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Title	Inclusion paradoxes in mental health: critical reflections on knowledge, (in)justice and privilege
Authors	Sapouna, Lydia
Publication date	04/09/2022
Original Citation	Sapouna, L. 2022. Inclusion paradoxes in mental health: critical reflections on knowledge, (in)justice and privilege. PhD Thesis, University College Cork.
Type of publication	Doctoral thesis
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Download date	2026-11-14 15:11:55
Item downloaded from	https://hdl.handle.net/10468/14554



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Inclusion paradoxes in mental health: Critical reflections on knowledge, (in)justice and privilege

(Volume Two)

Thesis presented by

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for the degree of

Doctor of Philosophy

University College Cork

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September 2022

Volume 2-The body of work

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Explanatory note

Volume Two of this thesis includes the twelve contributions submitted for consideration (body of work), in a pre-copy-edited form. The contributions are presented in chronological order starting with the most recent. Where the contributions have been carried out in collaboration with others, a statement of my contribution to the work is included before the citation. I would like to thank the publishers for agreeing to facilitate their inclusion in the digital version of this thesis. In the interests of style consistency, the contributions have been converted to the same font and endnotes have been converted to footnotes. Referencing house styles, as they pertain to individual publishing houses, have been retained. The contributions are followed and two appendices with (a) letters of confirmation from my co-authors and (b) publishers' permissions for the reproduction of previously published material as part of this thesis.

Service-user narratives in social work education; Co-production or co-option?

Citation: Sapouna, L. (2020) Service-user narratives in social work education; Co-production or co-option? *Social Work Education*, 40 (4): 505-521.

This is an accepted/original manuscript of an article published by Taylor & Francis Group in Social Work Education on 20 February 2020, available online: https://www.tandfonline.com/doi/full/10.1080/02615479.2020.1730316

Abstract

As a social work lecturer I have, over the years, developed strong links with service-user/survivor groups in an effort to contribute to a more context-focused and democratic approach to mental health education and practice. User narratives of psychiatric survival have been central in organising resistance toward dominant constructions of 'mental illness'. Within education, user narratives have created spaces for co-production with a transformative potential, as traditionally silenced voices can be heard and affirmed. However, recent debates suggest that such narratives are often used by mental health and educational systems to promote their own agendas. In this context, user narratives are no longer considered a transformative act of co-production or resistance. They are a commodity servicing primarily the interests of these systems. This paper adds to these debates through a self-reflexive discussion on my experience of including user/survivor narratives in Irish social work education, as user narratives remain insufficiently critiqued in this context. I consider the significance of power operations in the contexts where narratives are shared and heard and argue for the need to honour what has been achieved while problematising what may be lost through the inclusion of service-user narratives in social work education.

KEYWORDS: Mental health; service-users; narratives; co-production; co-option

Introduction

In this paper, I critically examine the practice of including service-user narratives in Irish social work education. I do this through a process of self-reflection, drawing on autoethnographic principles. Service-user involvement (SUI) is a relatively new development in Ireland, particularly in education, where user narratives remain largely unproblematised. This paper has emerged out of my own struggle to honour the contribution of the personal narrative while being increasingly concerned about its appropriation by mental health and educational institutions, including my own practice.

Including narratives of people with lived experience in professional education is a result of a broader policy commitment to SUI in mental health care (Department of Health and Children, 2006). In recent years in Ireland, in line with international trends, people with lived experience have been invited to participate, and share their testimonies, in policy and educational contexts, including in social work education. There is no formal requirement for SUI in professional social work programmes (Loughran & Broderick, 2017) and the revised Code of Practice guidelines of the Irish social work registration board makes no explicit reference to SUI (CORU, 2019a). However, the current accreditation process for social work programmes requires evidence of SUI in curriculum design, teaching or assessments (CORU, 2019b). To this day, SUI in professional education remains rather limited and ad-hoc in Ireland, with most social work programmes having guest service-users addressing students at some stage during their training.

The value of SUI in professional education is widely recognised within the literature as contributing to good practice, while also challenging and transforming dominant biomedical ways of knowing and practicing (Beresford, 2011; Tanner et al., 2015). Significant concerns have also been expressed about SUI being an exercise of tokenism, maintaining power imbalances between service-users and professionals within mental health and education systems, and co-opting and neutralising the service-user voice in these systems (Brosnan, 2013; Warren & Boxall, 2009). Two recent special editions of this journal (Vol 35, 2016 and Vol 36, 2017) make a significant contribution to the debate, by describing and evaluating a range of

creative examples of SUI in education and by theorising the development and use of service-user knowledge (Duffy, McKeever, McLaughlin, & Sadd, 2017).

A critical discussion on the inclusion of service-user narratives in the Irish context of education, policy and practice is rather limited. This is perhaps because SUI is still seen as the 'new good thing' in Ireland, something to be unconditionally endorsed rather than critiqued. There are a few important contributions, including Speed's (2002) research identifying a consumerist model of Irish mental health social movement organsations, Lakeman's et al. (2007) discussion on the 'celebrity status' some service users have attained through sharing their narratives of distress, and Brosnan's research (2013), highlighting the low level of control available to service-users in the processes they become involved in. Overall however, the inclusion of service-user narratives in Irish policy panels, co-production projects and professional education programmes is still considered inherently good. I am not proposing to treat the inclusion of user narratives as 'something that went wrong'. I am nevertheless suggesting that, while we keep honouring personal narratives, we stay alert to the nuanced relationship between these narratives and the power operations in the context where they are shared and heard.

In this paper I problematise what has been achieved, and highlight what may be lost, through the inclusion of service-user narratives in Irish social work education. Using an auto-ethnographic approach, I critically reflect on my experience of collaborating with service-users/survivors as part of developing a more democratic approach to mental health education and practice at University College Cork (UCC), Ireland. Autoethnography is a self-reflexive approach to research and, in the context of this paper, to writing that builds on the analysis of the personal experience to understand broader cultural and political contexts (Ellis, Adams, & Bochner, 2011). In the context of professional practice, auto-ethnography is an unsettling process as it involves opening out a professional's life, and remaking power relations in the process (Denshire, 2013). I found that such a self-reflexive enquiry opens up possibilities to use constructively my, often uneasy, relationship with social work and rethink issues I am passionate about (in this case SUI) beyond existing critiques of external systems. It enables me to value the complexity of meaningfully including service user narratives in education. Such methodologies are increasingly used to

critically consider mental health practice particularly in the fields of nursing (Bull, Gadsby, & Williams, 2018) and occupational therapy (Kinsella, 2006) but are rather limited in the area of social work.

In this paper I share observations from classroom and conference settings, and consider student feedback received over the years. I use my experience to ask wider questions about the transformative power of user narratives and about their co-option by mental health and educational institutions. My own unwitting contribution to such co-option is also considered. I explore the significance of the context in which service-user narratives are shared, and consider how the current use of such narratives in professional education may contribute to:

- a new individual pathology approach, focusing on individual responsibility to recover whilst excluding a consideration of contextual factors
- privileging certain types of knowledge through narratives that are considered inspirational' and/or 'insightful', at the expense of other (e.g. incoherent and verwhelming) expressions of distress
- overlooking the diversity of narratives constituting people's experience
- a co-production process encouraging compliance with, rather than transformation of, mental health systems.

I conclude with some thoughts on how to sustain the transformative value of narratives, while being cognisant of the challenges of doing so in professional education provided within an increasingly managerial, market-oriented university environment.

The transformative power of user narratives

Within, and outside, the psychiatric survivor movement there is a long tradition of personal and political narratives contesting the dehumanising process of psychiatric diagnosis and challenging the dominant constructions of 'mental illness' and pathology (Chamberlain, 1978; Church, 1995; Costa et al., 2012). These narratives promote a social justice agenda by addressing issues of discrimination, inequalities and human rights violations of people using mental health services. In that sense,

user narratives can be (and have been) an act of resistance through disrupting dominant practices and validating previously silenced voices (Crossley, 2006; Morrisson, 2005).

The value of user-narratives in social work education is well documented in literature, highlighting the contribution of SUI to both the micro-level of practice skills, and the macro-level of transforming current practice and culture. In relation to practice skills, personal testimonies and narratives can facilitate students develop a deeper insight into the experience of distress, of being at the receiving end of services (Fox, 2016; Tanner et al., 2015; Tew, Holley, & Caplen, 2012), of feeling trapped and not listened to (Hughes,2017). In contrast to traditional didactic approaches, these testimonies may engage 'the heart as well as the head' (Basset, 1999, p. 8), promote a dialogue (Sen, McLelland & Jowett, 2016) and therefore affect students' ability to be more empathetic. User narratives, and SUI generally in education, have been found to facilitate students' communication,partnership and advocacy skills (Beresford & Croft, 2004; Duffy, 2008), to reduce stigmatising attitudes (Cabiati & Raineri, 2016), and to enable students and practitioners to be more conscious of and reflective on the implications of their practice (Higgins et al., 2011).

There are also broader political implications of validating user-generated knowledge in education. Service-user narratives can be an act of resisting professional orthodoxies and power, through challenging a focus on individual pathology (Beresford & Croft, 2004; Harper, 2002). Valuing user-generated knowledge forces us to rethink traditional assumptions about credibility and legitimacy of knowledge-formation, and to develop a humility to learn from experts by experience (Videmšek, 2017). This can, in itself, be a significant challenge to academic traditions and the current marketised culture in higher education (Rooney, Unwin, & Osborne, 2016). Ultimately, service-user narratives can make a significant contribution to a social justice agenda, asserting the right to be mad, through recognising that there are many ways to 'be' and 'understand' (Costa et al., 2012).

Furthermore, for those sharing their narratives the process can be healing, therapeutic, an act of resistance (Chamberlin, 1978; Church, 1995; Cresswell, 2005). Having one's story listened to authentically can lead to raised self-esteem (Hitchin, 2016), empowerment and new insights, increased self-development and confidence

to manage their own care (Matka, River, Littlechild, & Powell, 2010; Rooney et al., 2016). Narrative-sharing can also facilitate transcending the victim role, interestingly articulated by Sadd (2011) as 'we are more than our story', and can contribute to new forms of solidarity and connection.

Narratives as transformative co-production?

I am particularly interested in the potential of service-user narratives to affirm new ways of knowing in education, thereby contributing to transformative co-production (Needham & Carr, 2009). Co-production has become a way of talking about service-user participation in mental health services (Gillard, Simons, Turner, Lucock, & Edwards, 2012; Needham & Carr, 2009). Acknowledging the value of experiential knowledge, co-production is now considered one of the four key principles in the most recent Irish Framework for Recovery (Health Service Executive, 2018; Health Service Executive, 2017). Co-production relies on a seemingly 'simple definition—people who use services collaborate in the production of services' (Needham & Carr, 2009, p. 4) and is generally presented as a 'valuable element of quality and service improvement' (Health Service Executive, 2018, p. 7). However, the concept of co-production is also known for its 'excessive elasticity, evident in the various ways in which it has been defined and interpreted' (Needham & Carr, 2009, p. 4). Not surprisingly, co-production has been described as a paradoxical space (Poursanidou, 2016; Spandler, 2009), with a potential to both reinforce and transform existing practices and systems (Beresford, 2002; Voronka, 2016). Needham and Carr (2009) provide a helpful distinction between three levels of co-production:

(a) At the lowest level, the people who use services may experience co-production imply as a *description* of how services rely on some productive input from users. At its simplest, this user-input may be just compliance with legal or social norms such as people *complying* with treatment plans and medication.

(b) At the intermediate level, co-production can be a tool for increased *recognition* and involvement of service-users, who are *invited* (often on an ad hoc unpaid basis) to make a greater contribution toward service improvement.

(c) At its most effective, co-production can be *transformative*, requiring a relocation of power and control, through the development of new user-led mechanisms of planning, delivery, management and governance.

It is important to be aware of these levels when claims are made about co-production in professional education. I argue that the contribution of user-narratives in education can only be meaningful in the context of pursuing the third level of transformative coproduction as described by Needham and Carr. In that sense, transformative user narratives have the power to become a 'gap-mending strategy' between expert and experiential knowledge (Askheim, Beresford, & Heule, 2017) as well as to disrupt dominant narratives of professional knowledge and expertise (Voronka, 2016). This requires professionals to shift from a tradition of paternalistic attitudes of helping or being the expert, to working in meaningful alliances. To do that, power inequalities in traditional systems, such as professional education, need to be acknowledged, rather that disguised under the rhetoric of 'equal partnerships'. This will involve seeing SUI 'not as a way of legitimising our commitment to inclusion but seeing service users/carers as coproducers and partners in the educational experience' (Hatton, 2017, p. 155). Transformative co-production is ultimately about awareness raising, resource mobilisation and social action, all of which are key aspects of critical pedagogy (Freire, 1972). As part of this pedagogy, the sharing of user narratives can create conditions for transformation at both personal and political levels. In the next section, I share some observations from my experience about the transformative impact of these narratives in social work education.

Observations from social work education

I started teaching mental health modules on professional social work programmes in the mid-nineties, bringing a strong commitment to critical education and to the politics of democratising psychiatry. My approach was strongly influenced by witnessing the exposure of the horrific conditions of Leros psychiatric hospital in Greece[1] in the middle eighties, during the time I did my social work training in Athens.

[1] For an overview see http://news.bbc.co.uk/2/hi/europe/8124976.stm.

In my experience, the sense of shame and discomfort many of us (students & professionals) felt during that time, has set the foundations to frame mental health care in political and human rights' terms.

Drawing from constructivist understandings of critical pedagogy, I consider that a critical approach to education facilitates students' development as critical citizens, capable of theorising and acting, to meaningfully engaging and changing the world with others (Giroux, 2011). Informed by Freire's (1972) ideas on critical pedagogy, I also approach social work education as a process that creates conditions of humanisation, of both students as learners/practitioners, and of the people they will be engaging with in practice. Adopting a critical approach to mental health education means that my teaching is primarily focused on contextual understandings of human distress rather than individual pathology. This requires a recognition of how social inequality and oppressive agency practices can contribute to the experience of distress. An understanding of the operations of power, politics, values, ethics and history in relation to mental health is central in this process.

I soon realised that education for such critical practice is a challenging task, as professional education is expected to prepare students for practice within dominant biomedical, and often, de-humanising systems. For example, students are expected to have knowledge about 'disorders' prior to starting some mental health placements, and lacking this knowledge has been identified as a weakness in the curriculum by some social work practitioners and students. I therefore recognised that I need to challenge dominant forms of knowledge in ways that help students understand and respond to distress beyond diagnostic labels. Realising that a part of the problem was seeking resources inwards (i.e. within existing systems), I started developing more systematic links with service-users/survivors, activist and advocacy groups in the early 2000s. This created exciting new possibilities for SUI in education through contributions in teaching, workshops, conference co-organisation, student selection and course accreditation (Sapouna, 2016). Sharing people's narratives of encounters with the mental health system into classroom and conference settings was a starting point in this process.

In line with the literature on the power of narratives discussed earlier, the shared user narratives were educational, informing students about the experience of

distress and the practices that are helpful in supporting people through distress. Student feedback suggests that listening to first-hand experiences is more influential than traditional teaching in understanding service-users' experiences, needs and preferences. Over the years, I have observed students becoming less preoccupied with diagnostics and clinical symptoms. Instead, they are developing a position of curiosity about the life-contexts of people who use mental health services, and about 'what happened' in their lives. I have observed students focusing more on recovery as articulated by service-users, therefore recognising that recovery is not about the eradication of symptoms, but about a sense of choice, power and agency over one's life. Social work is located in the interface between people and their social environment and recovery narratives provide opportunities to explore further what constitutes a recovery-conducive environment. While not all narratives take an explicitly political stance, they provide opportunities for a different kind of interaction for critical reflection, what Freire (1972) describes as conscientisation. User narratives help many students to become aware of the impact of coercive practices and to identify the pursuit of social justice as a core element of practice. Social work students are particularly appreciative of the opportunities to listen to survivor narratives through an annual critical perspectives conference which is part of the mental health module[2]. Having such an event fully integrated in the mental health curriculum provides students with opportunities to be in a space where different forms of knowledge- formation, learning and exchange take place.

There have also been critical comments over the years. A number of students have said that service-user narratives tend to portray services and professionals in a negative light, which can be discouraging for those who are about the enter the world of practice (see Anghel & Ramon, 2009). This position tends to be often framed as the need for 'balanced' narratives (e.g. acknowledging the strengths of the medical model, including positive service experiences), a request that has been also expressed by some social work practitioners involved in student education. The problem with this view of 'balance' however, is that it does not question whether

2 The annual critical perspectives conference is organised by the School of Applied Social Studies and the School of Nursing and Midwifery, University College Cork in association with the Critical Voices Network Ireland.

dominant practice is balanced. Furthermore, it assumes a binary between 'medical and social models', between 'good and bad experiences of services' (often described as 'two sides of the story'), rather than recognising the diversity of narratives. Reflecting on my enthusiasm about context-informed education and my passionate critique of medicalisation, I recognise that I may have inadvertently contributed to such binaries. Critical education is not about promoting model-based ways of looking at human difficulties, as such an approach fails to capture the complexity of human distress. From this perspective, social work education may be better framed as a balancing, rather than a balanced act (Newnes, Holmes, & Dunn, 1999). User narratives could be key to this 'balancing act', affirming new ways of knowing about distress and potentially contributing to a shift in power imbalances.

