td>Payment for time and effort</td>
</tr>
<tr>
<td>Co-option vs independence</td>
</tr>
<tr>
<td>Concluding</td>
</tr>
</tbody>
</table>
questions

How does service user involvement impact your work?

mental health services operate?

Some writers have raised the issue of service users having to accept the label of being a service user in order to be involved and they can feel they lose out by this, either in terms of status or creditability, what’s your opinion of this issue?

Have you noticed a personal cost to people who take up this role with mental health services? If so, can you elaborate?

Have you observed personal paybacks to people who get involved in this way? What is in it for them in your opinion?

Rewards of working this way?

To conclude, can you explain what you see as the rewards of working in this way?

Closing question

to SUs
Politics of recognition discussed by L Lewis Rewards for SUs

Thank you so much for being so generous with your time and sharing so much of your knowledge and experience with me. Have you any questions for me? Is there anything you’d like to add? Have we touched on all the topics that are important here? I may need to come back to you to clarify some information later but will be in touch if I need to do this. Is that ok with you?

Do you want a copy of the transcript of this interview? Do you want to review a draft of the write-up of the results of my research?

Finally, once again I really appreciate you giving me so much of your time.
Topic guide for interviews with experts by experience

Preamble

Thanks for agreeing to do this interview. I am interested in hearing about your experiences in relation to service user involvement. As you know it is the central issue discussed in Chapter 3 of Vision for Change, which talks about Partnership with services users. It suggests that service users need to be consulted and represented at local, regional and national level levels, including at HSE management level. I am interested in your views and hearing about your experience today. You have read about my study and the measures I outline in the ethical protocols I attached to my information letter, and read the informed consent form attached. I will proceed with my questions and our discussion if you are ready to sign the consent form? When you have done so I’ll start the recording.

I’d like to hear as much as you can tell me about what service user involvement means to you in the widest possible way and in as much detail as possible. Let us start with your own experiences.

<table>
<thead>
<tr>
<th>KEY TOPIC</th>
<th>SUB QUESTIONS AND PROMPTS</th>
<th>Notes/Rational</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Understanding of SUI?</td>
<td>Do you support service user involvement? Why? What do you understand by SUI?</td>
<td>Warm up</td>
</tr>
<tr>
<td>How did you initially get involved? Personal experiences of service user involvement?</td>
<td>Do you remember the <strong>first time you were at a meeting with mental health professionals present, a meeting that was not about your own care</strong>? Can you tell me more about that? What was that like? What measures, if any, were in place to help you? Did you get any training to help you prepare?</td>
<td>Observations from their experience</td>
</tr>
<tr>
<td>Specific experience</td>
<td>How long have you been active in mental health services in this way? What has changed over this time? For instance do you remember what it was like before the idea of including the service user voice was</td>
<td></td>
</tr>
</tbody>
</table>

359
<table>
<thead>
<tr>
<th>Professionals</th>
<th>Do you observe differences between professional groups in their attitude or understanding of SUI?</th>
<th>Observations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hierarchy in MHS</td>
<td>Do you think a professional’s position or status within the organisation is an issue in terms of promoting SUI?</td>
<td>(look for conceptual link?)</td>
</tr>
<tr>
<td>Recovery</td>
<td>Why do you believe the MHS are embracing SUI? Do you see a link with SUI and Recovery focused practice? If so how do you see it?</td>
<td></td>
</tr>
<tr>
<td>Research</td>
<td>Are you aware of service users doing research as in more than simply a participant answering questions? Have you been involved in research on issues to do with the user perspectives in mental health? Was it started by service users themselves or was it mental health services driven? What has user led research got to offer?</td>
<td>Research is a specific aspect of SUI (look for conceptual link?)</td>
</tr>
<tr>
<td>Training</td>
<td>Have you been involved in training or education of mental health professionals? What kind of training? What do you think this kind of involvement of users has to offer mental health services or other users?</td>
<td>Training as a specific aspect of SUI</td>
</tr>
<tr>
<td>HRBA</td>
<td>How do you see Human Rights in relation to Mental Health? Is there a relationship? Do you use HRBA in your work?</td>
<td></td>
</tr>
<tr>
<td>Scope of SUI in</td>
<td>What do you know about different levels of</td>
<td>Vision of how</td>
</tr>
<tr>
<td>Ireland, international best practice, Vision for development</td>
<td>service user involvement, especially examples of best practice? Can you give me some specific examples? Tell me about the different types of involvement you are aware of? How does it work in practice? Why is there such a difference in the level of involvement across the country? What do you know of developments in other countries?</td>
<td>things could develop.</td>
</tr>
</tbody>
</table>

2) Let us look at the **policies** that promote user involvement?

| How do you understand the new policies within mental health services of listening to the service user voice? What do you see as their purposes and goals? | For instance? What does Vision for Change, Chapter 3 mean to you? Can you give me an example of when you might have looked at it, or referred to it in training or a meeting? Are you aware of the Mental Health Commission Quality Framework document? If so Can you give me an example of when you might have looked at it, or referred to it in training or a meeting? Are you aware of the HSE Guide to User Involvement policy document? If so Can you give me an example of when you might have looked at it, or referred to it in training or a meeting? Are these policies useful to your work? In what way, can you give me an example? Have you been involved in drawing up any policies for the Mental Health Services yourself? If so what types of polices? Can you tell me more about that process? What did you contribute? Who else was involved? | References to specific policies? |

| Question 3 Mechanics and specific issues around involvement? | | |
| What kind of issues influence the **dynamics** between SU and professionals at meetings? | What have you learnt about the practicalities of SUI from your experiences? For instance, How are SU introduced at meetings? Do you feel a person’s identity as a service user matters at meetings? How might that influence the dynamics of meetings? Are people more careful how they speak when you or other SUs are present? Some writers have raised the issue of service users having to accept the label of **being a service user** in order to be involved and they can feel they lose out by this, either in terms of status or creditability, what’s your opinion of this issue? | Meeting dynamics  
Politics of recognition discussed by L Lewis (2009) |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sub-question a)</strong> What makes <strong>involvement work well?</strong></td>
<td>What, from your experience, makes SUI work well? What makes meetings work well? If they are good experiences, what makes them good experiences? What have you learnt about the process of good meetings?</td>
<td></td>
</tr>
<tr>
<td><strong>Sub-question b)</strong> What makes <strong>involvement difficult?</strong></td>
<td>What from your experience makes SUI difficult? When meetings don’t go well, can you identify what might have gone wrong? If you can think of an instance when it was not a good experience, what made it challenging? What have you learnt about the process of improving opportunities to allow sui work well or grow? Some people have talked about poor</td>
<td>Specific instances of WWW</td>
</tr>
</tbody>
</table>
information before meetings, decisions already been made before meetings, not knowing what was expected at meetings, not being aware who has decision making power, or how decisions are made, who to influence, how to get service user concerns onto the agenda, jargon being used all the time.

<table>
<thead>
<tr>
<th>Power imbalances</th>
<th>Have you witnessed <strong>power imbalances in meetings</strong>? If so, what form does this take? Can you explain, give me some examples?</th>
<th>power issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mentoring</td>
<td>The role of a mentor has been identified through some peoples’ experiences. Can you tell me what you think of this? Why do you think a mentor could be useful? Who should this be? What have they to offer?</td>
<td>Specific initiative in R&amp;R T</td>
</tr>
<tr>
<td><strong>Payment for time and effort</strong></td>
<td>People spoke about this as an important issue. What is your opinion? Do you see it as an important obstacle to involvement? Should meetings go ahead without resolving this issue to the satisfaction of service users? What about those who say volunteering is important in so many aspects of community life, like parent committees in schools, or coaching local football teams? What do you say to that argument?</td>
<td>Payment discussed by all su respondents</td>
</tr>
<tr>
<td>Voice of protest/co-option</td>
<td>Some have written about the fact that the su movement in UK has gone from being a voice of protest to being co-opted into the service of the MHS agenda, because of its focus on improving the conditions for SUI. What do you think of this?</td>
<td></td>
</tr>
</tbody>
</table>
3. subquestion d)

**How does service user involvement work impact the rest of your life?**

- Do you think the policy of service user involvement has made any difference to the way mental health services operate?
- What is your vision for the possible future development of SUI? Locally, Regionally or Nationally
- Have you noticed a personal cost to people who take up this role with mental health services? If so, can you elaborate?
- Have you observed personal paybacks to people who get involved in this way?
- What is in it for them in your opinion?

**Personal cost to SUs**  
Vision for SUI  
Rewards for SUs

**Rewards of working this way?**

- To conclude, can you explain what you see as the rewards of working in this way?

**closing question**

**Concluding Statement**

Thank you so much for being so generous with your time and sharing so much of your knowledge and experience with me. Have you any questions for me? Is there anything you’d like to add? Have we touched on all the topics that are important here?

I may need to come back to you to clarify some information later but will be in touch if I need to do this. Is that ok with you? Do you want a copy of the transcript of this interview? Do you want to see a copy of the write up of the results of my research?

Finally, once again I really appreciate you giving me so much of your time.
Appendix B: Research Ethics Application

FACULTY OF ARTS, HUMANITIES AND SOCIAL SCIENCES
RESEARCH ETHICS COMMITTEE
CHECKLIST

All applicants must fill in this checklist. If you answer “No” to all the questions, please then fill in the application form. If you answer “Yes” to any of these questions, you must also fill in the Advanced Ethics Application Form (Appendix C) which is specifically designed with social research methodologies in mind. All applications must be accompanied by an Information Sheet and Consent Form (Appendices A+B)

1. Does this application involve research with:
   a. People under the age of 18 NO
   b. People with psychological impairments NO
   c. People under the control or influence of others (e.g., people in care, prisoners) NO
   d. People with learning difficulties NO
   e. Relatives or parents of sick people NO
   f. People who only have a basic knowledge of English NO
   g. Students with whom the researcher has a teaching or supervisory relationship NO

2. Does this application deal with:
   a. Personally sensitive issues, such as suicide, bereavement, gender identity, sexuality, fertility, abortion, gambling, financial arrangements NO
   b. Illegal activities, illicit drug taking, substance abuse, engaging in criminal behaviour NO
   c. Any act that might diminish self-respect or cause shame, embarrassment or regret? NO
   d. Research into politically sensitive and/or racially/ethically
and/or commercially sensitive areas?