These new ways of knowing go beyond traditional teaching approaches to consider the expression of emotion, in particular the expression of anger. Over time, a number of students have said that they struggled with the expression of emotion and anger toward mental health services, while others recognise that such emotions should be respected as real parts of the lives of people they will be working with. Working with these tensions, recognising the relationship between the emotional content of the issues debated and the capacity of dialogue to achieve change is an important educational experience (Barnes, 2008; Freire, 1972). Critical education can provide an opportunity to understand that anger is a legitimate response to injustice and that silencing this anger is a political tactic of power (Lyman, 2004). Moreover, critical education can challenge dominant rules of engagement in mental health systems where expression of anger is seen as irrationality, or 'bad manners' (Church, 1996).

Reflecting on the power of narratives, I acknowledge that positioning myself at the interface of academia and the survivor movement has been, and still is, a personally challenging task. Being an academic who aims to be an ally of critically-minded survivors, often requires me take a step back and be less visible, while co-creating a space for user/survivor voices to be heard, an act of disappearance that Church (2013) describes as a political act. I am learning to step back and enjoy the privilege of transformative and disruptive co-production in social work education.

Concerns about the use of narratives

Despite their potentially transformative power, I have become increasingly concerned about the inclusion of user narratives in education. These concerns range from observations at a local classroom level, to structural inequalities at an institutional level, to the co-option of inclusion strategies by neoliberal policies. Even in the early days of my enthusiasm about SUI in education, I was uncomfortable with some students' fascination with a 'brave' individual's story at the expense of an interest in systemic change. Over the years, I have always been uncomfortable, by the unequal status of the, usually unpaid, 'invited speaker', which provides no real recognition or power to those sharing their experiences within educational institutions. And gradually I, along with many others, am becoming increasingly unsettled by witnessing something as powerful and transformative as user narratives becoming appropriated and co-opted by mainstream institutions including education (Costa et al., 2012; O' Donnell, Sapouna, & Brosnan, 2019; Pascal &Sagan, 2016; Woods, Hart, & Spandler, 2019).

Co-option, in general terms, can be described as a 'process by which a dominant group attempts to absorb or neutralise a weaker opposition that it believes poses a threat to its continued power' (Penney & Prescott, 2016, p. 35). Concerns about the co-option and appropriation of the service-user movement in mental health systems and the reduction of SUI to tokenism, have been voiced by many critical allies and activists (Beresford,2002; Brosnan, 2013; Pilgrim, 2005). Such concerns have primarily been analysed as being part of a neoliberal agenda, appropriating radical ideas (Hall, 2011) and reframing them in the market terms of consumerism and individual responsibility to recover, while at the same justifying the shrinking of the welfare state (Friedli & Stearn, 2015; Harper & Speed, 2012). It has been argued that, as part of this neoliberal agenda, personal narratives have been harnessed by mental health organisations to further their own interests, and in doing so have shifted these narratives from 'agents of change' to a commodity (Costa et al., 2012; O' Donnell et al., 2019; Voronka, 2016). As a result of these trends, many commentators argue that the conditions under which people's narratives are told and heard continue to perpetuate the marginalisation of madness (Costa et al., 2012;

Pascal & Sagan, 2016), leading to further inequalities and exclusion (Beresford & Boxall, 2012; Warren & Boxall, 2009).

The majority of these critiques are set in the context of the UK and Canadian mental health systems with a debate problematising the politics of user involvement, including narratives, in Ireland being rather limited to date. I am not proposing that the inclusion of user narratives is 'something that went wrong', nor am I arguing that some narratives (for example those critical of mental health systems) are more valuable than others. Rather I am suggesting that, while we keep valuing personal narratives, we stay alert to the complex relationship between these narratives and the power contexts where they are shared and heard. This argument is explored in the following sections by further discussing what may be lost through the current use of narratives in education and by critically examining my own, unwitting, contribution to such losses.

Risk of individualising mental health difficulties

Over the years, service-user narratives through classroom, video and conference presentations have exposed students to some powerful testimonies. However, this presents its own challenges as the focus on and the curiosity about the personal story can endanger a culture of voyeurism (McFarlane, 2001) which in turn justifies the 'otherness' madness (Costa et al., 2012). I have already identified my unease with the apparent student fascination with details of individual narratives along with the description of people sharing their experiences as 'brave' and 'inspiring'. Paradoxically, a focus on individual strength and resilience seems to complement rather than challenge individual-pathology approaches to distress.

Person-centeredness is often heralded as the counter-narrative to medicalisation, however, as Pascal and Sagan (2016) argue, we need to take a critical and reflexive standpoint and consider what happens though the inclusion and use of person-centred narratives and, in particular, what may be lost in this pursuit of 'voice'. They explain how the current policy emphasis on 'voice' apprehends the discourse of activism colluding 'in this shift toward individualism, albeit under the guise of participation, collaboration and co-production' (p. 3). This is not an argument against inclusion, it is rather a call to problematise how 'inclusion unfolds for

survivors when suddenly invited to work for systems that have long been sites of systemic discrimination' (Voronka, 2016, p. 1).

The argument needs to be explored in the context of recovery, now broadly acknowledged as the dominant approach to Western mental health systems, with narrative work becoming 'an established technology in "recovery-oriented" mental health services' (Smith-Merry, Freeman, & Sturdy, 2011, p. 4). The sharing of individual journeys of recovery, including narratives of strength, hope and resilience have been a central feature of service-user contributions to professional education. A common thread running through these narratives is a sense of individual responsibility (often following a script from tragedy to triumph) and self-governance, recognising the importance of positive beliefs, values and behaviors (Harper & Speed, 2012). Once again, the argument is not about denying the value of the individual narrative, but considering what may be lost through an, often exclusively, individual focus. A focus on individual journeys and a fascination with details of individual lives, often excludes a consideration of the 'social, political, cultural and economic context in which people become mentally distressed and recover' (Morrow, 2013, p. 325); Narratives can then inadvertently isolate the person from the context of their lives.

I do not aim to polarise between 'good structural' vs. 'bad individual' narratives in social work education. Through such binaries the complexity of the human experience gets lost. Within education we need to support students to engage with the complexity and diversity of distress, while being cognisant of agency, culture and structural contexts (Sapouna, 2016). I remain uncertain about the extent to which we (students, narrators and I) have fully engaged with such complexities through the sharing of narratives. This is not because of the limitations of the actual narratives, but because of the context in which they were shared. Therefore, we need to question whether the conditions in which narratives are shared and heard provide an opportunity to value the complexity and, ultimately, the messiness of life.

What knowledge do we privilege?

As said earlier, service-user narratives have often been described by students as inspiring and insightful. I agree that can be. I have been inspired by these narratives and have consequently decided to include them in the curriculum as they articulate,

much better than I can, experiences of distress and psychiatric care. But here lies the very problem. I hold the power to invite people whose narratives I consider to be passionate, inspiring and insightful, narratives that articulate a critique of medicalisation, narratives that help students see the links between life experiences and madness (e.g. narratives of childhood adversity, trauma and psychosis). And I recognise that, even in my attempts at critical education, I may be inadvertently perpetuating patterns of knowledge exclusion by privileging certain narratives over others. The relationship between the narrator and the audience is important here. If the audience decides on the value of narratives, this value is no longer embedded in the power of the story, rather, it lies in the perception of the audience. As a result, the 'Recovery Narrative can, like other narratives, also silence and exclude, by privileging and valuing certain kinds of reasoning and knowledge' (Fitzpatrick, 2016, p. 266).

I have become increasingly aware of what may be lost through a focus on, what Woods et al. (2019) describe as, a 'genre of inspiration and insight' (p. 11). Do I only include articulate narrators in education? What about people who struggle to share their stories? What about the incoherent and overwhelming stories? What about people who refuse to share their stories, don't they have a story to share? What about those who identify as 'unrecovered' and in need of long-term support? Do we privilege certain types of narrative generated knowledge over others? Being involved in critical education does not render my teaching immune from such acts of privileging. As said earlier, I have privileged well articulated stories of trauma and distress and critiques of medicalisation. Recognising this inadvertent act of privileging I create opportunities to regularly discuss these matters with students, particularly after listening to moving, well-articulated testimonies of trauma and psychosis. Not all people have words for their experiences, not all stories make sense neatly. We therefore need to create spaces to listen, validate and explore diverse forms of expression, including narratives that are chaotic, incoherent, angry in a way that is not easily justified (e.g. because of trauma). This can be a long and challenging process. In a service culture of evidence-based practice, fast quantifiable outcomes and performance indicators, teaching the value of 'being with' confusion and uncertainty is not easy. Furthermore, it is important not to always assume the

existence, or denial, of experiences of a particular type of trauma and abuse. As professionals we can facilitate conversations about meanings, but we are not the makers of the meaning (Sapouna, 2016, 2019).

Reflecting on my motivations to include certain user narratives in social work education, made me see more clearly that critical education and humanising curricula are not limited to challenging visible operations of power and oppression. In a context where radical rhetoric is co-opted by neoliberal ideologies, it is important to make invisible operations of power visible. The power to silence certain expressions of distress was not only exercised during the old days of institutional psychiatry. Contemporary, recovery-oriented mental health and education systems, can implicitly discourage expressions of distress that are not helpful to their aims. This, in turn, may be contributing to the 'othering' of individuals who seem chaotic and overwhelmed, those who remain unrecovered, those who are not thriving, coping, smiling (Ehrenreich, 2010; Pascal & Sagan, 2016).

Authenticity and representation

One of my initial aims of SUI in education was to provide an authentic representation of the service-user experience. However, this singular model of representation can be rather naïve and problematic. How can an individual narrative represent a collective experience? Rose (2016) observes that service users are often deemed 'unrepresentative' of those that they are brought in to represent. Voronka (2016a) refers to this as an 'authenticity paradox', suggesting that service users can either be 'too professional' and therefore not effectively representing abjection, or 'too abject' and thus incomprehensible to respectability. An appreciation and an understanding of representation politics helps us to be aware of how we hear service-user narratives within education, possibly moving to what Fox (2016) describes as a collective model of representation.

There is, of course, no homogeneity in the lived experience of distress, and it would be simplistic for it to be represented as such. While user narratives contribute to articulating the diversity of the lived experience, there is a concern about what may be lost when an individual narrative becomes the only narrative, wonderfully articulated by Chimamanda Ngozi Adichie's TED talk The danger of the single story

(Adichie, 2009). Adichi explains how the single story creates stereotypes, highlighting that 'the problem with stereotypes is not that they are untrue, but that they are incomplete, they make the one story become the only story'. And here, it seems, is another paradox: narratives that are meant to counteract the stereotyping of people through a single story (e.g. psychiatric diagnosis) may create different stereotypes viewing people through the limitations of a single identity (e.g. trauma-survivor, inspiring, brave).

There is a diversity of narratives embedded in people's experiences. Stories change, one person's experience of distress and mental health care doesn't always produce the same narrative. In my experience of including service-user narratives in education, I have heard the same person presenting their experience in different ways at different times. I have also heard diverse narratives, some focusing on individual journeys, others focusing on experiences of treatment and human rights, and others doing both. There have been unpredictable narratives, some of which made me, as the educator, and the students uncomfortable, as these were not the narratives we expected to be delivered. I remember one particular incident, in my early days of SUI, when I invited somebody I had previously heard speaking very eloquently about the impact of involuntary admissions and about difficulties experienced with everyday tasks after long-term hospitalisation. I thought this would be a 'perfect' session on forced treatment and institutionalisation. However, what was presented in class was a very different narrative drawing on the individual's religious convictions and negative views about divorce. This was not what we expected, the session made me uncomfortable and many students were left feeling confused and angry. Such situations, however, provide opportunities to deal with unsettling questions, for example dealing with people whose value systems are challenging our own and people with whom we struggle to empathise or engage with. These experiences can help us to explore in more depth our nuanced relationships with distress. Shying away from these nuances, and from what makes us 'uncomfortable', may ultimately lead to further exclusion, because we still don't know how to be with the 'other'.

Co-production: in whose interest?

Reflecting on the previous concerns, I will now reconsider whether service-user narratives in education are contributing to the third level of transformative co-production, as outlined by Needham and Carr (2009), in other words a process of relocating power and control in the production of knowledge. For many years I thought that the key barrier for SUI in education was power inequalities, evidenced in the tokenistic status of the invited speaker, the lack of proper conditions of participation and payment in educational structures. These conditions remain problematic, however, in this discussion I have identified power inequalities beyond the status of the invited speaker. I have argued that the structures within which the narratives are shared, heard and valued can lead to subtler forms of power inequalities and otherness. Within such conditions of inequality, the power remains within mental health and education systems, with myself as an academic, as well as with the audience of these systems, to decide on the value of the narrative, on the basis of its 'genre of inspiration and insight' (Woods et al., 2019), or on the basis of articulating criticality in a way that supports my approach to teaching.

Problematising user narratives is not an easy undertaking, as it may be perceived as discrediting and disrespecting such narratives. Reading Costa's et al. (2012) paper R*ecovering Our Stories* provided me with a framework to problematise, while still honouring, the use of narratives. This paper was based on a community event (Toronto, June 2011) organised 'in response to the appropriation and overreliance on the psychiatric patient "personal story"' (p. 85). The event judged this type of narratives to be not just problematic, but 'pornographic'. The provocative terms 'disability tourism' and 'patient porn' were used to show how 'while some people reveal their most intimate personal details, others achieve relief through passive watching, while still others profit from the collaboration of those on the front lines in compromised positions' (p. 86). Costa at al. recognise that the term 'porn' can be experienced as offensive, however, it is used to consider how service-user narratives can become commodified.

To date I have not experienced user narratives as 'patient porn', but I have seen how mental health organisations and professionals (possibly myself included)

may use narratives to promote their own agenda rather than change their culture. For example, over the past five years, in line with international trends, SUI has become more mainstream in Ireland with the development of recovery colleges, peer-support posts in statutory services, and the establishment of the Mental Health Engagement and Recovery Office[3]. Coproduction is now a key feature of the Irish mental health recovery framework (Health Service Executive, 2017.) In this context, service-user narratives are beginning to occupy a more central space in mental health matters, particularly those focused on recovery, resilience, self-care, reaching-out and seeking help early. Most mental health events and conferences now include the 'user perspective', however the narrative sought tends to be affirming rather than challenging the aims of the organising institution. As Brosnan's research on SUI in Ireland demonstrated, 'The satisfied service-user is welcome, they after all provide reassurance that "we can't be doing everything wrong"' (O' Donnell et al., 2019, p. 4). These narratives are not disrupting the dominant narrative, they are simply complementing it. This type of co- production encourages what Needham and Carr (2009) describe as compliance (lowest level), rather than any real transformation.

As user narratives are now heralded as a method of co-production in Irish mental health and educational systems we need to keep asking: Whose interests are served? Needham and Carr's (2009) framework provides a helpful guide to consider how we use narratives in these systems. Do we just describe what we already do as co-production (lowest level)? Is the use of narratives about recognition (intermediate level) and, if yes, who is recognised? The narrator, or the practitioner or academic who are 'the good guys' by including the 'grateful' narrator? What about redistribution of power (transformative level)? Within Irish mental health systems, co-production is primarily framed in an instrumental manner as a model of service delivery and management rather than an approach challenging power structures and transforming services. Within such an instrumental approach the potential for democratising and humanising mental health thinking and practice may be lost. With narratives becoming increasingly mainstreamed in mental health systems, it is

3 An office established within the Irish statutory health system, with the task of developing structures, systems and mechanisms for service user, family member and carer engagement.

important that social work does not appropriate them but recognises critical voices as essential components of transforming and humanising education and practice.

Conclusion

Using an auto-ethnographic approach to writing this paper, helped me connect my own practice with wider concerns about the inclusion of user narratives within dominant structures and ideologies. While writing this paper, I have become very aware that a critical discussion of user narratives can be perceived as undermining achievements that have been fought for a long time: inclusion, user involvement, co-production, affirmation of the lived-experience. However, my motivation throughout this paper has been to honour user narratives, and uphold the value of their original contribution, which is to challenge and disrupt dominant, simplistic and unhelpful understandings of and responses to human distress.

Within social work education, user narratives are providing opportunities to model a pedagogy of collaboration, dialogue-based learning, recognising the complexity, diversity and context of distress. However, over time, I have also identified reasons to remain unsettled about a voyeuristic approach to narratives, reinforcing the otherness of madness; the co-option of narratives and their potential reduction to yet another tickbox in the management of mental health and educational institutions; the responsibilisation of the individual, perpetuating an individual pathology approach; the popularity of stories of recovery and resilience, as long as they do not challenge power imbalances; the continuous inequalities experienced by people who share their experiences, as they remain disadvantaged, often unpaid partners in such institutions.

At the same time, I remain optimistic by not losing sight of the potential of user narratives to contribute to a transformative co-production process. This means that the narrator is not a passive recipient of an invitation to represent the user experience and a recognition for sharing this experience. It means that the narrator is actively claiming power (Brosnan, 2013) in the contexts where their story is shared. As Woods et al. (2019) argue, the political effects of narratives are 'only as benign as the context in which they are materialised will allow' (p. 17). Therefore, an awareness

of power relations in the context where narratives are shared, heard and valued is key to transformation.

In that sense, an informal context outside mainstream institutions may be a better space for narratives to be shared and honoured (Woods et al., 2019). Does that render professional education an impossible space? I would argue that it is not inevitable, as long as the links between the micro-level of practice skills and the macro-level of political action are recognised. Over the years, I have been trying to make these links by challenging the 'single narrative'; by exploring ways of being with complexity, ambiguity and confusion; by recognising silenced, chaotic stories, and by challenging systemic injustice. These are little acts of resistance, affirming different ways of learning, and somehow disrupting dominant ways of knowing, by complicating the way that knowledge is produced (Voronka, 2016a).

I have also created, with others, alternative spaces for criticality beyond the classroom setting. An annual critical mental health conference has become an integral part of the social work curriculum in UCC, providing another context where narratives are shared. The space is very different from the classroom. The students interact with narrators in diverse ways, as conference delegates in workshops and presentations, at the registration desk, in corridors, over coffee. In such a context, students engage with a diversity of individual and collective narratives. These experiences have often been evaluated by students as the best part of the mental health module. This learning reflects what the critical group Recovery in the Bin argue for: *We need a broader range of Survivor narratives to be recognised, honoured, respected and promoted that include an understanding of the difficulties and struggles that people face every day when unable to 'recover', not just 'successful recovery' type stories* (Recovery in the Bin, n.d.).

Finally, as educators, we need to be remain alert to the dangers of co-option and keep problematising what has been achieved and what has been lost through practices of inclusion. We need to stay engaged with the question: in whose interest?

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Social work education as a critical space

Citation: Sapouna L. (2019) Social work education as a critical space. In H. Gijbels, L. Sapouna, & G. Sidley (eds.), *Inside out, outside in: Transforming mental health practices.* Ross-on-Wye: PCCS Books, 17-39. (Reproduced with permission from PCCS Books).

This chapter draws from my experience in mental health social work education. It is based on an earlier paper (Sapouna, 2016) discussing my contribution to innovative approaches in teaching for critical practice and the challenges in this process. Having become increasingly conscious of the need to challenge and problematise what is heralded as innovation and inclusion in mental health education and practice, I am now revisiting the 2016 paper to reconsider the way I teach, in the pursuit of critical education. Some material of the original paper will be used to provide context to the discussion.

I started teaching mental health on professional social work programmes at University College Cork (UCC) in the mid-1990s. While, over the years, my thinking and approaches to education have changed considerably, some of the challenges I experience are ongoing and persistent. A key challenge is managing the tension between my commitment to social justice and the expectation to prepare students for practice in a predominantly biomedical context that is often experienced as coercive. At several points throughout these years, I found myself becoming frustrated with the apparent incompatibility between critical thinking and the 'reality' of practice, possibly feeding into the view that critical thinking is only suitable for the 'ivory tower' of academia but not for 'real life'. Indeed, I found my teaching becoming stagnant at times, as I was lacking resources to provide education for meaningful alternatives to the dominant way of thinking and practising in mental health (Sapouna, 2016).

Realising that a part of the problem was seeking resources inwards (ie.within existing systems), rather than outwards, in the early 2000s I started developing more systematic links with service users/survivors and activist and advocacy groups. I also

started collaborating with other professionals who had identified the need for a more user-focused and democratic mental health practice. Through such links a pool of diverse resources was created, including enhanced input of service users in mental health education; conference coorganisation; co-authored publications; dissemination of user-led research, and service-user involvement in student selection and professional course accreditation processes. Such alliances also created possibilities to develop critical spaces inside and outside the university to consider mental health practice. An annual Critical Perspectives Conference, now fully integrated in the UCC social work mental health curriculum, and the emergence of the Critical Voices Network Ireland (Sapouna & Gijbels, 2016) are two examples of creating such critical spaces within and beyond professional education. I acknowledge that a lot of work remains to be done to develop meaningful partnerships with service users in the Irish social work education system. At the same time, I remain alert to and alarmed by the dangers of institutionalising service-user involvement. Nevertheless, these 'outside the box' alliances and the emerging critical forums have created opportunities for transformation, as I have had to rethink my ways of knowing and teaching.

I begin this discussion by briefly setting the context of mental health social work in Ireland and making an argument for the contribution of social work education in transforming dominant biomedical practice. I argue that such a transformation should involve rethinking issues of knowledge formation, power operation, language, narrative and identity, all of which are components of critical practice (Fook, 2002). Based on my 2016 paper, I will go on to discuss selective aspects of course curriculum and teaching approaches that can contribute to this process. These include:

- rethinking knowledge formation – reconsidering the 'social'
- rethinking narrative, language and identity – engaging with voice-hearing, reconsidering trauma
- rethinking power – engaging with critical spaces – the Critical Voices Network Ireland.

I will also discuss student feedback and student experiences from mental health placements to highlight the challenges of upholding social work values in hegemonic

practice contexts. These approaches are not presented triumphantly as innovative antidotes to medicalisation in their own right. Taking a step further from the 2016 paper, I will problematise these aspects, questioning the appropriation of practices of innovation and inclusion in mental health systems. For the purpose of this chapter I focus on three examples of what I previously considered to be innovation in mental health education: recovery approaches, trauma-informed practice and user narratives. This problematisation involves asking questions such as: Whose interests do these practices serve? Do they provide a meaningful shift away from an individual pathology approach? Do they contribute to changing power imbalances in mental health systems, or do they ultimately serve dominant ideologies and practices? This is a rather unsettling consideration as I am confronted with my own contribution and role in such appropriation. Nevertheless, asking such questions recognises the nuances and messiness of changing mental health systems from the 'inside'.

Articulating the 'social' in mental health social work – why is it needed?

In recent times we have seen possibilities for change in the field of mental health in Ireland through the adoption of community-based care, a recovery orientation and a commitment to user involvement in their care. However, despite the rhetoric of a bio-psycho-social approach, policy implementation has been slow and inconsistent across the country (Mental Health Commission, 2013; Mental Health Reform, 2015) and the main responses to people in distress remain medical/pharmacological in nature. Social work is located at the interface between the person and their social environment and is therefore ideally placed to engage with the context of people's lives – a long-neglected element in biomedical mental health services. While there are several examples of social workers in Ireland engaging with a social recovery approach to practice (Kelly & Donnelly, 2018), social work remains under-represented in mental health services, with several multidisciplinary teams still operating without a full-time social work post. Within a predominantly medical framework of thinking and practising, mental health social workers often consider themselves powerless to articulate a valid 'social' approach and question coercive practices (Brosnan & Sapouna, 2015; Manchester, 2015; Allen, 2014). As a result,

students on mental health placements do not often have the opportunity to witness a confident expression of a context-informed practice.

Within interdisciplinary contexts, there is still a tendency to view the primary role of social work as responding to practical concerns in people's lives, such as welfare benefits, housing and employment. While this focus is not an insignificant or 'lesser' role for social workers, such a role does not in itself lead to a broader understanding of emotional distress. Students need to embrace an approach to practice that views emotional distress as a meaningful response to problems of living, trauma, injustice and adverse life experiences, rather than a chemical imbalance or individual pathology. This is an approach in which context, relationships and meanings are put at the centre of our interventions (Bracken & Thomas, 2005). This is also an approach that addresses issues of oppression and injustice often experienced by people using mental health services. Such an approach involves a radical rethink of knowledge, power, language and identity. Social work education has a significant contribution to make in this process.

Social work education as a critical space – what is it?

Social workers have distinctive skills in working alongside people and supporting them to overcome barriers to achieving their potential by adopting a community perspective, as well as an individual one. However, their potential to fully embrace this role can be seriously impeded by the identity social work has developed over the past two decades in Ireland. Social work as a profession seems to be increasingly defined by procedural and managerial guidelines for practice (McGregor & Quin, 2015) and is focused on individualised work and risk management rather than supporting people experiencing adversity (Cuskelly, 2013; Featherstone et al, 2018). Furthermore, in times of intensive neoliberalisation, social workers' commitment to social justice risks being continuously eroded (Conneely & Garrett, 2015; Garrett, 2018). In this context, there is a danger that the role of social work education can be reduced to preparing students for procedurally correct practice, with a primary focus on managing individual difficulties, while a consideration of broader contextual factors is often viewed as 'too abstract' to be useful in practice. In the area of mental health, such a trend is often witnessed in the argument of some social work students

and practitioners that education focusing on critical or social perspectives does not adequately prepare students for practice in the current mental health system. Such education, it is argued, doesn't teach them 'how to do the job'. In increasingly corporate-minded university environments, critical education can become an endangered species.

I am not arguing for a 'broad social' education instead of a 'narrow medical' one. Such a binary is unhelpful and can feed into another type of battle for superiority. Social workers need to move beyond binaries and engage with the complexity and diversity of human experience while being cognisant of agency, culture and structural contexts. This can be facilitated by the creation of a critical space in social work education to rethink about (Fook, 2002):

- knowledge about experiences of human distress – this involves questioning dominant hegemonies in mental health knowledge formation and recognising that user/survivor knowledge is vital in exploring the context and the meaning of human distress
- operations of power – this involves understanding powerlessness and injustice as precursors of distress and the importance of empowerment, choice and dignity as cornerstones of a user-defined recovery process
- language and narrative – this involves a shift away from the language of symptoms and individual pathology towards locating people's narratives and meanings in the centre of social work practice
- identity – this involves a move away from the identity of the 'patient' to an understanding of the multiple and diverse aspects of people's lives. It also involves a validation of the emerging identities of user/survivors as equal partners in mental health practice.

A critical approach to education promotes knowledge formation beyond the domains of formal knowledge and self-reflection, towards critical action in the domain of the world (Barnett, 1997). Ultimately, a critical approach to mental health education can be transformative, as it seeks to change the way we understand and respond to

human distress. To operationalise such a transformation, social work students require a value base that is informed by the principles of social justice, anti-oppressive practice and genuine partnerships that recognise the expertise of people with experiences of distress (Brosnan & Sapouna, 2015). Social work students also require a knowledge base that gives them confidence to advocate for a context-informed social approach. Social approaches are often considered to lack a coherent body of theory backed up by research in comparison with the medical perspective (Tew, 2011). Social work students need to be informed of the research evidence demonstrating the strong links between life adversity, injustice and emotional distress.

Social work education as a critical space – what does it involve?

A mental health module is delivered separately to the undergraduate (BSW) and postgraduate (MSW) social work programmes in UCC. The curriculum encourages students to engage with critical questions in mental health and to understand the experience of distress beyond diagnostic categories. Community development approaches, anti-oppressive practice and person-centred, strength-focused and solidarity-based responses to distress are explored as the foundations of good practice. Service-user/survivor knowledge, issues of professional power, human rights, citizenship and working in genuine alliances with service users are central in this course. Teaching methodologies include experiential and interactive approaches to explore different ways of engaging with distress and unusual experiences such as voice-hearing. The curriculum incorporates practice examples of democratic, recovery-focused approaches such as Open Dialogue and the Sli Eile social farm (see Chapters 5 and 9). The annual Critical Perspectives Conference at UCC, discussed later in this chapter, is an integral part of the module.

Rethinking knowledge formation: reconsidering the 'social'

The mental health curriculum includes a significant body of research challenging beliefs that madness can be explained without reference to the context of people's lives. This research problematises the excessive preoccupation with individual pathology, chemical imbalances and genetic predispositions as causes of human

misery, including experiences that are labelled 'schizophrenia' (Rapley, Moncrieff & Dillon, 2011; Read & Dillon, 2013; Johnstone et al, 2018; Watson, 2019). Furthermore, the role of the pharmaceutical industry in promoting a narrow pharmacological approach to treating human distress has increasingly been called into question (Angell, 2005; Moncrieff, 2008, 2013; Whitaker, 2010).

Mental health education considers how life events and broader environments affect the likelihood of experiencing distress at some stage in our lives. Research confirms the relationship between inequality and poorer mental health, with particularly strong correlations between the incidence of distress and disadvantage, including unemployment, homelessness, lack of education and growing up in socially disadvantaged areas (Read, Johnstone & Taitimu, 2013; Rogers & Pilgrim, 2014). Furthermore, a considerable body of research has correlated membership of social groups that are subject to systematic experiences of oppression or disadvantage with higher rates of mental health difficulties (Thomas, 2014; Fernando, 2003, 2011). A 2009 World Health Organization (WHO) report concluded:

> ... levels of mental distress among communities need to be understood less in terms of individual pathology and more as a response to relative deprivation and social injustice, which erode the emotional, spiritual and intellectual resources essential to psychological wellbeing.
> (WHO, 2009: iii)

International research indicates that the experience of injustice and inequality may be more damaging to mental health than absolute levels of deprivation (WHO, 2009; Read, Johnstone & Taitimu, 2013). An influential contribution to this argument comes from the work of Wilkinson and Pickett (2009), which identifies the profound effects of living in unequal societies. Their research summarises multiple studies demonstrating that poverty leads to exclusion from community life and from a sense of belonging and being valued, all of which result in people suffering 'social pain'. This argument concurs with other evidence suggesting that inequality and injustice feed into a sense of 'otherness', worthlessness and shame (Janssen et al, 2004).

The challenge for education is to enable students to use this knowledge with confidence. Such knowledge should help practitioners develop context-focused

assessments and interventions, rather than resorting to the dominant language of 'diagnosis' and 'treatment'. For example, rather than considering maternal mental health in clinical and risk assessment terms, we propose to look at women's life experiences, including experiences of inequality, powerlessness and abuse. On that basis, we define the primary social work role as family support and advocacy, rather than surveillance. Ultimately, it is about adopting a social justice approach to practice that can facilitate the consideration of explicit experiences of discrimination and injustice, such as sexism, racism, homophobia, ageism, and also more subtle experiences of being made to feel powerless, inadequate, inferior and left out. Within educational settings, it is important to acknowledge the evidence from both national and international research on distress within ethnic minorities, migrant populations (Fernando, 2011; Priebe Giacco & El-Nagib, 2016) and lesbian, gay, bisexual and transgender groups (Higgins et al, 2011, 2016).This research can provide a useful framework for student social workers to consider the experiences of people from marginalised and/or disadvantaged groups on the basis of the personal story of the individual in the social context of their lives. Such a framework can help students think beyond individual pathologies towards community development and social action approaches with groups that have been traditionally excluded. It can also help students think about recovery-conducive environments in socio-political, rather than merely individualised terms.

Problematising recovery and the 'social'

At this point I would like to share some observations about recovery-informed teaching, as it has been a complex and nuanced learning curve for me. When the concept of recovery was first introduced in the Irish mental health strategy *A Vision for Change* (Department of Health and Children, 2006), I embraced it with considerable optimism and introduced it to students as a hopeful alternative to medicalisation. Recovery was (originally) a user-led concept, a move away from a pre-occupation with symptoms. It was about people taking control of their own lives, countering the pervasive, pessimistic references to 'severe and enduring mental illness' in traditional psychiatry. Recovery contested definitions of mental health and, because of that, was initially met with significant resistance from the mental health

establishment. However, in less than a decade, most mainstream Irish mental health services now claim to be 'recovery oriented'. A sign of progress? Unfortunately not, as there is little evidence to suggest a significant shift from a focus on individual pathology. Furthermore, as Liz Brosnan's study on user involvement in Ireland found, recovery has been appropriated and assimilated into institutionalised practice: 'What they're actually talking about is the medical model redressed' (Brosnan, 2013: 221).

While I still teach about recovery, my teaching has become more critical of its application and its political implications. For example, we examine how recovery is increasingly becoming a neoliberal rationale to justify service cutbacks, as people who 'recover' have no need for support services (Wallcraft, 2014; Friedli & Stearn, 2015). We also examine how the current implementation of recovery remains focused on individuals' responsibility to change (Harper & Speed, 2012). Paradoxically, a focus on being autonomous, having a job and living in a decent house can overlook the structural conditions that impact on welfare, employment and housing. A key influence on my thinking is the service-user/survivor group Recovery in the Bin (RITB)4, formed in 2014 in response to what was increasingly being regarded as the ideological colonisation of the recovery model. RITB argues for the right to un-recover, as its members are:

> ... fed up with the way… 'recovery' is being used to discipline and control those who are trying to find a place in the world, to live as they wish, trying to deal with the very real mental distress they encounter on a daily basis. (RITB, undated)

This critique is captured in RITB's 'unrecovery star' (Figure 1)5, which was developed as a response to the recovery star (Figure 2)6 used in traditional mental health services to plan and record service users' goals for 'recovery' and progress towards them. Comparing the two stars and critiquing recovery – a concept that is still

4 recoveryinthebin.org (accessed 6 August 2019).