   NO

e. Issues which might otherwise give rise to a risk of loss of employment for the participant?  NO

3. Does the proposed research procedures involve:
   a. Use of personal records without consent  NO
   b. Deception of participants or use of placebos  NO
   c. The offer of inducements to participate  NO
   d. Audio or visual recording without consent  NO
   e. Invasive physical interventions or treatment  NO
   f. Research that might put researchers or participants at substantial risk?  NO
        Storage of data for less than 7 years?
       NO
   g. Revealing the identity of participants?  NO
   h. Dealing with topics, using methodologies, or reporting of findings in a way that is likely to cause pain, discomfort, embarrassment, or changes of lifestyle for the participant?  NO
All applicants must complete this form and include an information sheet and consent form with their application. If you have ticked “yes” to any question on the checklist, please complete this form and the “Advanced Ethics Application Form”.

For Office Use Only: Application No.: ____________

approval reference number FAHSS_REC225

Applicant Details:
Name: Liz Brosnan
ID Number: 0887668
E-mail Address: liz.brosnan@ul.ie
Department/Programme of Study: Sociology
Type of Project (FYP/MA/PhD/Faculty): PhD
Funding Body (where appropriate): PRTLI 4, ISSP
Project: User Involvement In Mental Health Services: The Impact Of Policy Changes

Supervisor/Other Investigators:
Dr Orla McDonnell, Department of Sociology
Dr Elizabeth McKay, Department of Occupational Therapy

Signature of Applicant ____________________________ Date
Signature of Supervisor/HoD _______________________ Date
**Project Details:**

1. Research Plan: (100-200 words)

I seek to advance understanding of user involvement initiatives within mental health services by studying several instances of the practices of this new policy area, examining the particular, as well as the common, features of cases in Co X initially but also developments in Co Y. The key objectives are to explore the perceptions and experiences of front-line mental health professionals and service user activists in the emerging practices of user involvement. This study will seek to develop an understanding of how different professionals conceptualise their approach to developing user involvement mechanisms and how service users in turn frame their involvement. By interviewing and observing those who have been active in pioneering these initiatives, their learning can contribute to the growing scholarship on this emergent theme in health services.

**Summary Research Plan**

<table>
<thead>
<tr>
<th>Stages</th>
<th>Tasks</th>
<th>Completion date</th>
</tr>
</thead>
<tbody>
<tr>
<td>REC</td>
<td>Ethical Approval submitted to FAHSS REC for non HSE sample</td>
<td>June 2010</td>
</tr>
<tr>
<td></td>
<td>Ethical Approval submitted to HSE REC for HSE employees sample</td>
<td>June 2010</td>
</tr>
<tr>
<td>Data</td>
<td>Commence Data collection</td>
<td>September 2010</td>
</tr>
<tr>
<td></td>
<td>Transcription</td>
<td>September 2010</td>
</tr>
<tr>
<td></td>
<td>Immersion</td>
<td>September 2010</td>
</tr>
<tr>
<td>Analysis</td>
<td>Initial analysis using NVivo begins</td>
<td>October 2010</td>
</tr>
<tr>
<td></td>
<td>Cycle of data collection, analysis, and return to data continues throughout data collection period</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Data collection ceases</td>
<td>June 2011</td>
</tr>
<tr>
<td></td>
<td>Analysis cycle continues</td>
<td>September 2011</td>
</tr>
<tr>
<td>Writing</td>
<td>Initial drafting period</td>
<td>September 2011 to April 2012</td>
</tr>
<tr>
<td></td>
<td>First complete draft submitted</td>
<td>May 1st 2012</td>
</tr>
<tr>
<td></td>
<td>Corrections and second draft</td>
<td>May 31st 2012</td>
</tr>
<tr>
<td>Submission</td>
<td>Final draft of thesis submitted</td>
<td>June 2012</td>
</tr>
</tbody>
</table>
2. Research Purpose (100-200 words)

Mental health services in Ireland have adopted the policy goal of user involvement as a key principle of good practice. Embedded in A Vision for Change (2006, Department of Health and Children), the policies for the Mental Health Commission, (MHC 2004, 2005, 2006) and new HSE policy (McEvoy 2008), are guidelines and standards for service user involvement which are expected to inform and drive the modernisation of mental health services. Efforts to affect modernisation in this context of care provision have been patchy and incremental (Mc Donnell, 2007).

User involvement raises many problematic issues, from consideration of how it emerged, whether it is driven by a ‘Consumerist ’ or ‘Democratic’ agenda (Beresford 2004); how issues such as recognition, (Lewis 2009), power (McDaid 2009) and influence effect change (Rutter et al. 2004) play out on the ground.

To date there is little systematic, qualitative social research available in Ireland to inform us as to how the proposed changes are being received by frontline mental health professionals or service user leaders. The focus of this research seeks to address this information gap, critical to all stakeholders invested in helping to shape the development of services over the coming years.

3. Research Methodology (100-200 words)

I propose to use a case study methodology to examine the issues emerging in the concept and practices of user involvement in Mental Health Services in Counties X, Y and Z.