5 https://recoveryinthebin.org/unrecovery-star-2/ (accessed 26 August 2019).

6 Reproduced with permission from Triangle Consulting Social Enterprise Ltd. www.outcomesstar.org.uk (accessed 26 August 2019).

heralded as innovative – can initially be confusing and unsettling for students. However, it is an opportunity to reclaim key social work knowledge, skills and values, such as social justice and anti-oppressive practice, in addressing the elements of the unrecovery star.

Figure 1: Unrecovery Star ((cc) RecoveryintheBin, 2017)

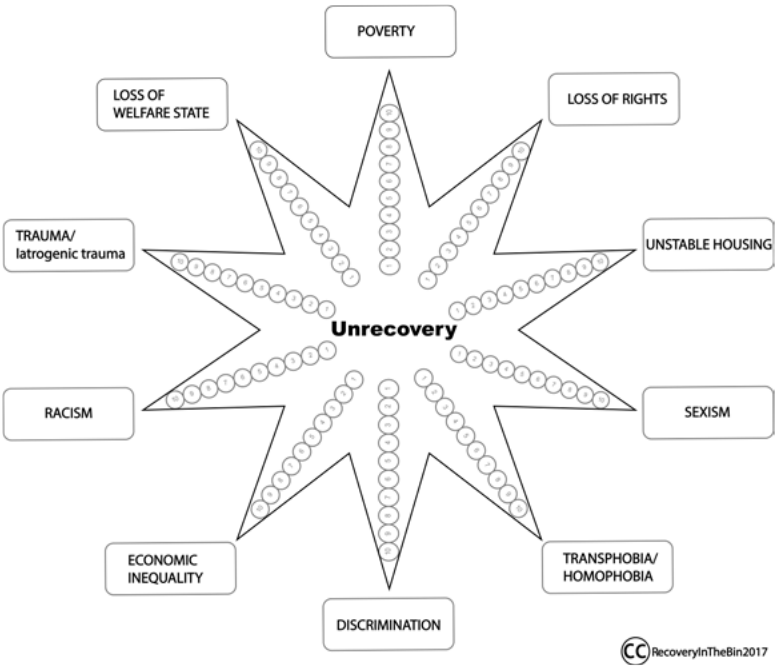
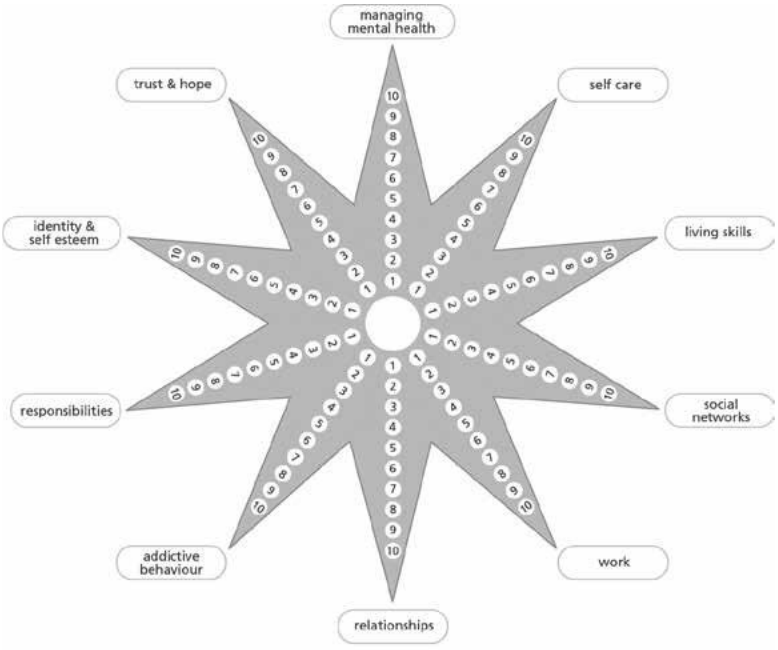


Figure 2: Recovery Star (© Triangle Consulting Social Enterprise Ltd)



Recovery Star™ © Triangle Consulting Social Enterprise ltd and Mental Health Providers Forum
Authors: Sara Burns and Joy MacKeith
www.outcomesstar.org.uk

A critical look at recovery also offers an opportunity to reconsider what is presented as innovation and what can happen when movements become models. It can encourage students to think beyond the comfort of models and technical frameworks. Indeed, while I advocate for a social approach (as a broader knowledge base), I am becoming increasingly aware of the dangers associated with considering the social perspective as *the* solution to medicalisation. In that sense, I reiterate that a binary between a 'coercive'medical model and a 'progressive' social model is unhelpful. While social workers focus on people's life contexts, they are not experts in people's lives. Furthermore, a social approach is not in itself a meaningful alternative to biomedical hegemony. As Szasz warns:

> Nonmedical mental health and counselling professions are medicalisation cubed: as if to compensate for their lack of medical knowledge and qualifications, nonmedical mental-health 'professionals' are even more deeply committed than psychiatrists to their claim of special expertise in the diagnosis and treatment of mental illness. (Szasz, 2008: 31)

On a similar note, Manchester (2015: 150) argues that social perspectives have been assimilated into the prevailing bio-psycho-social paradigm and 'remain an adjunct to the view that people with mental health problems inevitably have some kind of pathological flaw that needs fixing, whether biological or psychological or both'. Rather than being preoccupied with the credibility of the social work role and perspective, it may be more helpful to take a grassroots approach in which survivors' language and narratives are the centre of education and practice.

Rethinking narrative, language and identity: engaging with voice-hearing

In order to actively listen to service users' meanings and stories, it is important to engage with forms of expression and language that may be unconventional and perhaps unfamiliar to mental health professionals (Tew, 2002). In preparation for student engagement with such forms of expression, the curriculum draws from the work of the Hearing Voices Network7 (HVN) and includes methodologies of working with people who hear voices and/or have other unusual sensory experiences. A key premise of this approach is that voice-hearing experiences are not viewed as pathological symptoms but rather as emotional responses to traumatic life events. The HVN, founded more than 30 years ago, is now an international movement and an influential example of people getting together as peers to share experiences and understandings of voice-hearing. Originating in the work of Dutch social psychiatrist Marius Romme and researcher Sandra Escher (Romme & Escher, 2000, 2005), the HVN challenges traditional biomedical practice and presents a new territory for mental health social workers who have been conventionally taught not to engage with 'auditory hallucinations', in the belief that such engagement may intensify psychotic symptoms. This radical shift from the pathologising language of *auditory hallucinations* to the ordinary language of *hearing voices* can be a mechanism to transform thinking and practice in mental health care.

Recent research shows HVN groups to be an important resource for helping people who have been primarily defined through their diagnosis to reclaim new identities through exploring their experiences and developing their own frameworks

7 www.hearing-voices.org (accessed 6 August 2019).

for coping and recovery (Longden, Read & Dillon, 2017). Awareness of and involvement in HVN groups also have benefits for professional practice. As Longden and colleagues suggest (2017: 188), such collaboration 'may help professionals gain knowledge and confidence for supporting voice hearers as well as enhance and inform their practice with the survivor-led and social psychiatric philosophies'.

Discussing the contribution HVN approaches can make to mental health social work, Sapey and Bullimore (2013: 624) suggest that social workers need to:

- develop a different understanding of voices to the traditional view of biomedical
- psychiatry that they are hallucinations indicating an underlying illness
- develop positive attitudes to voice hearers, respecting their expertise and experiences as valid
- understand the role of childhood trauma, particularly abuse and neglect, in hearing voices
- develop therapeutic skills so as to work with voice hearers and with voices.

Helping social work students to understand the relationship between individual history and psychotic symptoms is of crucial importance. Perhaps the most influential body of evidence that has emerged over the past two decades in relation to life events and psychiatric diagnoses is the research linking childhood adversity and psychosis. Psychosis has been traditionally treated as a biochemical problem. During the past 15 years, however, there has been an avalanche of ground-breaking international studies showing that adverse life events, trauma, loss and neglect in childhood increase vulnerability to emotional distress (for example, Varese et al, 2012; Read & Bentall, 2012; Janssen et al, 2004). Yet, these research developments are only significant if mental health professionals act on them by asking people 'What happened?' in their lives and responding respectfully to the stories they hear. Hammersley and colleagues argue that:

> The current approach which asks people 'what is wrong with you?' rather than 'what has happened to you?' misses the crucial point that all distress and behaviour, however seemingly bizarre, is a meaningful

> attempt to survive maddening experiences in what for some of us can be a crazy world. (2008: 19)

Social workers, as a profession carrying out psychosocial assessments, need to find a language to ask questions that haven't been asked before about people's lives, including questions about abuse, bullying, neglect and loss (Read, 2013). Through such questions, professionals can facilitate people to make connections 'between elements of experience that had previously seemed confusing or contradictory' (Tew, 2002: 146) and take control of their own recovery.

Problematising trauma-informed practice

Nevertheless, making these connections is not in itself a remedy to medicalisation. Focusing only on the individual story of 'what happened' can be another form of pathologising. Friedli (2018) warns that, by only focusing on the individual story, we may lose sight of the broader context – the question of 'why it happened', which leads to a deeper engagement with the context of people's lives. In a culture where being trauma informed has become the new 'big thing' for mental health professionals, we need to be aware of the critiques of trauma-informed practice. Approaching distress through a trauma framework seems like a 'feel-good' alternative to medicalisation. However, it can also perpetuate a disease model by focusing exclusively on adverse individual experiences at the expense of acknowledging adverse community environments (Ellis & Dietz, 2017). Indeed, looking at the widely used Adverse Childhood Experiences (ACE) questionnaire (Felitti et al, 1998), it is striking to note what is not included (eg. experiences of racism are not considered ACEs).

ACEs have helped to bring the language of trauma and adversity into mental health education and practice, but in a rather narrow way that, not unlike psychiatry, may fail to recognise what is not visible or measurable. Not all experiences of trauma are neatly articulated or easily identified as valid sources of distress. We need to be careful not to create a hierarchy of trauma where some types of trauma lead to justifiable distress and others don't (Hunter, 2018). This is a point I regularly discuss with students after listening to moving, well-articulated testimonies of trauma and

psychosis. Not all people have words for their experiences; not all stories make sense. We therefore need to create spaces to listen, validate and explore diverse forms of expression, and this can be a long and messy process. In a service culture of evidence-based practice, quantifiable, rapid outcomes and performance indicators, teaching students about 'being with' confusion and uncertainty is not easy. Furthermore, it is important not to always assume the existence or denial of experiences of a particular type of trauma and abuse. As professionals, we can facilitate conversations about meanings, but we are not the makers of the meaning.

Nevertheless, I found that teaching about trauma and psychosis has helped students to contextualise human distress by seeing it as a meaningful human experience. Learning about voice-hearing is not presented as the only or best way to work with people experiencing psychosis. It is rather used as an example of challenging traditions of biological psychiatry in which the voice of the service user is primarily used to diagnose disorders. This learning has helped students to develop knowledge, skills and values in working with diverse experiences and expressions and listen to people in their own terms and language in all areas of practice. In Ireland alone, since 2012, more than 20 hearing-voices support groups have been set up, both within and outside mental health services, and some student social workers have had the opportunity to engage with these groups during their placements. Although they are a relatively recent arrival in the Irish context, international experience has demonstrated that hearing-voices groups are effective communal solutions that enable people to make profound, positive changes in their lives (Dillon et al, 2013).

Social workers should be active participants in seeking such communal solutions. This can be achieved by forming alliances with other voices of resistance, with forward-thinking stakeholders within and outside mental health systems, to facilitate the development of critical spaces for rethinking the way we understand and respond to distress. The following section discusses the development of the annual Critical Perspectives Conferences in UCC and the Critical Voices Network Ireland (CVNI) as examples of such spaces which are also an integral part of social work education.

Rethinking power, developing critical spaces

Over the past number of years, critical perspectives have emerged to raise concerns about the state of mental health systems in Ireland and to question dominant thinking and practice. Over many years, Ireland's Mental Health Commission has raised in its annual reports and inspections concerns about coercive practices, lack of treatment choices, abuse of professional power, over-reliance on and excessive use of medication, discrimination and stigmatisation, inhumane physical conditions in hospital units and lack of meaningful community-based alternatives to hospitalisation (see also Mental Health Reform, 2019). Questions have also been raised about the interests served by the adoption of so-called strategies of inclusion in mental health systems, such as 'user involvement', 'peer support' and 'co-production' (Brosnan, 2012; Costa et al, 2012; Voronka, 2016). These questions and concerns have been articulated in various ways by a diverse range of 'actors', including people who describe themselves as service users, survivors, patients, members of the mad community, carers, family members, professionals, academics, and members of the public, all of whom are dissatisfied with current forms of care and its underpinning bio-medical philosophy (Sapouna & Gijbels, 2016).

In an attempt to provide a broader platform to discuss and debate concerns and share new initiatives and approaches, since 2009 an annual Critical Perspectives Conference has been organised by the Schools of Applied Social Studies and Nursing and Midwifery at UCC. Now in its 11th year, the conference, with an annual attendance of more than 500 delegates over two days, is considered one of the most significant events of its kind nationally and internationally, attracting speakers and delegates from across the continents. The Critical Perspectives Conferences are unique, as they bring together people from diverse backgrounds (self-experience, survivors, professionals, academics and carers) to present, discuss and debate critical perspectives in mental health.

The Critical Voices Network Ireland8 (CVNI) emerged out of these deliberations in 2010 as a coalition of service users, carers, professionals, academics, national campaigning and advocacy groups, all looking for a mental health system

8 www.cvni.ie (accessed 6 August 2019).

not based on the traditional bio-medical model. This network provides a democratic space with no hierarchical structures that is open to everybody who wishes to join its discussions. An e-list and a Facebook page[9] have been established for people to begin to share, debate and discuss issues of concern and different ways of working. An important aspect of these developments is the beginning of a dialogue between stakeholders who have been separated in the past. Through the CVNI, a space has been created where different and sometimes conflicting voices and agendas can be heard and respected rather than silenced. Professionals, students and people with self-experience exchange views freely as part of this forum. This is not always an easy exchange. Challenging mental health practice can be unsettling as it may require positions of certainty to be reviewed and possibly relinquished. But the transformative potential of this space can also encourage participants to recognise that there are many truths, to shift from a position of certainty and to strive to understand the 'other'. Through these exchanges there is an opportunity to share stories, make sense of experiences and reconstruct meanings, particularly previously silenced meanings (Sapouna, 2012). The following section, informed by student evaluations and feedback, considers the student experience of engaging with critical mental health education.

The educational impact of critical spaces – does it help?

The feedback of social work students who have attended the Critical Perspectives Conferences has been overwhelmingly positive, with many saying that they are 'the best part of the mental health module'. Having such an event fully integrated in the educational curriculum provides students with opportunities to be in a space where different forms of knowledge formation, learning and exchange take place.

Students appreciate the opportunity to listen to survivor, carer and professional perspectives and the diverse approaches and languages used in the deliberations. They also enjoy being part of an environment that has been described by participants as egalitarian and democratic, with a positive 'buzz' in the

9 www.facebook.com/groups/Irishnetworkofcriticalvoicesinmentalhealth?_rdr=p (accessed 6 August 2019).

atmosphere and lively discussions in university corridors and over coffee. As one student put it: 'I was sitting next to someone and didn't know whether they were a professional or a service user; it didn't matter and this was so refreshing.' Students also appreciate being in a space where survivor narratives are considered a valid way of learning about good practice.

On the other hand, critical comments suggest that, at times, services and professionals are portrayed in a negative way and this can be discouraging for students who are about to enter the world of practice. Over the years a few delegates, including students, have said that they found the expression of emotion and anger towards mental health services uneasy and unsettling. Others, however, recognise that such emotions should be respected as real parts of the lives of people they will be working with. Recognising the relationship between the emotional content of the issues debated and the capacity of dialogue within these spaces to achieve change is an important educational experience (Barnes, 2008). This process provides opportunities for capacity-building through learning how to deal with complex issues of practice and not avoid issues of injustice and oppression because they are emotionally charged. It is also an opportunity to be part of a process that models a shift in power and control as a way of transforming practice.

Feedback on classroom-based learning follows similar trends, while presenting some additional challenges. Overall, social work students tend to give positive feedback to the broader social perspective and the user-focused values embraced in the classroom, with many students describing the mental health module as 'thought-provoking', an 'eye-opener' and as generating an interest in area of practice they have not considered before. However, some students also question the extent to which this module prepares them for practice because it does not cover enough 'mental health conditions' or provide enough information on the 'medical model'. For example, in the past six years when we have included more material on voice-hearing, some students have argued that there is too much emphasis on psychosis at the expense of other experiences, such as 'depression' and 'anxiety', which are considered to be more common in social work caseloads. Other critical comments suggest that the module does not provide a 'balanced' input on the

medical and social approaches and, as a result, students may not be equipped to work in a predominantly biomedical practice setting.