Following due process of obtaining informed consent, the data will be co-created with participants during guided interviews, and periods of observation of meetings. The interviews will be audio recorded, and transcribed by a professional transcriber, who has signed a confidentiality declaration, (see attached).

Analysis will be conducted with the aid of NVivo software after complete ‘immersion’. Common themes will be sought, coded, and each code further examined. Overlapping codes will be collapsed, to form larger more inclusive categories, making explicit the links between categories. A hierarchical structure of themes will emerge, showing categories and their subcategories. The final categories will be organised into meaningful clusters that best match the data.
Results will be written up, theoretical perspectives examined within previous literature in the area, and new theoretical understanding presented on this recent policy development in Irish Mental Health Services

**Ethical Considerations for the Proposed Research:**

1. **Who** will your informants be?

**Professional Sample**

All members of the identified local multidisciplinary team in X Mental Health Service will be approached. (This team includes a consultant psychiatrist, occupational therapist, social worker, psychologist and mental health nurses). Also those who completed the Trialogue Leadership Project: a unique project that brings a service user, carer and professional together from the same mental health service for training and mutual learning in DCU

(see [http://www.dcu.ie/health4life/conferences/2009/symposium2flyer.pdf](http://www.dcu.ie/health4life/conferences/2009/symposium2flyer.pdf) for further information) Three teams have completed this initiative in Co X and these will be sought as participants. In addition, those members of the managerial teams, (e.g the General Manager of X Mental health Services, and Senior Mental Health Nurse Managers) who support the various user involvement forums: (such as consumer panels: which consist of service user and carer representatives convened to advise on mental health service planning and development: and the leadership project), will be requested to provide interview opportunities. In addition professionals involved in other initiatives, (i.e. Psychiatrists, Mental Health Nurses, Social Workers Occupational Therapists, Psychologists, and Service Managers) in Counties Y and Z will approached if considered appropriate to extend the case study.

**Service User Activists**

There are various forums within County X Mental Health Services in which people participate by providing the benefits of their experiences of being ex-users or users of mental health services. These people are affiliated to one or more of the Mental Health Non-Governmental Organisations, such as the Irish Advocacy Network, and the local X Advocacy Group, the National Service User Executive, Aware, GROW or Phrenz, (the self-help support group affiliated to Shine).

**Summary of initial sampling frame in X Mental Health Services (MHS)**

- People with experience of mental health activism.
- x Advocacy Group (8-10 people) (this is a group of people trained and supported by the Irish Advocacy Network)
- Consumer Panel (5 people)
Trialogue Leadership Project team Members Each team has had three members: a professional, a service user and a carer (3 people x 3 years)

Professional Cohort in x MHS

Multi-disciplinary team members (6-10)

Top Management Triad, Administrator, Clinical Director and Director Of Nursing (3)

In addition, professionals and service user leaders may be sampled in Co y and z.

2. How do you plan to gain access to/contact/approach your potential informants?

The management of the HSE in the area will be written to with details of the study, and the decisions of the HSE REC and the FAHASS REC.

All professionals involved in the case study initiatives will be contacted informally initially, then written to formally (see attached letter).

As a member of the Board of Management of the Irish Advocacy Network, and through my work with the Western Alliance for Mental Health, I have established strong working relationships with service-user groups. Therefore people will be approached directly as activists in their own right, rather than through HSE gatekeepers. Purposive sampling of those involved in forums mentioned earlier, such as the Consumer Panel, the Research Project and the Leadership Project should lead to snowball sampling which will identify those people not already known to me.

3. What arrangements have you made for anonymity or confidentiality (if appropriate)?

All raw data collected during interviews will be handled only by the researcher. Anonymised interview transcripts may be made available to the researcher’s supervisors at the University of Limerick in order to substantiate claims or aid interpretation. A professional transcriber may be employed to assist with transcribing. The transcriber will be required to sign the attached confidentiality agreement. (Appendix D)

All identifying markers will be removed from the data by the researcher. Participants will be asked to provide feedback on any markers in the transcript or draft report that could compromise their anonymity. These will be removed.

The data (hard and electronic copies) will be securely held by the researcher in a locked filing cabinet in her study, to which no one else will have access. Electronic
information will be data protected by password, and stored on a password protected external hard drive. Information will NOT be stored on a laptop.

4. What, if any, is the particular vulnerability of your informants?

Contrary to prevalent misconceptions, people with a history of engagement with mental health services are no more or no less likely to be vulnerable than other people in the general population. Someone who is acutely unwell, whether physically or mentally, is in a fragile and vulnerable period of their lives, but that is not the population under consideration here. Indeed my population are not the majority population of those who use mental health services but those who have become leaders and representatives of their peers. They are the individuals who choose to engage in work which is usually voluntary and often unrecognised and unrewarded, work which seeks to improve conditions for all those who use mental health services.

An important principle under codes of ethics is that of ‘non-malfeasance’, the researcher must seek to avoid harm, or minimise the potential for harm as much as possible. Sometimes research can lead to unintended consequences for participants, resulting in a ‘sense of frustration, alienation, potential exploitation,’ (Kirsh, 2005: p 2163). This is far more likely to occur if the researcher is not paying attention to the burden on the participant, for instance, having someone fill out long unwieldy or intrusive questionnaires, or continuing interviews without recognition of the responses of the interviewee, or their comfort levels. Therefore the researcher must seek to avoid harm, e.g. undue stress, unwanted attention, loss of reputation, invasion of privacy.

While this principle sounds desirable, in practice it has often been construed as patronising and paternalistic, especially in mental health service user-led research. Alison Faulkner published research carried out on the research process by service user researchers and her work raises the interesting issue of how service users themselves viewed this concept of protection from harm. Many saw it somewhat ‘patronising, paternalistic and inappropriate’, with the view expressed that people can be distressed but wish to continue. People rarely have opportunity to speak for an hour about themselves or to tell their story so being interviewed about their experiences can be a positive benefit. Faulkner reported that service user researchers believed that Research Ethics Committees are more designed to protect vulnerable people than hear their voice, (Faulkner 2004, p 31-2). Davidson et al (2009 p: 94) suggest that the most appropriate way to ensure the protection of the rights and interests of mental health service users is for them to become active members of Research Ethics Committees.
5. What arrangements are in place to ensure that informants know the **purpose of the research** and what their part in the research will be?

A detailed information letter, ethical protocol statement, and informed consent form will be sent to participants after an informal contact to explain the study and acquire their preferred contact details. They will have 7 days to consider these before follow-up phone contact to determine their response. I will be seeking written informed consent from all participants following verbal agreement to take part.

7. What are the psychological and/or physical safety issues for the researcher and/or the informant (if any) that arise from the research, and how will you deal with them?

There are no anticipated psychological and/or physical safety issues for the researcher and/or the informant arising directly from the research. However, if the researcher becomes aware of a potential risk to another, through that person expressing a desire to attempt suicide, or to harm another, there is a responsibility to bring that to the attention of an appropriate staff member. Therefore any promise made to research participants carries that caveat, which is discussed with them. Apart from this caveat there are no likely additional safety issues beyond the standard research practice of ensuring the well-being of participants afterwards by offering an opportunity for de-briefing.

Participants will not be asked about their experiences of illness directly, only about their experiences of services. Given my previous relationships, including as a researcher, with some participants, both professionals and activists, I will be making very clear to them that this research interview is just that: I may need to remind them this will not be a social encounter, but a clearly bounded data creation encounter, that what people say will be recorded, and used to develop theoretical ideas about user involvement.

In terms of researcher safety, my research journal: a research tool which aids both data collection, reflection on the research process, and re-collection of the learning through-out the research period, will be an immediate resource to process any uncomfortable feelings afterwards. Should an interview, however, be particularly difficult or stressful I will have access to a peer mentor, with whom a reciprocal mentoring relationship has been established. I also can avail of the ongoing support of my
supervisors, with whom I can discuss a difficult or challenging encounter immediately by phone, if it is not possible to arrange a prompt meeting.

8. How do you propose to store the information, and for how long?

All recordings and hard and soft copies of transcripts will be kept securely in a locked filing cabinet. Password protected external hard drives will be used to store electronic data, and this will be kept in a locked filing cabinet. Information will not be stored on a laptop.

HSE REC and Data protection guidelines suggest data must be stored for 10 years. Unless there is a storage facility available at UL upon completion of the study, they will be held in a locked filing cabinet at the researcher’s home.
On following pages

Appendix A Information letter about interviews

Appendix A1 Information letter about meeting observation

Appendix B Consent form

Appendix C Ethical Protocol

Appendix D Courtesy Information letter to senior management in the area

Appendix E Confidentiality Agreement for Transcriber
Dear

I am a postgraduate student at the University of Limerick undertaking a PhD in Sociology. My research topic is ‘User Involvement in Mental Health Services: The Impact of Policy Changes.’ This study will seek to develop an understanding of how different professionals conceptualise their approach to developing user involvement mechanisms and how service users in turn frame their involvement. By interviewing and observing those who have been active in pioneering these initiatives, your learning can contribute to the growing scholarship on this emergent theme in health services.

During the interview you will be asked to discuss such issues as:

- The extent to which you have been involved in user involvement forums in your mental health service?
- What does user involvement mean to you?
- How you see the facilitators? and barriers to effective user involvement?

If you volunteer to take part in this research, you will be asked to participate in a one-to-one interview at a time and place convenient to you. Interviews will be recorded and will last approximately 1 hour. If you volunteer to participate in this study, you may choose not to answer any of the questions put to you,
including during the interview. Further, you may choose to withdraw from the study at any time without giving a reason.

In the days following our meeting, I will type up an account of our interview. I will remove any non-essential information that might identify you from that typed account. I will contact you to offer you the opportunity to check the account to satisfy yourself that I have adequately protected your identity. I intend to publish the findings of this research, but I will not use your name in any such publications. If you indicate you wish to read this draft before publication I will contact you again to inform you it is available.

If you have any questions regarding this research, or would like additional information to assist you in reaching a decision about participation, please don’t hesitate to contact me, (Liz Brosnan) at (087 7779551 or liz.brosnan@ul.ie ). You are also welcome to contact my supervisors, Dr. Orla McDonnell orla.mcdonnell@ul.ie or Dr Elizabeth McKay, elizabeth.mckay@brunel.ac.uk . We would be happy to answer any queries you may have.