The experience of UCC social work students who have undertaken a mental health placement[10] has not yet been systematically researched. In verbal feedback, many students report that they benefited from the value-base they developed through the mental health module, which allowed them to take an advocacy/human rights approach to practice. Other students argue that they struggled with what they describe as 'a requirement to speak the medical language' and the need to know more about diagnoses in order to have a voice in the multidisciplinary team. Most student experiences of placements suggest that discussions about service delivery are dominated by biomedical frameworks, a trend evidenced in the clinical responsibility and leadership of the multidisciplinary team remaining with the consultant psychiatrist; criteria for intervention being based on clinical diagnosis; hegemonic views on mental 'illness' and subsequent 'cures' within the various disciplines, and the use of medical terminology in contemporaneous case notes/discussions, case conferences, team meetings and ward rounds (Clifford, 2014).

Some social work students who have completed mental health placements report that their education is not perceived as 'balanced' by their practice teachers, some of whom view it as disproportionately favouring a 'social model' and occasionally describe it as 'anti-psychiatry'. The problem with this view of 'balance' is that it assumes a binary between 'social and medical models', often described as 'two sides of the story', rather recognising that there are many stories. As argued earlier, advocating the superiority of a social model over a medical one fails to recognise that a model-based way of looking at human difficulties fails to capture the complexity and messiness of human distress (Bracken, 2007). In that sense, social work education may be better framed as a *balancing,* rather than a *balanced,* act

[10] Social work students in UCC undertake two 14-week placements during their studies in various statutory and community settings (eg. child protection, hospitals, disability, probation, mental health services, community family support). Not all students will have a mental health placement as part of their social work studies.

(Newnes, Holmes & Dunn, 1999; Read & Dillon, 2013); it aims to provide a *balancing* view to the hegemonic expert models that dominate professional education and practice.

Problematising user narratives in education

The participation of service users/survivors in social work education is a key element of this balancing act in that it validates new ways of knowing about experiences of distress and, therefore, contributes to a shift in power imbalances. Over the years, survivor accounts through classroom, conference and video presentations have exposed students to some powerful stories. Students listened enthusiastically to these narratives; they appreciated the diversity of the experiences shared, and they saw the person beyond the symptom. These stories were an antidote to medicalisation. However, I soon became uncomfortable with some students' fascination with a 'brave individual's' story at the expense of an interest in structural change (O'Donnell, Sapouna & Brosnan, 2019). There is indeed a danger that a focus on and curiosity about the personal testimony can promote a culture of voyeurism (McFarlane, 2001, 2006) – a trend that Costa and colleagues (2012) describe as 'disability porn'. In an article on user narratives, Anne O'Donnell (community educator), Liz Brosnan (survivor researcher) and I have reflected on the commodifying of survivor stories, with mental health organisations and educational institutions using them primarily to promote their own agendas (O'Donnell, Sapouna & Brosnan, 2019). We discuss our disillusionment that something as powerful and transformative as telling stories can become neutralised and co-opted (see also Costa et al, 2012). We express our discomfort and rage with the unequal status of the service user as 'invited speaker', which gives no real recognition or power to those who share their stories within education. We also remain hopeful about the potential of stories to challenge mental health practices by 'seeking out more diverse individual and collective stories and listening carefully to those stories which challenge us to move beyond complacency' (O'Donnell, Sapouna & Brosnan, 2019).

User involvement is more than a narrative; it is a value for a more democratic way of working and, therefore, the issue of power needs to be addressed. As argued by Cowden and Singh (2007: 15-16), without addressing the issue of power, 'the voice

of the user becomes a fetish – something which can be held up as a representative of authenticity and truth, but which at the same time has no real influence over decision making'. With user involvement becoming increasingly mainstreamed in professional service provision and education, it is important that social work education does not appropriate the user movement but recognises critical voices as essential contributors to the education process.

Reflection

Working at the interface of academia and survivor movements is a personally challenging task. As an academic who works collaboratively with critically minded survivors, I often have to take a step back while creating a platform for user/survivor voices to be heard – an act of disappearance that Church (2013) describes as political. While this discussion goes beyond the scope of this chapter, it is important to say that collaborating with survivors means that my work is not only complemented but also, at times, superseded by their dynamic, interesting and colourful insights. Over the years I am learning to become more comfortable with stepping back and enjoying the privilege of co-working, which has transformed my engagement with social work education. At the same time, I am becoming increasingly uncomfortable with the co-option of user involvement in educational institutions. Somehow these tensions help me to remain critically engaged with what I do!

Conclusion

This chapter has considered the contribution of social work education in transforming dominant biomedical practice in mental health care. Within current practice contexts, social workers often find themselves powerless to articulate an alternative to the medicalisation of human distress and to challenge practices of coercion. Social work education needs to support students to embrace a critical approach to practice that views emotional distress as a meaningful response to problems of living, trauma and adversity, rather than as individual pathology or chemical imbalance. This critical approach also addresses issues of injustice often experienced by mental health service users. In order to facilitate this process, education needs to become a critical space to:

- rethink issues of knowledge formation in mental health and recognise the importance of user/survivor knowledge in exploring the context and the meaning of human distress
- unlearn the language of symptoms and individual pathology – learn how to engage with people's unusual experiences and how to ask people 'what happened' rather that 'what's wrong' with them; learn how to ask 'why it happened', and therefore focus on wider life contexts and structures
- rethink issues of identity – move away from seeing people as 'patients' towards an understanding of the multiple and diverse aspects of their lives
- rethink issues and power – engage with critical spaces to consider different ways of responding to human distress and validate the emerging identities of users/survivors as equal partners in mental health practice
- stay engaged with and open to critiques of innovation and inclusion strategies, and keep asking the uncomfortable question, 'In whose interest is this?'

As this approach to education challenges current mental health ideologies and practice, it is at times criticised for not preparing students for the 'reality' of service provision. A further criticism of this approach is that it is 'not balanced', as it does not consider the medical model, often described as 'the other side of the story'. Moving beyond model-thinking, I propose that social work education may be better viewed as a *balancing* rather than a *balanced* act. This involves providing a balancing view to the hegemonic expert models that dominate professional education and practice.

A balancing act also implies that education is not an avenue for social workers to become the 'new experts' in the field of mental health. Rather, the voice of users/survivors becomes central to all practice. At the same time, such a balancing act requires us to constantly problematise the co-option and institutionalisation of innovation in mental health systems. By engaging in a paradigmatic shift and by forming meaningful partnerships with service users, survivors and people with self-experience, social work can reclaim its social identity and respond to human distress in a way that is user driven, respectful, context aware, and informed by human rights principles.

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Storytelling: An act of resistance or a commodity?

Co-authored contribution. Joined lead author with Anne O' Donnell (40% each), jointly formulating the structure of the paper, developing the structure for the discussion, identifying key concepts and developing the thematic analysis.

Citation: O' Donnell, A., Sapouna, L., Brosnan, L. (2019) Storytelling: An act of resistance or a commodity? *Journal of Ethics in Mental Health,* Special Theme Issue VI: Disordering Social Inclusion: Ethics, Critiques, Collaborations, Futurities. (Reproduced with permission from the Journal of Ethics in Mental Health).

Open Access available at:
https://jemh.ca/issues/v9/documents/JEMH%20Inclusion%20ix.pdf

Abstract

Telling our own stories of our experiences of distress and madness, of oppression and treatment, of survival and resistance, is a source of power for people who use or are forced to use mental health services. Storytelling has created a space for people, whose voices have been traditionally silenced, to be heard, affirmed, and to organise into collective action. However, recent trends suggest that these stories are becoming a commodity with mental health organisations and educational institutions using them primarily to promote their own agendas.

Many stories matter. Stories have been used to disempower and to humanise. Stories can break the dignity of a people, but stories can also repair that broken dignity. (Adichie, 2009)

We three women are activists (survivors, researchers, and educators) and, drawing from our experiences in the Scottish and Irish contexts, we discuss the need to constantly problematise what has been achieved through the user movement. We are frustrated because people who share their stories remain disadvantaged, often unpaid, unequal partners while organisations, professionals, and academics benefit through receiving funding and building a career path on the basis of user involvement. While this is an

unsettling position, we believe that we can make the best of it by being critical rather than cynical, by staying hopeful and engaged with the constantly changing demands of activism.

Keywords: stories, mental health, user involvement, survivor movement, co-option

Introduction - Positioning Ourselves

This paper is a narrative exploration of the politics of storytelling in the context of mental health systems. We are informed by our experiences in Scotland and Ireland as people who have been invited to tell our stories (Liz, Anne) and invite others to tell their stories in our institutions (Lydia, Anne).

We are three white women with educational privilege which gives us opportunities to articulate our concerns. We are conscious that our experiences and thoughts are not representative of more silenced and absent voices.

Although the politics of storytelling by psychiatrised people has been discussed before (in particular by Costa et al., 2012), it continues to be a contentious issue. We are involved in a variety of Mad Activism, e.g. Critical Voices Network Ireland (Sapouna & Gijbels, 2016), the independent advocacy movement in Scotland (Sapouna & O'Donnell, 2017), research, and education. Yet in these spaces, storytelling is often unproblematized and depoliticised. Drawing inspiration from Costa et al. (2012), we consider the relevance of their critique to find ways to remain alert to the politics of storytelling in our different contexts. We start this discussion with each of us relating our experience of storytelling. We identify our hopes about the potential of stories to challenge mental health systems, and our worries about the appropriation of stories by the very same systems. Reflecting on our experiences of madness, advocacy, research, education, and activism, we identify the power of stories and our concerns about their co-option. This ambivalence towards storytelling remains a key feature in our discussion. However, as our conversation progresses we seem to regain our optimism about the potential of storytelling to challenge biomedical ideologies and oppressive power structures. We conclude with some suggestions about remaining hopeful about and engaged with the politics of storytelling.

Anne

I am an Irish woman who has lived in Scotland since the mid-90s where I became homeless, got a mental health diagnosis, and found collective advocacy, all within a year of moving here. Then, hearing other people tell their stories helped me feel less alone and more outraged. A good combination!

Service user involvement (SUI) seemed great at first, but I soon realised that a lot of it was very conditional on saying what funders and professionals wanted to hear. One of the first things I did when I became a service user group representative was to attend a big National Health Service (NHS) event where a very senior person pounced on me, delighted to see some 'fresh blood', telling me she wanted to hear from real people like me, not 'these activists'. At the same event, we were arguing for non-hospital crisis services. A general practitioner asked me what I would do when in crisis, and when I started telling him, he said "see how Anne manages it, we don't need a crisis centre!" before even hearing me out. These two incidents on one day made me very wary of my role as a service user representative in professional spaces and of "telling my story".

Since then, the increase in demand for people to tell their stories of distress, of stigma, and of recovery in ways which fit dominant ideas has worried me. I hear stories which are moulded to fit templates of grateful recipients of services, of taking individual responsibility, of combating stigma and opening up about suicidal thoughts to sympathetic family and professionals. These weren't the stories of people I knew; they didn't show the complexity of our experiences or the systemic problems we faced or the power of collective work.

I also manage a small project, part of an independent mental health advocacy organisation which provides mental health courses designed, developed, and delivered by people with lived experiences. Participants appreciate hearing our stories but I wonder how they actually make sense of those stories? And I wonder about the impact on us of telling stories of our experiences of distress, invalidation, and discrimination.

Liz

My encounters with Irish mental health services commenced in 1989 and were

initially involuntary. After a lost decade I became involved in service-user led research and advisory committee work. My initial excitement about the apparent revolution, heralded into Irish services in the 2000s by the adoption of the Recovery and SUI mantra, was fuelled by belief in the power of stories to effect change. But gradually it became obvious that it was often window-dressing, in spite of the best intentions of many committed allies. As an optimist I know we can influence individuals but given years of experience it seems systemic change is nigh impossible.

My research on power dynamics within SUI practice for a sociology PhD sparked an uncomfortable awakening (Brosnan, 2013). My whole life trajectory has been shaped by abuses of power (gendered, sexual, and religious) and so the dynamics in mental health services and in academia are uncomfortably familiar. I observe the same old games play out in forums with professionals; how recovery discourses mask the unseen, unspoken privileges conferred on "sane" professionals, while the token service-user is welcomed as long as she is not too "mad" or too angry and does not threaten the unspoken, invisible boundaries that determine how "things are done around here". Similarly, narratives of recovery are welcomed as long as there is a redemptive feature for professionals: many participants in my PhD research spoke of hearing a story rejected because it was too negative, it did not give a "balanced view". The satisfied service-user is welcome, they after all provide reassurance that "we can't be doing everything wrong". Of course, as the theorists of power (Foucault, 1980; Lukes, 1974; 2005) point out, power is most potent when the subjected believe the system is working in their best interests and that no alternative is possible. Most professionals (and the public) are caught up in this trick of hegemony: professional sanity (and avoidance of cognitive dissonance, see Cooper, 2007) depends on the recovery narratives underpinning their practice (Brosnan, 2012).

Lydia

I have taught mental health in social work programmes in University College Cork, Ireland, for over 20 years. I started this work with a strong commitment to critical education and practice but soon realised the challenges of this task as students are expected to practice within dominant biomedical systems. At the same time, I recognised my own limited resources to think and practice outside the box. Building

alliances with the emerging user movement in Ireland created exciting new possibilities for engagement with critical practice (Sapouna, 2016).

A starting point of this process was SUI in education which included the sharing of people's stories of encounters with psychiatry in classroom and conference settings. I was very proud about this 'innovation', seeing such stories as a tool to challenge dominant understandings of distress. Indeed, students listened enthusiastically to these narratives, they appreciated the diversity of the experiences shared, and they saw the person beyond the symptom. These stories were an antidote to medicalization. However, even in these early days of my enthusiasm about SUI, I was uncomfortable with some students' fascination with a 'brave individual's' story at the expense of an interest in systemic change. I was also uncomfortable with the request, expressed by some students and many practitioners, for these stories to be more 'balanced' rather than, what was perceived as, constantly criticising service-provision. I was unsettled by the unequal status of the 'invited speaker' which gave no real recognition or power to those sharing their stories within education. Still, for almost a decade I was happy to 'pioneer' SUI in Irish social work education. The stories were educational, alerting future practitioners about how people experiencing distress want to be treated. I observed students becoming less preoccupied with diagnostics and instead developing a position of curiosity about the life-contexts of people who use mental health services. I observed students focusing on recovery, becoming aware of the impact of coercive practices and identifying the pursuit of social justice as a core element of changing mental health systems. People sharing their stories spoke about feeling affirmed and valued and, through their contribution, the authority of professional and academic expert knowledge was challenged, a welcome development! In many ways it seemed that stories had the potential to radically transform thinking and practice.

However, such stories are increasingly becoming mainstream within mental health institutions including education. And now I am even more uncomfortable! So what's my problem? Isn't this what I advocated for all along? Greater SUI in education? Co-production? It seems that when stories become part of mainstream discourses they lose their potential to be an agent of change. Many of these stories don't make their audiences uncomfortable any more. And I think this can be a real problem.

Discovering the power of stories

While we all got involved in activism in different places and at different times, we were inspired by stories: from fellow activists, such as Judy Chamberlin in *On Our Own* (1978), Louise Pembroke on self-harm (Pembroke, 1994), Kate Millett (1990), and stories on the meaning of voice-hearing by Paddy McGowan, Noreen Fitzgibbon (The Irish Advocacy Network), Jacqui Dillon and Eleanor Longden (Hearing Voices Network, UK). We were also inspired by the less celebrated stories of people who, by struggling to tell their story, taught us the importance of being respectful of different positions and of listening to diverse voices. We usually hear, or are affected by, well-articulated stories of extreme coercion or successful recovery. Nevertheless, we also need to hear the stories of those who can't find the words to tell them, those whose experiences confuse us or challenge us because they may be far removed from our comfort zone. Through storytelling we can develop the art of listening.

Anne: I had listened to so many other survivors' stories which had inspired me greatly. I had been made to feel for so long that I myself had nothing to say. So being encouraged to tell my story was liberation. Being asked and being listened by fellow survivors gave me a sense that I mattered, my experiences mattered and my understanding of them mattered. But those experiences of having my own story of madness dismissed as 'one person's experience,' and of it being appropriated, silenced me again. I've been telling my story of activism much more freely (Sapouna and O'Donnell, 2017). It is only recently that I feel able to tell my own stories of my madness.

Liz: I found that I so under-valued myself that, like Anne, I thought either I had nothing original to say or that what I had to say had already been said before. Plus, my first attempts to write my story had been rubbished as 'just stream of consciousness' by someone I trusted, (wrongly as it turned out). This harsh opinion had wounded me so deeply I destroyed several years of notebooks and kept silent for years. It was through reading and listening to other survivors tell their stories that I began to believe my own story is valuable. That is why I both value and fear the power of stories. Now people come to me and say they value my work and my stories. Even professionals have come up quietly after classes to say my story reminded them of their own, but they don't feel in a position to share theirs.

Lydia: It is interesting that both Anne and Liz mention their feeling of having nothing worth saying as I felt the very same from my different position. Not belonging in the 'mad community', and also not being fully comfortable in the world of academia, I struggled with what I had to offer beyond what is often perceived as 'vague' passion and vision. Stories of survivors articulating the importance of context, of 'what happened', of being treated with respect and dignity filled that gap. In this process of story-sharing I often found myself taking a step back with my role becoming effectively invisible/redundant. This is not always a comfortable place to be. But if this 'disappearing' is about 'creating spaces' it can be a political act (see also Church, 2013).

Questioning co-option

So other people's stories have inspired us and being invited to tell our stories has felt very empowering. For many people, a request to speak to nursing students or to be interviewed by researchers or to speak at a conference may be the first time their opinion has been actively sought and attended to. Through telling their story, they believe they can make a positive difference, and be valued for experiences which were often invalidating and painful. Furthermore, inviting people to share their stories can also be a significant political act in terms of challenging dominant cultures in educational institutions.

However, what might be experienced as empowering has a dark side (Pascal and Sagan, 2016). As we have each described, we have become disillusioned by how we have seen something as powerful and transformative as telling stories becoming neutralised and co-opted (see Costa et al., 2012).

We see survivors' stories becoming commodities for mental health organisations and educational institutions to use primarily to promote their own agendas. These mainstream institutions claim to be involving service users, promoting recovery, and fighting stigma, but stories which do not fit their agenda are ignored and silenced.

Telling our stories has become compulsory in some contexts (e.g. professional education) and that is inherently disempowering: as the critical survivor group, Recovery in the Bin (RITB) put it "being made to feel like you have to tell your 'story' to justify your

experience is a form of disempowerment, under the guise of empowerment." (Recovery in the Bin, n.d.)

People who share their stories remain disadvantaged, and are often unpaid, unequal partners. They often have very little say in how their story is retold or used, often as a substitute for meaningful participation. In writing down our stories they can be used as material without our involvement or control, not recognising that stories are not static and nuances shift as our lives evolve and thinking changes over time. Without real influence over curriculum development and student assessment, SUI in education is tokenistic, and the practice of bringing someone in to tell their story to a class is patronising and meaningless. The lack of respectful conditions of participation was a strong theme in Liz's research with twenty activists engaged in SUI in Ireland, leaving many wondering if their efforts were having any impact (Brosnan, 2013). To date, there has been one part-time peer-academic post created in a one department in one University in Ireland. User/survivor research positions are even more precarious than postdoctoral research contracts in general. These concerns are also evident in mental health services, in particular in the arena of SUI. People are invited into SUI spaces without adequate problematising of the power dynamics inherent for service users in a hierarchical bureaucracy, dominated by bio-medical professionals. Narrating recovery stories at professional conferences or bringing common sense to bear on how proposed changes would impact grassroots people, are common activities that offer people a sense they are making a difference, a sense that grows increasingly elusive the longer someone is engaged with the system. Participants in Liz's research frequently reported a lack of meaningful recognition of the role that service users can contribute to culture change (Brosnan, 2013). Until the power structures that maintain the status quo are addressed, service users are limited in what they can do.

…

At first, when we began our conversation about stories, we felt deflated and discouraged. However, as we talked to each other and to others, we found ourselves telling stories and we felt yet again the possibility of these stories. And in telling and listening to stories, we reawakened our belief in their radical potential and felt even more the need to challenge their appropriation.

Stories can bring to our attention to human rights violations in a way that facts and statistics can't. Such as that of psychiatric survivor Dorothea Buck (Buck-Zerchin, 2017), and her experiences of surviving the Nazi T4 programme. Her story brings the reality of the Nazi genocide of people who were diagnosed with mental health conditions to our attention in a way that facts and statistics can't. Psychiatry was complicit in this genocide programme, and in maintaining the Soviet order, and yet the learning is being forgotten. And these stories remind us that the UN human rights frameworks, which are being attacked relentlessly in the current political climate, were set up to ensure that the massive violations that occurred in the early 20th century should never be allowed again.

All storytelling is political; there is no neutral story. Telling stories about experiences of mental distress and madness, of oppression and treatment, and of survival and resistance, is a source of power for people who use or are forced to use mental health services. Stories are part of how we - survivors and allies - resist the dehumanising experiences in the mental health system and reclaim our humanity, our subjectivity, our agency. Our stories affirm us as people. They help us create meaning where others see none and to help us channel our anger and rage into political action. They allow us to challenge bio-psychiatry and dominant understandings of human distress and to create alternative views; most importantly, they connect us with each other as we find we are not alone. This is the most significant potential of narrating our experiences; it builds community and allows a politicised, collective consciousness to emerge among psychiatrised people.

So what now?

Whether it was the senior NHS person looking for 'fresh blood' from Anne, insisting she didn't want to hear from 'those activists' or Lydia's students who wanted the 'brave individual's' stories, or the professionals who welcomed the token, non-threatening service user who is 'not too "mad" or too angry' in Liz's research, the demand from 'consumers' of stories is for safe stories, for 'balanced stories', for stories which do not discomfort or challenge them.

But we all - service providers, researchers, educators, and policymakers as well as survivors and allies - need the stories which do challenge and unsettle us! Some of the

stories Anne has struggled to hear are how some survivors have felt unwelcome or not listened to in the groups she has belonged to. Lydia struggles with stories of people who resort to seeking more coercion for family members because of issues of 'risk' and 'safety'. Liz struggles with hearing stories from people that justify coercion and contested practices such as seclusion and electroconvulsive therapy (ECT) because they helped them in the past, without believing other options are possible.

It is because our stories are so powerful that we are so concerned when we experience and witness the co-option and appropriation of our stories. But just because they are stolen from us, does not make the act of telling them invalid. In fact, it makes telling them even more important.

We believe that real change and real activism are grounded in and arise from the stories of the oppressed. And these stories are collective and diverse (including but not limited to poverty, domestic violence, abortion, legal guardianship, colonisation, genocide). As bell hooks (2014, 2003) reminds us, activism is grounded in the community of people who come together and learn from each other. By keeping a focus on community and by avoiding elitism, we will reduce the chances of the commodification of our stories. Other theorists of power and community (Gaventa, 2006; Cornwall & Coelho, 2007) speak of the need for collective spaces to resist the capture by the dominant worldview, the professionalization of development, of change, of resistance.

We need to tell and hear more stories which capture the complexity and messiness of our experiences; stories not of heroes - 'recovery porn' (Costa et al. 2012) - but the stories from people whose acute distress makes it messy to find a response (other than resort to coercion) because we know no better.

We need to hear more stories from people who are not like us. Those of us in the movement, as well as those in services, need to hear from people who are left out, overlooked, invisible, people who are not usually listened to. Our movement has been dominated by white people and the stories of people of colour are still not being listened to (Gorman et al, 2013; Griffiths, 2018). We need to hear from people with different experiences of distress and madness and people who have had different responses to their distress and madness.

We need to give more space for more stories. We need to be able to say, 'if you want my story for your students, pay me for my story.' And we need to give people space to say "no, I am not telling my story, not here, not now, not in this context".

Conclusion

While this is an unsettling position, we believe that we, as storytellers and as people who invite storytelling, can make the best of it by being critical rather than cynical, by staying hopeful and engaged with the constantly changing demands of activism. Through our discussion we identified some ways to remain alert to the politics of storytelling.

We propose seeking out more diverse individual and collective stories and listening carefully to those stories which challenge us to move beyond complacency. We also argue for the recognition, respect, and promotion of a broader range of Survivor narratives. These would include an understanding of the difficulties and struggle that people face every day, not just 'successful recovery' type stories (RITB principles). Essential in this process is a move from the rhetoric of equality to offering people proper conditions for participation, such as recognising that payment is also political, and providing genuine opportunities to influence education, policy, and practice. Ultimately we argue for the need to protect our own spaces for engagement and being alert to co-option.

We conclude with a brief reflection on the writing of this article. The three of us started this discussion because of our shared frustration with the use and abuse of survivors' stories within mental health services and education. However, writing this article required us to share our individual stories in order to talk about stories more generally. We had to decide what to share with each other, what to use, and what to discard. And in order to write a 'coherent' article we had to balance our individual views with the collective. And interestingly this story-sharing made us regain confidence in the power of collective stories to help us stay engaged with activism and the pursuit of social justice.

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‘Madness’ and activism in Ireland and Scotland, a dialogue

Co-autored contribution. Lead author, contributing 60% of the formulation, structure for the discussion, execution, thematic analysis and publication.

Citation: Sapouna, L. & O’Donnell, A. (2017) Reflections dialogue: ‘Madness’ and Activism in Ireland and Scotland, *Community Development Journal,* 52(3):524-34. (Reproduced with permission from Oxford University Press).

Abstract

Anne O’Donnell and Lydia Sapouna, based in Scotland and Ireland respectively, are activists and writers who have made long-standing contributions to the debate about mental health and recovery. In this dialogue they exchange analyses of the achievements and lessons to be learned from mental health activism that has resisted dominant narratives of mental illness and that has created innovative, collaborative and critical spaces for the exchange of ideas, experiences and enthusiasms. The dialogue seeks to evoke the distinctive styles of activism adopted in each context, the successes engendered and the kinds of dilemmas and tactical choices navigated. Ann and Lydia have initiated a process of reflection and exchange, and out of this they have constructed a dialogical piece that highlights key organisational issues for mental health activists and for community based social movements more generally.

Keywords Madness, activism, user/survivor movement, co-option, power

Introduction

This conversation between a psychiatric survivor-activist and an academic-activist is focused on spaces and voices of resistance to the dominant biomedical mental health systems in Scotland and Ireland. We discuss the achievements and lessons to be learned from challenging narratives of mental ‘illness’ and from creating innovative, collaborative and critical spaces for the exchange of ideas, experiences, concerns and enthusiasms.

Through our initial correspondence we found that, despite our different backgrounds, we share similar values and perspectives on what we see as the politics of human distress and the mental health field. Furthermore, we are both strong advocates of meaningful user involvement in mental health.

We were therefore a bit concerned that all we would do when we did meet in person was to agree with each other, and that our conversation might be rather limited. We were wrong! We found that what we shared was very interesting in the context of different countries, backgrounds and current positions. This paper is based on our conversations in Edinburgh in June 2016. We identified shared tensions in our different positions, together with concerns and struggles to stay engaged with the movement in our respective contexts. These key themes form the basis of our paper.

Positioning ourselves

Anne: I left Ireland in 1988, aged 22, to live in London and then in 1993, I moved to Scotland permanently. I have been active in the mental health service user movement since 1994 when I first started using mental health services. Because I had some previous experience of political activity, it made sense to me to join with others who had experience of distress and mental health service use. That led to studying community education at Edinburgh University. More recently, I have become very active in the new field of Mad Studies. I currently work as a coordinator of a mental health, advocacy and recovery education project.

Lydia: I grew up in Greece during the post-dictatorship era, with 'the personal is political' as a key feature of my formative experiences. I did social work training in Athens in the late 1980s, the time of the so-called psychiatric reform in Greece which was fueled by the exposure of the horrific conditions at the Leros Asylum in 1989. I think the sense of shame and discomfort many of us experienced during that time has set the foundations to frame mental health care in political and human rights terms. Inspired by the work of Franco Basaglia and the links between the Italian psychiatric hospital closure and wider social movements (e.g. students and trade

unions), I developed a keen interest in de-institutionalisation. When I moved to Cork, Ireland, in the early 1990s to do postgraduate research in this area, I was surprised to find that 'community' mental health policy and practice evolved, both geographically and ideologically, in institutional settings. For the past twenty years I have worked as a mental health educator in University College Cork (UCC), trying to promote critical thinking and practice skills for working with human distress.

Anne: So how has it been for you, as an academic training mental health workers on one hand and on the other, being someone who sees things in political and human rights terms?

Lydia: I would like to describe myself as an activist/academic but I am not sure how genuine this is! I struggle with managing the ongoing tension between my commitment to social justice and the expectation to prepare students for practice in a predominantly biomedical and often coercive context. Developing systematic links with service users/survivors, advocacy groups, campaigns and like-minded professionals, has provided me with resources to think and practise outside the box. Such coalitions created possibilities to develop critical spaces both inside and outside the University within which to consider mental health practice. This has been an eye-opening but also unsettling journey.

Anne: So why is this unsettling?

Lydia: I increasingly position myself as an ally of the mad community, often at the expense of my academic or professional identities, whatever these mean! However, I am not a member of the mad community myself. While I have been through tough times, I haven't used mental health services. Kathryn Church's (2011) description of her position between the survivor community and the academy as 'familiar with both but uncomfortable in both' resonates deeply with me! So maybe it's about making the best of this position?

Anne: I have my own experience of similar discomfort, as I am a survivor activist, still dealing with mental distress, as well as being a paid worker in the advocacy organisation through which I have channeled most of my activism. It can be difficult to manage the different ways I am pulled as a worker and as an activist. The survivor community isn't homogenous - a view from outside is that I should be part of that community. I feel at home there but I also feel unsettled because some of my ideas

are at variance with those of a lot of people in the movement. Of course my ideas have shifted and changed over time. So as you say, it's about making the best of this position by acknowledging the discomfort. By speaking about these tensions, we know we are not alone and we are better able to think critically together.

What is happening in Ireland and Scotland?

Anne: When I left Ireland, I had no sense that people with mental health issues were organising. So what has been happening?

Lydia: Indeed, the mental health user/survivor movement is a relatively recent development in Ireland. Up to the late 1990s most mental health groups were primarily consumer or patient organisations, concerned with self-help, resources and funding for services, and more recently with anti-stigma campaigns. The origins of the user/survivor movement can be traced to the Irish Advocacy Network (IAN) in 1999. IAN, a peer-run organisation, secured government funding in the early 2000s to provide peer advocacy in inpatient settings. Through IAN, peer advocates also make contributions to policy and management groups, research and education. Overall, in the 2000s we see an increase in user representation in Ireland as a direct result of government policy through, for example, the establishment of consumer panels and the *Office of Service User, Family Member & Carer Engagement*. On the other hand, during the 2000s more grassroots groups such as MindFreedom Ireland and Madpride Ireland emerged, articulating a strong critique of human rights violations in psychiatry, highlighting the harmful effects of Electro Convulsive Therapy (ECT), psychotropic medication and forced treatment. More recently, in 2010, the Critical Voices Network Ireland (CVNI) was developed as a critical space to promote ideas and practice for a user-run democratic approach to human distress.

Lydia: My impression is that there is a stronger sense of collective action in Scotland. Can you tell me a bit more about it?

Anne: Well, the service user movement here in Scotland began in 1971 with the Scottish Union of Mental Patients (Roberts, 2009, p.16) but it didn't really take off until the late 1980s and early 1990s (CAPS, 2010). Care in the Community policy meant that service providers needed to consult with people using those services but,

at the same time, people were gathering to share experiences and demand change. This meant there was some funding available for user groups in Scotland, so user-led organisations like CAPS, an independent advocacy organisation in the Lothians, and the Highland Users Group started. The earlier groups usually included people active in other movements and in political parties, so they had a sense of politics and of collective action. Scotland as a whole does pride itself on how collective minded it is. But this isn't always a good thing. For instance, there is a popular belief in the consensual nature of politics in Scotland which is much praised as being enabling and inclusive, especially in comparison with the more divisive practices of the UK government. But this can mean that a lot goes unchallenged. I think it explains why a lot of the time the service user movement in Scotland focuses on improving and extending services and not on direct challenges to psychiatry or to structural causes of mental ill-health. There are individuals who do critique psychiatry, they're just not part of the main discourse. We are on the whole cautious and we are also under-resourced. I think we should be demanding more from the state but that always comes at a cost! It's a problem common to most social and political movements.

Lydia*:* This is a very interesting observation. In Ireland also many mental health groups campaign for more resources, particularly as mental health services have been significantly disadvantaged during the recent recession, and consequent health sector cutbacks. But resources to do what? A preoccupation with lack of resources fails to see that the main problem lies in the current service culture, and entrenched power imbalances between professionals and service users within mental health institutions. I think Sedgwick's (1972) work on psychopolitics is very relevant here. We need to take a political position about what type of care is needed rather than merely advocate for more resources.

Anne: Sedgwick has argued that 'the exclusion of mental health users from society can only be rectified by transforming the social, political and economic structures of late capitalism' (in Thomas, 2016, p. 7). However, while a lot of seemingly radical groups are against psychiatry, they don't necessarily appreciate or critique the wider political and social context.

How political are service user groups?

Anne: So from what we've been discussing, despite the differences in our respective contexts, we can see some key things in common in the service user movement. For example, the focus being either on service provision and funding on one hand, or on critiquing psychiatry and medication on the other, especially in Ireland. However these are not necessarily political positions.

Lydia: Yes, I think there is a lack of explicit political positioning within the Irish user/survivor movement. To make sense of that we need to look at the Irish context. In Ireland, as elsewhere, the user movement grew out of dissatisfaction with a system where people felt oppressed, voiceless and coerced. As Ireland has a strong institutional tradition, and the biomedical approach is still the dominant practice, we have a very powerful critique of biopsychiatry articulated by individuals and groups. This critique is focused on the overuse of medication, the damage caused by medication, forced treatment and specifically ECT, which can still be administered involuntarily once an individual is deemed 'unable' to consent by two consultant psychiatrists. Over the past fifteen years, people have come together in conferences and other community events, to share moving and powerful individual stories and experiences and generate a strong critique of coercive psychiatric practice. In these spaces some individuals have emerged as particularly 'gifted' in providing both inspiration and leadership. It is important however not to miss the voice of the less confident (and, as a result, less articulate) people in this process.