I will contact you again in seven three days to seek your decision. I ask you to review the attached ethical protocol which I offer as a statement of the considerations I have given to the ethical dimension of this research project. If you are happy to consent to be interviewed, I will ask you to sign the attached form, which details your rights as a participant. Although the study does not benefit you directly, it does offer you the opportunity to contribute your experience and insights into the way user involvement in mental health services is making changes to how services are delivered. As such, I would like to thank you for taking the time to consider participating in this project.

Yours sincerely,

Liz Brosnan
087 7779551 liz.brosnan@ul.ie

If you have concerns about this study and wish to contact someone independent, you may contact The Chairman of the University of Limerick Research Ethics Committee
c/o Anne O’Dwyer
Graduate School
University of Limerick Tel: (061) 202672
Ms Liz Brosnan
FG 114
Department of Sociology
University Of Limerick
Castletroy
Limerick
Date

(Information Letter, including informed consent for meeting observation)

Dear

I am a postgraduate student at the University of Limerick undertaking a PhD in Sociology. My research topic is ‘User Involvement in Mental Health Services: The Impact of Policy Changes.’ This study will seek to develop an understanding of how different professionals conceptualise their approach to developing user involvement mechanisms and how service users in turn frame their involvement. By interviewing and observing those who have been active in pioneering these initiatives, your learning can contribute to the growing scholarship on this emergent theme in health services. In addition to conducting interviews with professionals and service user leaders who are active in user involvement forums in your mental health services, I wish to attend steering group meetings and other planning meetings concerned with the development of user involvement policies and practices.

If you volunteer to participate, you will be asked to agree to my presence at meetings. At these meetings I will make handwritten notes of the discussions, the interactions between group members, and decisions reached, in order to develop my understanding of the processes which develop and enhance the
implementation of user involvement initiatives in your service. I will type these notes and return them to you to confirm their accuracy in the days following the meeting. You may choose to withdraw your consent to my presence at the meetings at any time without giving a reason.

I cannot guarantee confidentiality because others in the meeting may reveal what has been said there in, but I can agree to remove the names of those involved from written reports.

If you have any questions regarding this research, or would like additional information to assist you in reaching a decision about participation, please don’t hesitate to contact me, (Liz Brosnan) at (087 7779551 or liz.brosnan@ul.ie ). You are also welcome to contact my supervisors, Dr. Orla McDonnell orla.mcdonnell@ul.ie or Dr Elizabeth McKay, elizabeth.mckay@brunel.ac.uk. We would be happy to answer any queries you may have.

I will contact you again in seven days to seek your decision. I ask you to review the attached ethical protocol which I offer as a statement of the considerations I have given to the ethical dimension of this research project. If you are happy to consent to be observed at meetings, I will ask you to sign the attached form, which details your rights as a participant. Your informed consent will be assumed to be continuous once you have given it and signed the consent form unless you indicate otherwise.

Although the study does not benefit you directly, it does offer you the opportunity to contribute your experience and insights into the way user involvement in mental health services is making changes to how services are delivered. As such, I would like to thank you for taking the time to consider participating in this project.

Yours sincerely,

______________________________
Liz Brosnan
087 7779551 liz.brosnan@ul.ie

If you have concerns about this study and wish to contact someone independent, you may contact The Chairman of the University of Limerick Research Ethics Committee c/o Anne O'Dwyer

Graduate School, University of Limerick, Tel: (061) 202672
Consent Section:

I, the undersigned, declare that I am willing to take part in research for the project entitled “User Involvement in Mental Health Services: The Impact of Policy Changes”.

- I declare that I have been fully briefed on the nature of this study and my role in it and have been given the opportunity to ask questions before agreeing to participate.
- The nature of my participation has been explained to me and I have full knowledge of how the information collected will be used.
- I am also aware that my participation in this study may be recorded (audio) and I agree to this. However, should I feel uncomfortable at any time I can request that the recording equipment be switched off. I am entitled to copies of all recordings made and am fully informed as to what will happen to these recordings once the study is completed.
- I fully understand that there is no obligation on me to participate in this study.
- I fully understand that I am free to withdraw my participation at any time without having to explain or give a reason.
- I am also entitled to full confidentiality in terms of my participation and personal details.

____________________________________________________________
Signature of participant                                               Date

If you have concerns about this study and wish to contact someone independent, you may contact The Chairman of the University of Limerick Research Ethics Committee
c/o Anne O’Dwyer
Graduate School University of Limerick Tel: (061) 202672
Appendix C

Ethical Protocol for Participants information
(Accompanying the information and consent form)

Ethical considerations in this project include ensuring that the:

- Research participants fully understand what is involved in participating in the research process and how the research material will be used;
- Research environment and process is supportive, safe and enjoyable; and promotes free participation by all;
- Research participants feel that they have been respected, their experiences heard, and the material that they have shared has been accurately recorded, interpreted and reported.
- Time will be made available after each interview to de-brief should anyone request such support. Information on local support services will also be available should information be required.
- The terms of the Data Protection Act (1998) will be complied with. This includes making sure data is anonymised in order to protect both the confidentiality and privacy of participants from both the public, and staff of Mental Health Services; and that data is securely held, in a locked cabinet and/or on password protected/encrypted files, and then destroyed after the legally required period of time (ten years) upon completion of the PhD process by the researcher;
- Participants clearly understand that participation in the project is voluntary and that they have the right to withdraw at any time;
- Material collected is used in a way that promotes the voice of people with experience contributing to, and staff involved, in user involvement initiatives.