Anne: What about the voices of people who are saying things which are more critical, because they directly challenge people and structures?

Lydia: Often such voices are discredited as 'trouble-making' or just a 'rant'. This may be partly due to our limited capacity, or even limited knowledge-base, to do something constructive with the discontent people experience. It is important to move towards a more collective storytelling, which incorporates a stronger political message beyond merely critiquing psychiatry and medication, thereby creating a context where critical voices can be more influential. The challenge is to build capacity to develop communities that are more active in promoting alternatives, in

promoting hope, in promoting collective action. I suppose we need to start asking more questions about all forms of power, not just the power of psychiatry.

Anne: Ranting is necessary; certainly it was people getting angry who claimed the spaces in the first place! But ranting on its own is not enough - where does the analysis and the action come from? Maybe people don't feel that need or it's too difficult to do that. People don't have the capacity yet maybe because you can't just develop that capacity on its own. It's kind of an education thing! You need it around you, you need to be exposed to ideas, you need to be able to have discussions and you need to have your skills developed and that's again where a community development approach is crucial.

Lydia: I think community development can be very useful in making sense of power operations. It can help us develop an understanding of power distribution and provide a framework to claim power for a more democratic system of mental health care. However, we need to be careful not to reduce it to a technocratic intervention, a 'tool' for the development of services in the community without taking a critical stance towards service provision.

Anne: Having studied community education has given me ways to understand power and the dangers of progressive ways of working being co-opted into what you call technocratic interventions. I like that maxim, 'you start where people are at but you don't leave them there'; and the promise that every interaction is an educational opportunity for both the educator and the individual or group you're working with.

Lydia: So do you see a role for theory in all this? Very often activist groups take a rather hostile stance towards theory; what's your experience?

Anne: Yes, theory is crucial yet many people distrust it. But without theory, you act without thinking things through. Theory for me has been a guide and a tool for understanding what might be going on. The most relevant theory for us has been the *Powercube* (Gaventa, 2006) and especially how Liz Brosnan (2012) has applied it to an analysis of user involvement. To give a very brief overview of something quite complex and dynamic, the powercube has three dimensions – *forms, spaces* and *levels* of power. Basically, power operates in visible, hidden and invisible forms. Visible power is in operation when a government says they are consulting on a new mental health policy. Hidden power operates to decide what goes on the agenda for

the consultation. And invisible power operates to keep the real issues from our consciousness. And then there are spaces of power: closed space is where the decisions are made by those in power, invited spaces are where those in power invite others to participate on their terms. Claimed spaces are created by people who have something in common who want to speak up and make changes. Finally, there are levels of involvement, which in the case of user involvement, Brosnan has labelled as individual, operational and strategic. A person may be involved in their own care and treatment on an individual level, in how a particular service is delivered, i.e. on an operational level, and on a strategic level whereby the person is involved nationally and internationally in developing policy.

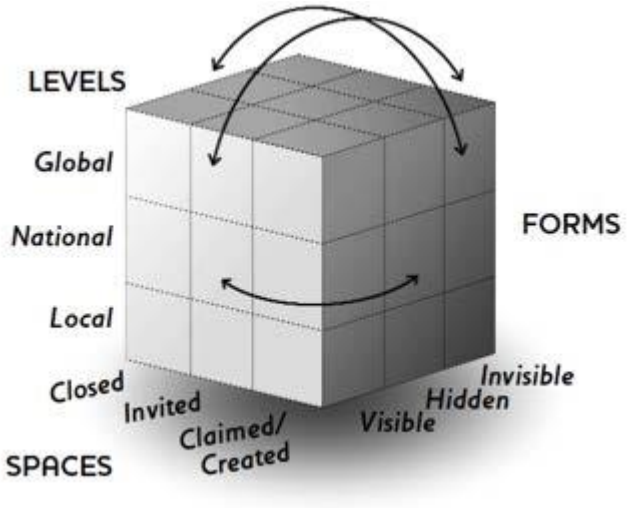


Figure 1: the power cube: levels, spaces and forms of power (Gaventa, 2006, p. 25 and http://www.powercube.net cited in Brosnan, 2012, p. 56)

We've found that thinking in terms of the Powercube has been very helpful in figuring out what we are doing: are we claiming space or are we being invited in? Is the power visible or invisible? Are we being involved operationally i.e. 'tell us how this service can be improved'? Or strategically? How do these different aspects interact? So for example, it seems to me that in Ireland the invited space has been strong but in Scotland, at least initially, there was as much claimed space as invited. But I think most space now is invited and it is hard to find the resources for claimed space - though it is more possible to do so online. And the closed spaces are still there and

that's still where the real power lies, for all the fine 'Recovery' rhetoric (O'Donnell and Shaw, 2016). We need to develop and nurture our claimed spaces, because they give us the strength and focus to be able to work in the invited spaces and not become absorbed in the demands of services and policy makers. And they also help us to make strategic decisions about what to become involved with, and why.

Co-option of user involvement: a shared concern

Throughout our conversation, the co-option of user involvement seemed to be a common concern…

Lydia: The provision of space for service user involvement in Ireland can be seen as the provision of an invited space, created in a top-down manner. The concept of user involvement has been institutionalised into Irish government policy and structures very quickly. It is particularly striking how comfortably the language of 'user involvement' has been adopted in traditional mental health systems while these systems remain, equally comfortably, under medical hegemony. For example, despite the rhetoric of user involvement in mental health care, research continues to raise concerns about the quality of such involvement, about tokenism, and about the lack of resources to support meaningful user involvement (McDaid 2009; Brosnan 2012). Brosnan's (2012, p. 62) research suggests that, like recovery, user involvement is 'incorporated into the official discourses without sufficient attention being paid to the complexities of the social justice issues inherent in the user-perspective and failing to problematise the power dynamics service-users must engage with if they choose to enter the new spaces into which they are being invited'. Brosnan also argues that the presence of service users at the table may suggest the democratic face of 'inclusive' practice while simultaneously legitimising the practices of the mental health establishment. Drawing from Nancy Fraser's (2000) ideas on social justice, we can argue that while there is talk about the 'recognition' of user experiences, leading to some level of 'representation' of service users at policy and management levels, there is no evidence of the 'redistribution' of power within mental health systems.

Anne: I recognise similar processes here in Scotland… some groups like CAPS started as claimed spaces, while other groups were created in order to fit into invited spaces. And when we don't appreciate or realise the difference between claimed and invited spaces, we don't recognise what is going on in terms of power dynamics, but wonder why we are running around responding to demands to take part in consultation but getting nowhere.

Creating and claiming new spaces

Anne: I am aware of the CVNI, which is a new claimed space in Irish mental health. Can you tell me more about it?

Lydia: The CVNI emerged out of a series of critical conferences organised since 2009 by the Schools of Applied Social Studies and Nursing and Midwifery in University College Cork. These conferences are unique as they are free of charge and involve survivors, professionals, academics and carers presenting, discussing and debating critical perspectives in mental health. From this, the CVNI emerged as a claimed space to develop ideas and act more collectively. It is 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. The idea is that the network now provides a democratic space with no hierarchical structures, open to everybody who wishes to join its discussions, mainly through a Facebook page.

Anne: Having been to a CVNI conference and joining the Facebook group, my impression is that it's uncritically anti-psychiatry, like many groups that seem quite radical, but actually aren't questioning or challenging wider power and political aspects. Are there people there who are looking beyond the narrower anti-psychiatry stance?

Lydia: Yes, the political views within the CVNI are very diverse and this is a challenge. As we discussed earlier, we need to move beyond a critique of psychiatry to a broader political critique. Our November 2016 conference is focused on activism and acts of resistance, thus recognising the importance of this broader political focus. Despite

these challenges the CVNI has given a 'home' for people to get the confidence to articulate different opinions (Sapouna and Gijbels, 2016).

Anne: As I said before, we need to develop and nurture our claimed spaces - and I think there are new exciting developments which enable this, such as Mad Studies. This new field, both academic and activist, is a 'project of inquiry, knowledge production and political action' by people who identify as mad and our allies (LeFrançois *et al*, 2013, p. 13). As Lucy Costa (2014, n.p.) says 'maybe it's time we stop answering [user involvement] questions and have Mad Studies develop our own questions and research agendas'. It is definitely about claiming space! It feels more politically aware and more geared to both analysis and action than anything else I have seen in the international survivor movement in a long time.

What keeps us going?

Anne: So to summarise, we both operate in tense yet creative positions - me as a worker and an activist and you as an educator/activist. We are trying to balance the cynicism from our experiences and yet keep hope. So why do we do what we do? What keeps us going?

Lydia: I can't teach something I don't believe in. It is as simple as that. I consider myself lucky to be doing a job that combines a personal and political passion with the possibility to make a living!

Anne: But it can be an uncomfortable place. So what keeps you going in this uncomfortable place?

Lydia: Well, for a long time I was uncomfortable on my own. What can be done in formal education is rather limited and I soon realised that my own knowledge-base was inadequate. I was frustrated with the system, but I didn't have many resources to develop alternative ways of knowing and inquiring. Things started to change when I first connected with service user advocates and like-minded professionals. Through this process I expanded my ways of knowing and thinking and therefore I feel I have more to offer. So this is what keeps me going: a connection with a movement; a collective process of change. I suppose I made some contribution in developing a critical space within the university and I would like to see that continuing. As a next step it would be great to see Mad Studies in our University!

Anne: What keeps me going? Well, I have seen some small changes which helps keep me going. I feel a commitment to people and a community to which I feel an uneasy sense of belonging, and I want to continue to be involved in speaking out against injustice, even when I feel we can't do anything else but highlight it. And, finally, I am very excited by Mad Studies from an academic and activist perspective …. even as I worry about its co-option.

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Anne O'Donnell is a community educator working in mental health advocacy. She has been an activist since the mid 90s. She is particularly interested in the political and social context in which mental health and mental illness are constructed, understood and responded to.

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Social movements in mental health: The case of the Critical Voices Network Ireland

Co-authored contribution. Lead author contributing 70% of the formulation, execution, analysis and publication.

Citation: Sapouna, L. & Gijbels, H. (2016) Social movements in mental health: the case of the Critical Voices Network Ireland, *Critical and Radical Social Work*, 4 (3): 397-402.

This is a post-peer-review, pre-copy edited version of an extract/chapter published in *Critical and Radical Social Work*. The definitive publisher-authenticated version: Sapouna, L. & Gijbels, H. (2016) Social movements in mental health: the case of the Critical Voices Network Ireland, Critical and Radical Social Work, 4 (3): 397-402 is available online at: https://doi.org/10.1332/204986016X14721364317492

Introduction and Background

In this paper we provide an overview of the emergence and subsequent work of the Critical Voices Network Ireland (CVNI), within the context of Irish mental health care and policy. We give examples of initiatives aiming to critique and transform the dominant biopsychiatric system, followed by a discussion on the development of the CVNI as a critical platform and some observations about the politics of transforming the Irish mental health system.

In recent times we have seen possibilities for change in Irish mental health care. A bio-psycho-social as opposed to a purely biological approach to mental health care has been advocated by key Irish policies e.g. A Vision for Change (Department of Health and Children, 2006) and the Recovery Approach within the Irish Mental Health Services (Mental Health Commission, 2008). Policy recommendations include the provision of a comprehensive, recovery-oriented, person-centred service, and the promotion of service-user involvement in decision-making regarding personal care plans, service and policy development.

Nevertheless, policy implementation has been slow and inconsistent across the country (Mental Health Commission, 2013), with concerns about the state of mental health care in Ireland continuing to prevail. Such concerns include coercive practices, lack of treatment choices, abuse of professional power, over-reliance on and excessive use of medication, discrimination and stigmatisation, inhumane physical conditions in hospital units and lack of meaningful community-based alternatives to hospitalisation. Furthermore while the language of 'recovery' and 'user-involvement' feature quite comfortably in mental health service provision there are increasing concerns about these terms being assimilated in the current biomedical discourse, thus losing their transformative potential (Brosnan 2012; Higgins and McGowan 2014).

Critical perspectives have emerged to question this dominant thinking and practice. These have been voiced in various ways by a diverse range of 'actors', including people who describe themselves as service users, survivors, patients, members of the mad community, carers, family members, practitioners, professionals, academics, and members of the public all of whom are dissatisfied with current forms of care and its underpinning bio-medical philosophy. In the following section we provide some examples of initiatives and campaigns which have attempted to capture these perspectives and have contributed significantly to widen the debate within and beyond mental health services.

Examples of campaigning initiatives

Two examples of campaigning initiatives, set up by individuals motivated by their experiences of coercive psychiatric services, are those of Madpride Ireland and MindFreedom Ireland. Madpride Ireland's family fun days have been a lively public event in a central park in Cork city for a number of years. Madpride Ireland's founder, the late John McCarthy, said "we believe that the best way to promote understanding of issues surrounding mental health is to engage the community through active participation in a fun environment. We do that by hosting family events that are inclusive, fun and suitable for children, teenagers, adults and families. These events

do not bombard people with pamphlets extolling the virtues of one approach over another. Rather they show the world that madness is an everyday occurrence that affects us and can be dealt with openly lovingly and without fear. Have we opened the national debate on mental health? We sure have" (Madpride Ireland, 2012). Such approaches can break the silence of 'madness' moving it from nothingness to community engagement and visibility, often celebrating the 'gift' and 'normality of madness' (McCarthy, 2011).

MindFreedom Ireland (affiliated to MindFreedom International) was set up by Mary Maddock in 2003. It is a voluntarily run organisation which 'promotes alternatives to the mainstream psychiatric model and which campaigns to abolish the power of psychiatry within the present 'mental health' system' (http://www.mindfreedomireland.com). Its work includes activism, advocacy, peaceful protest, public education, media engagement, policy submissions and mutual support.

A campaign in which both Madpride Ireland and Mindfreedom Ireland were involved, together with a number of academics and professionals, was the campaign to delete section 59b of the 2001 Mental Health Act (2010) (www.delete59b.com). Until December 2015 Section 59b of Ireland's Mental Health Act (2001) 'allowed for the involuntary administration of ECT where a patient is unable or unwilling to give such consent and where it is approved (in a form specified by the Commission) by the consultant psychiatrist responsible for the care and treatment of the patient and also authorised (in a form specified by the Commission) by another consultant psychiatrist following referral of the matter to him or her by the first-mentioned psychiatrist' (Irish Statute Book). The campaigners argued for the complete deletion of both 'unable' and 'unwilling', thereby seeking the end of forced administration of ECT. In 2010, as a result of the campaign, a proposal to delete section 59b was discussed in the Irish Senate with representations by the campaigners and other interest groups including Amnesty International Ireland and the College of Psychiatry of Ireland, both of whom had contrasting views about the deletion of section 59b. As a result of these deliberations the term 'unwilling' to consent to the administration

of ECT was deleted from the Mental Health Act, 2001 (s. 59 (1) (b)). The Bill was signed into Law by the President of Ireland in December 2015 with one national paper giving the impression that compulsory ECT had now been 'outlawed' (Irish Examiner, 2015). The reality however is that people can still be administered ECT without their permission once they are deemed 'unable' to consent by their treating psychiatrist and another psychiatrist under the 2001 Act (Irish Examiner, 2016).

Examples of service development initiatives

Two examples of service development initiatives, both outside of and within the formal mental health services, are those of Slí Eile Housing Association and West Cork Mental Health Services.

The idea for what is now known as the Slí Eile Housing Association first emerged in the early 2000's when Joan Hamilton, the founder of Slí Eile, having become increasingly frustrated, angry and disillusioned with the psychiatric system in which her daughter found herself, developed, with a number of like-minded individuals, 'another way' (Slí Eile in Irish) in supporting people caught up in the psychiatric revolving door system. Following a period of setting up the organisation, its first housing and support project opened in 2006 in Charleville, a small market town in Co. Cork, after various months of protests by local residents against having people with mental health problems living together in a house in their residential area. This was followed in 2012 by a move to a 50 acre organic farm, which offers people experiencing mental health difficulties a place where they can find safety, acceptance and support to recover through supported housing and structured farming and horticultural activities (www.slieile.ie). Slí Eile is partly funded by the state mental health services. In addition to a small number of paid staff, Slí Eile draws on volunteers who make valuable contributions to the day to day activities on the farm. Examples such as Slí Eile reflect Sedgwick's nuanced views on the relationship between the voluntary sector and the State in building 'cross-sectional alliances' to pursue collective welfare demands (1982).

Innovative ideas and practice have also been developed within some state run mental health services. The West Cork Mental Health Services (WCMHS) have become an innovative and transformative service under the leadership and vision of Pat Bracken, a consultant psychiatrist, and a founder member of Critical Psychiatry Network, UK. The service prides itself on pioneering partnerships with community organisations, working closely with those who use services and their families in service development, and introducing innovative practices such as the Open Dialogue approach. WCMHS is an excellent example of putting the principles and values of recovery into practice.