In order to address these ethical considerations, the following protocols have been put in place.

1. Each research participant will be sent a Participant Information Sheet and Consent Form in advance of the interview.
2. A Consent Form will be signed by each research participant at the start of the interview.
3. Members of any group or professional team being observed by the researcher will be made aware of the presence of the researcher in advance, will be sent a Participant Information Sheet and Consent Form in advance of the meeting, and a Consent Form will be obtained before the meeting commences. Any participant will have an opportunity to refuse to allow observation of the meeting without prejudicing their position.

4. Research participants will be given opportunities throughout the research process to ask questions about the research project.

5. Contact information for the researcher will be provided to each participant.

6. After the initial contact with participants (recruitment and information regarding the research), communication with the participants will occur at different stages of the research process.

7. All data collected during interviews will be handled only by the researcher, or made available to the researcher’s Ph.D. supervisors at the University of Limerick in order to substantiate claims or aid interpretation. However this will be the anonymised version with all identifying information removed. A professional transcribing service may be employed to assist with transcribing non sensitive material.

8. All non-essential identifying markers will be removed from the data by the researcher. Participants will be asked to provide feedback on any markers in the transcript or draft report that could compromise their anonymity. These will be removed.

9. The data (hard and electronic copies) will be securely held by the researcher, in a locked filing cabinet in her study, to which no one else will have access. Electronic information will be data protected by password, and stored on a password protected external hard drive. Information will NOT be stored on a laptop.

10. The data will be securely stored for 10 years after completion of the PhD process and then destroyed by the researcher.

11. A transcript of the interviews will be made available by email for participants to read, comment on, amend and correct within a month of
the interview. For those who do not have access to the internet, and who specifically request such, a printed copy of the transcript will be posted to them.

12. A draft report of the findings based on these revised transcripts will be made available in a similar way to participants to read, comment on, amend and correct.

13. A copy of the completed thesis will be electronically provided upon completion should it be requested by any participant.

14. Any subsequent publication, in any form, which is based upon or uses the material provided by participants will also be made available to read, and comment on before going into the public domain.

15. There can be times when it is not possible to maintain complete confidentiality, if the researcher becomes aware of a potential risk to another, through that person expressing a desire to attempt suicide, or to harm another. They have a responsibility to bring that to the attention of an appropriate staff member. Therefore any promise of confidentiality made to research participants carries that single caveat.
Ms Liz Brosnan  
FG 114  
Department of Sociology  
University Of Limerick  
Castletroy  
Limerick  
24-08-10

Mr A  
Local Health Office Manager  
HSE PCCC Offices  
Dear Mr A

I am currently on unpaid leave from the Western Alliance for Mental Health to study for a PhD in Sociology. My topic area is User Involvement in Mental Health Services: The Impact of Policy Changes. This study will seek to develop an understanding of how different professionals conceptualise their approach to developing user involvement mechanisms and how service users in turn frame their involvement. By interviewing and observing those who have been active in pioneering these initiatives, the participants’ learning can contribute to the growing scholarship on this emergent theme in health services.

I am about to begin data collection and want to engage in a case study of the Mental Health Services in Co X. There are several instances of good practice in implementing policy recommendations in a *Vision for Change* (DoHC 2006) and *Guidelines for User Involvement* (HSE 2008) occurring in the X Mental Health Services. Initiatives like the long term partnership between the Irish Advocacy Network and the HSE, more recent developments such as the Consumer Panel, the support provided to the X Advocacy Network, plus the three years of the DCU Leadership project are worthy of study in order to make the learning from these projects replicable in other areas.
I wish to carry out interviews with HSE professionals working in various sectors of the Mental Health Services involved with these initiatives to explore the lessons they have learned, the enhancers and obstacles to user involvement. I will individually negotiate and obtain informed consent from everyone before commencing interviews. I attach a copy of the information letter and consent form for your information. Interviews will be conducted at a time and place of convenience to the staff members.

I also hope to negotiate permission from individuals attending team meetings concerned with these and similar initiatives, to attend as a non participant observer. These meetings would not be concerned with clinical care of individuals but are the service development planning meetings that Irish Advocacy Network advocates or members of the consumer panel would attend.

I will also seek to interview people who represent the service user voice at these meetings, and will contact these people through the Irish Advocacy Network advocates. As a member of the Board of Management of the Irish Advocacy Network, I have kept the A/CEO and Regional Co-ordinator, fully informed of my research plans and they are fully supportive of my study.

This study has been successfully submitted for full ethical review to the University of Limerick Research Ethics Committee and the HSE Research Ethics Committee (approval reference number FAHSS_REC225). I can supply these application forms or any additional details should you wish more information. I hope to commence fieldwork in September 2010 and will complete this stage by end of May 2011.

If you have any questions regarding this research, or would like additional information to assist you in reaching a decision about allowing me access to HSE employees, please don’t hesitate to contact me, (Liz Brosnan) at (087 7779551 or liz.brosnan@ul.ie ). You are also welcome to contact my supervisors, Dr. Orla McDonnell orla.mcdonnell@ul.ie or Dr Elizabeth McKay,
elizabeth.mckay@brunel.ac.uk. We would be happy to answer any queries you may have.

I look forward to hearing from you at your convenience, and will promptly seek to answer any queries you may have.

Yours Truly

Liz Brosnan

Cc
Mr B, General Manager, X Mental Health Services
Dr C, A/Clinical Director, X Mental Health Services
Mr D, Director of Nursing, X Mental Health Services
Ms E, A/CEO Irish Advocacy Network,
Ms F, Regional Co-ordinator, Irish Advocacy Network
Appendix E

University of Limerick

Ms Liz Brosnan
FG 114
Department of Sociology
University Of Limerick
Castletroy
Limerick
Date

Confidentiality agreement for completion by transcriber

This study (User Involvement in Mental Health Services: The Impact of Policy Changes.) is being undertaken by Liz Brosnan through the Department of Sociology for a PhD thesis. The study seeks to develop an understanding of how different professionals conceptualise their approach to developing user involvement mechanisms and how service users in turn frame their involvement. By interviewing and observing those who have been active in pioneering these initiatives, the participants’ learning can contribute to the growing scholarship on this emergent theme in health services.

Transcriber (name here)

I __________________________ the transcriber, agree to:

1. keep all research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., discs, tapes, transcripts) would anyone other than the researcher.

2. Keep all research information in any format (e.g., discs, tapes, transcripts) secure while it is in my possession.
3. Return all the research information in any format (e.g., discs, tapes, transcripts) to the researcher when I have completed the research tasks.

4. After consulting with the researcher, erase or destroy all research information in any form or format regarding this research project that is not returnable to the researcher (e.g., information stored on computer hard drive).

Transcriber __________________________
Researcher __________________________

If you have concerns about this study and wish to contact someone independent, you may contact

The Chairman of the University of Limerick Research Ethics Committee
c/o Anne O'Dwyer
Graduate School
University of Limerick
Limerick
Tel: (061) 202672
Appendix C: Service User Advisor Role Description

10th November 2010

Role Description

Service User Advisor to the Multi-disciplinary Team Stakeholders Group

The X Mental Health Multi-disciplinary Team is committed to partnership working and in having service users at the centre of decision making. This happens at the individual, operational and strategic level. The stake holder’s group has been formed to deal with issues at an operational level, advising on the development of the Multi-disciplinary Team services on an ongoing basis.

The stakeholders group comprises of staff members from the various professional disciplines, service user advisors, representatives from the Irish Advocacy Network (IAN) and relative/friend advisors.

The role of the service user advisor is to advise the group on operational issues as they arise taking a service user perspective. It is the service user’s unique perspective on how she/he has experienced the mental health services that is invaluable to this group. This is a voluntary role under the joint supervision of the Multi-disciplinary Team and the Irish Advocacy Network. To date the post holder has been able to claim some out-of-pocket expenses. This is facilitated by the X Consumer panel.

Time Commitment:

Service user advisor is requested to commit to a 2 year involvement

Meetings: The Stakeholders Group meets on the second Wednesday of each month @ 9.30 in the Multi-disciplinary Team HQ. The meeting lasts for approximately one hour, followed by a tea break.

Other time commitments to be discussed with HSE mentor. These may include ....

Preparation: Reading minutes, preparing responses, communication, research
Mentoring: HSE mentor and IAN mentor
Training: Dependent on opportunities as they arise, ability to fund these and your time
Commitments

Role Supports:

Minutes/Agenda: These will be sent out at least one week before the next meeting

Resource Room: There is a resource room available in the Multi-disciplinary HQ for preparation and research at agreed times

Telephone: A telephone is available as required Telephone number as per the Multi-disciplinary HQ

Messages to be left with the Multi-disciplinary secretary

To be contacted on private phone only by the HSE mentor and the IAN mentor at agreed times.

Internet/Computer: Available for use.

Petrol/attendance Will be available for attending the Stakeholders meeting

Code of Conduct:

The service user advisor is expected to comply with the IAN code of conduct. Any difficulties for the advisor or within the stakeholders group will be dealt with in conjunction with the mentors.

Professional Team Members responsibilities:

HSE mentor – Name removed for Anonymity

Induction into the role

Be mindful of time constraints for the advisor

Clarity expectations for each request made of the advisor

Consumer panel
Pay out-of-pocket expenses as agreed by the HSE mentor and the X Consumer Panel treasurer

**Selection Process**

Expressions of interest to IAN representatives or other service user representatives

Appoint small group with the majority being service user reps to select candidate

Preferably have undertaken training and/or are experienced in working in mental health voluntary organisations and/or have life experience in working in similar groups/organisations
IAN training – Empowerment/advocacy capacity building
DCU Cooperative Leadership Course