The approaches described above can be both critical and transformative as they question self-evident mental health knowledge and practice and construct new ways of knowing and understanding human experiences of distress (Sapouna, 2016). Such approaches are therefore contributing to a shift away from medicalising human distress, while at the same time putting the voice of the service user/survivor at the centre of knowledge formation.

While these campaigns, initiatives and new practices demonstrated some transformative potential, they nevertheless remained quite isolated and fragmented. As such they did not manage to significantly influence the bigger scheme of mental health policy and practice at a national level. The need for collective action and communal solutions towards transforming mental health practice was recognised by a number of survivors, practitioners and academics.

Origins of the Critical Voices Network Ireland

Within the context of this paper we argue that mental health survivors, practitioners and academics should be active participants in engaging in such collective actions and seeking communal solutions. This was achieved by forming alliances with other voices of resistance, forward thinking stakeholders within and outside mental health systems to facilitate the development of critical spaces for rethinking the way we understand and respond to distress. The development of the Critical Mental Health

Conferences in University College Cork (UCC) and the Critical Voices Network Ireland (CVNI) are examples of such spaces.

In an attempt to provide a broader platform to discuss and debate concerns and share new initiatives and ideas, we, through our respective Schools (Applied Social Studies and Nursing and Midwifery), have organised a series of annual critical perspectives conferences in University College Cork, Ireland. These conferences are unique as they are a free event and involve people from diverse backgrounds (self-experience, survivors, professionals, academics, carers) presenting, discussing and debating critical and creative perspectives in mental health. Since 2009 these conferences have focused on themes such as recovery, medicalisation, meanings of madness, trauma and distress, the value of psychiatric diagnosis and the therapy industry. The conference, now at its eighth year, has an annual attendance of over five hundred delegates and is considered one of the most significant events of its kind nationally and internationally, attracting speakers and delegates from across the continents. The 2016 conference will focus on the area of activism and acts of resistance in mental health.

The 2010 conference saw the launch of the Critical Voices Network Ireland (CVNI) 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 bio-medical model. This network provides a democratic space with no hierarchical structures, open to everybody who wishes to join its discussions. An e-list and a Facebook page have been established for people to begin to share, debate and discuss issues of concern and different ways of working. During the first two years national and regional meetings were held quarterly which were open to all and were organised around a series of round table discussions, followed by a plenary session, focusing on creative approaches (e.g. setting up residential crisis and recovery facilities) and critical perspectives in mental health care (e.g. overuse of medication, forced 'treatment' issues, capacity legislation). Networking groups were set up to undertake work in specific areas. These debates have been enriching, and have in many ways shaped new ways of knowing about mental health issues. Whilst regional

and national meetings now take place less frequently, the CVNI continues to provide a platform for its members to make public contributions through interviews, participation in debates, letters to the editor and newspaper articles.

Since its launch the CVNI, together with the Schools of Applied Social Studies and Nursing and Midwifery UCC, has been associated with the critical mental health conferences. The CVNI, in partnership with other groups, has organised a series of public talks (including American medical journalist Robert Whitaker), seminars (including Professor of Social Work David Cohen) and a one day conference with Health Action International, focusing on conflicts of interest on the relationship of the pharmaceutical industry with science and medicine. Furthermore, the CVNI offers a resource to draw on in critical mental health education in nursing and social work, with the annual conference being part of the curriculum for mental health nursing students and for social work students. As educators ourselves we have become more active and confident in articulating critiques of biopsychiatry, in drawing on the expertise of users/survivors, in promoting partnerships with users/survivors as essential skills for practice, and in developing different ways to understand and work with 'unusual experiences' such as voice hearing experiences. As members of the CVNI we have also been part of establishing a University-wide disability and mental health research cluster, which aims to explore the meanings of mental health and disability with a particular focus on building capacity for critically-informed and engaged research and mad activism in academia. Since the launch of the network the CVNI has struggled to be a prefigurative example of 'mutual aid' (Sedgwick, 1982), in other words to consistently model a democratic way of self-organisation and action. We think that the biggest challenge for the CVNI is to establish itself as a politically engaged movement and to influence mental health issues at a wider socio-political level.

Conclusion

In this paper we have described and discussed the emergence of the Critical Voices Network Ireland (CVNI). We have given examples of actions and initiatives within and outside mental health systems that have contributed to a broader understanding of

human distress. The CVNI emerged to provide a collective response to concerns around the dominance of biopsychiatry in Irish mental health systems. Through the CVNI an environment has been created where different and sometimes conflicting voices and agendas can be heard and respected rather than silenced. Professionals, students, people with experience have a free exchange as part of this environment. This can be a challenging process. Questioning mental health practice can be unsettling as it may require positions of certainty to be reviewed and possibly relinquished. Nevertheless the power of these exchanges lies in the opportunity to tell stories, to make sense of experiences and to reconstruct meanings, particularly previously silenced meanings. We hope that the CVNI continues to provide such a space but that it will also engage more explicitly with social activism and acts of resistance.

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Education for critical practice in mental health: opportunities and challenges

Citation: Sapouna, L. (2016) Education for critical practice in mental health: opportunities and challenges, *Critical and Radical Social Work,* 4 (1): 59–76.

This is a post-peer-review, pre-copy edited version of an extract/chapter published in *Critical and Radical Social Work*. The definitive publisher-authenticated version: Sapouna, L. (2016) Education for critical practice in mental health: opportunities and challenges, *Critical and Radical Social Work,* 4 (1): 59–76, is available online at: http://dx.doi.org/10.1332/204986016X14525988005449

Abstract

This article discusses an approach to mental health education that aims to prepare students to become critical practitioners with a vision and skills to understand human distress in life contexts. This approach questions traditional knowledge-formation in mental health as it is not focused on psychiatric diagnoses as a tool to learn about 'mental illnesses'. It also involves rethinking issues of power, language and identity by encouraging students to question what is often experienced as an oppressive, coercive mental health system and by putting the voice of service-users/survivors in the centre of practice. Such an education often clashes with the ethos and practice of current mental health services which, despite heralding a recovery agenda, remain in their majority medical in focus. Drawing from the author's experience in mental health education, the paper highlights the potential of educational processes to transform hegemonic practice and the challenges and opportunities contained in this process.

Keywords: mental health, social work education, critical practice, power, identity

Introduction and background

Over the past twenty years of teaching mental health on undergraduate and postgraduate professional social work programmes in University College Cork (UCC), Ireland, my thinking and educational approaches have changed considerably. An on-going challenge during this time has been managing the tension between my commitment to social justice and the expectation to prepare students for practice in a predominantly biomedical context, which is often experienced as coercive. At several points throughout these years, I found myself becoming frustrated with the apparent incompatibility between critical thinking and the 'reality' of practice, possibly feeding into the view that critical thinking is only suitable for the 'ivory tower' of academia but not for 'real life'. Indeed, my teaching became stagnant at times, as I was lacking resources to provide education for meaningful alternatives to the dominant way of thinking and practicing in mental health.

Realising that a part of the problem was seeking resources inwards (i.e. within existing systems) rather than outwards, I started developing more systematic links with service-users/survivors, mental health campaigns and advocacy groups. I also started collaborating with other professionals who had identified the need for a more democratic, user-centred mental health practice. Through such links, a pool of diverse resources was created including: enhanced input of service-users in mental health education; conference co-organisation; co-authored publications; dissemination of user-led research; and service-user involvement in student selection and professional course accreditation processes. Such coalitions also created possibilities to develop critical spaces inside and outside the University to consider mental health practice. An Annual Critical Perspectives Conference, now fully integrated in the social work mental health curriculum and the emergence of the Critical Voices Network Ireland (CVNI) are two examples of creating such critical spaces within and beyond professional education. A lot of work remains to be done to bring user-experts as equal partners in the Irish social work education system, a discussion that goes beyond the scope of this paper. However these 'outside the box'

alliances, and the emerging critical forums, have created opportunities for some form of co-production which has a transformative potential (Needham and Carr, 2009).

This form of co-production has transformed my own approach to mental health education as I had to rethink my ways of knowing and teaching. It has also provided me with resources to facilitate students' engagement with transformative practice through:

- Moving away from a focus on symptoms to exploring experiences of distress in life contexts
- Challenging medical hegemony through recovery-informed practice
- Developing a commitment to meaningful user involvement.
  (Brosnan and Sapouna, 2015)

This article draws from my experience as a mental health educator and discusses aspects of course curriculum and teaching approaches which aim to facilitate critical practice. Challenges in this process are considered on the basis of feedback received from students over the years. The student feedback discussed in this article is informed by end-of-module written and verbal evaluations. The discussion begins by outlining the context of mental health social work in Ireland and considers the contribution of education in transforming dominant biomedical practice. It is argued that such a transformation should involve rethinking issues of knowledge-formation, power-operation, language, narrative and identity all of which are components of critical practice (Fook, 2002). Selective aspects of course curriculum and teaching approaches that can contribute to this process are then discussed. These include:

- Rethinking knowledge formation: social work addressing life contexts
- Rethinking narrative, language and identity: engaging with voice-hearing
- Rethinking power: engaging with critical spaces- the Critical Voices Network Ireland.

Student feedback and student experiences from mental health placements are then considered and the challenges of upholding social work values in hegemonic practice contexts are discussed. This paper does not cover the full range of themes and

approaches used in the classroom, neither does it address all the significant aspects of critical education. It is rather a consideration of some examples that highlight the potential of education to transform dominant ways of thinking and practicing in mental health.

Mental health social work in Ireland

In recent times we have seen possibilities for change in the field of mental health in Ireland. These possibilities go beyond shifting the location of care from institutional to community settings towards exploring experiences of human distress and recovery within a social context. The need for reform of the Irish mental health services is almost universally accepted as necessary (Sapouna, 2006; MacGabhann et al, 2010; Bracken, 2012; Higgins and McDaid, 2014;). A bio-psycho-social as opposed to a purely biological approach to mental health providing a comprehensive, recovery-oriented and person-centred service has been advocated by key Irish policies such as *A Vision for Change* (Department of Health and Children, 2006) and the *Recovery Approach within the Irish Mental Health Services* (Mental Health Commission, 2008).

Nevertheless, despite the rhetoric of change, policy implementation has been slow and inconsistent across the country (Mental Health Commission, 2013). The economic crisis is considered to have 'stalled' this process due to its impact on resource allocation with health sector cutbacks impacting disproportionally on mental health services. However, there is a serious danger that as a society, due to fear and financial insecurity at the present time, we consider the lack of resources as *the problem* and advocate for the maintenance of services which can often be experienced as unhelpful and/or damaging by people who use them. A preoccupation with the lack of resources fails to see that the problem lies within the current mental health system, including attitudinal values, power imbalances between professionals and service users and the hegemony of the biomedical model in defining and treating human experiences of distress (Brosnan and Sapouna, 2015).

Indeed, over the past number of years there has been an increasing articulation of concerns about the current state of mental health services in Ireland. Such concerns include the inhumane physical conditions in hospital units, over-

reliance on and excessive use of medication, lack of meaningful community-based alternatives to hospitalisation, forced treatment, abuse of professional power, lack of information and choice in relation to 'treatment' options (Gijbels and Sapouna, 2011). Despite the rhetoric of a bio-psycho-social approach the main responses to people in distress remain medical/pharmacological in nature (Bracken et al., 2012).

Within this predominantly medical framework of thinking and practising, mental health social workers often consider themselves powerless to articulate a valid 'social' approach to emotional distress and to question practices of coercion. Yet, what service-users want is a social approach to practice which can make their contact with services more meaningful and 'human' (Brosnan, 2013). Social work is located at the interface between the person and their social environment and is therefore ideally placed to engage with the context of people's lives, a long-neglected element in biomedical mental health services. While there are several examples of social workers in Ireland engaging with social recovery approach to practice, overall, the profession has yet to articulate a confident social approach to mental health. Many multidisciplinary teams still operate without a full-time social work post, and within a predominantly medical hegemony there has been a limited space to consider a broader holistic practice. As a result, students on mental health placements don't always have the opportunity to witness a confident expression of such practice. Such practice is crucial in addressing the connections between people's emotional distress and life experiences (Brosnan and Sapouna, 2015).

Within interdisciplinary contexts there is still a tendency to view the primary role of social work as responding to practical concerns in people's lives such as welfare benefits, housing, and employment. While this focus is not an insignificant or 'lesser' role for social workers, such a role does not in self lead to a broader understanding of emotional distress. Students need to embrace a social approach to practice which views emotional distress as a meaningful response to problems of living, trauma and adverse life experiences, rather than a chemical imbalance. This is an approach in which context, relationships, and meanings are put at the centre of our interventions (Bracken and Thomas, 2005). This is also an approach that addresses issues of oppression and injustice often experienced by people using mental health services. Such an approach involves a radical rethink of knowledge,

power, language and identity and social work education has a significant contribution to make in this process.

Social work education as a critical space

Social workers have distinctive practice capabilities in working alongside people and supporting them to overcome barriers to achieving their potential by adopting a community, as well as an individual, perspective. However, their potential to fully embrace this role can be seriously impeded by the identity social work has developed over the past two decades in Ireland. Social work as a profession seems to be increasingly defined by procedural, managerial guidelines to practice (McGregor and Quin, 2015) and focused on individualised work and risk management (Ferguson, 2010). In this context, there is a danger that the role of social work education can be reduced to preparing students for procedurally correct practice, with a primary focus on managing individual difficulties, while a consideration of broader contextual factors is often viewed as 'too abstract' to be useful in practice. In the area of mental health such a trend is often witnessed in the argument of some social work students and practitioners that education focusing on critical or social perspectives does not adequately prepare students for practice in the current context of mental health services.

This article does not aim to polarise 'broad social' vs. 'narrow medical' education as such a binary is unhelpful and can feed into another type of superiority strive. Social workers need to move beyond binaries and engage with the complexity and diversity of human experience while being cognisant of agency, culture and structural contexts. This can be facilitated by the creation of a critical space in social work education to rethink about (Fook, 2002):

- Knowledge about experiences of human distress; this involves questioning dominant hegemonies in mental health knowledge-formation and recognising that user/survivor knowledge is vital in exploring the context and the meaning of human distress.
- Operations of power; this involves understanding powerlessness as a precursor of distress and the importance of empowerment, choice and dignity as cornerstones of the recovery process.

- Language and narrative; this involves a shift away from the language of symptoms and individual pathology towards locating people's narratives and meanings in the centre of social work practice.
- Identity; this involves a move away from the identity of the 'patient' to an understanding of the multiple and diverse aspects of people's lives. It also involves a validation of the emerging identities of user/survivors as equal partners in mental health practice.

A critical approach to education promotes knowledge-formation beyond the domains of formal knowledge and self-reflection, towards critical action in the domain of the world (Barnett, 1997). Ultimately a critical approach to mental health education can be transformative as it seeks to change the way we understand and respond to human distress. To operationalise such a transformation, social work students require a value-base which is informed by the principles of empowerment, social justice, anti-oppressive practice and genuine partnerships that recognise the expertise of people with experiences of distress (Brosnan and Sapouna, 2015). Social work students also require a knowledgebase that gives them confidence to advocate for a holistic, social approach. Social approaches are often considered to be lacking a coherent body of theory backed up by research compared to the medical perspective (Tew, 2011). Social work students need to be informed of the research evidence demonstrating the strong links between life adversity and emotional distress.

Rethinking knowledge-formation: social work addressing life contexts

Our mental health curriculum includes a significant body of research challenging beliefs that madness can be explained without reference to the context of people's lives. This research problematises the excessive preoccupation with chemical imbalances and genetic predispositions as causes of human misery, including the conditions that are given the name 'schizophrenia' (Rapley et al., 2011; Read and Dillon, 2013). Furthermore, the role of the pharmaceutical industry in promoting a narrow biomedical approach to treating human distress has increasingly been called into question (Angell, 2005; Moncrieff, 2008; Whitaker, 2010).

Mental health education considers how life events and broader environments affect the likelihood of experiencing distress at some stage in our lives. Research confirms the relationship between inequality and poorer mental health, with particularly strong correlations between the incidence of distress and disadvantage including unemployment, homelessness, lack of education and being brought up in socially disadvantaged areas (Rogers and Pilgrim, 2010; Read et al., 2013). Furthermore, a considerable body of research has correlated membership of social groups that are subject to systematic experiences of oppression or disadvantage with higher rates of mental health difficulties (Fernando, 2003; 2011). A 2009 World Health Organisation (WHO) report concluded that 'levels of mental distress among communities need to be understood less in terms of individual pathology and more as a response to relative deprivation and social injustice, which erode the emotional, spiritual and intellectual resources essential to psychological wellbeing' (WHO 2009, p.iii).

Irish policy identifies poverty as a key risk factor for poor mental health (Department of Health and Children, 2006; National Economic and Social Forum, 2007). Irish health statistics consistently show that people from lower socio-economic backgrounds are up to seven times more likely than their middle/upper class counterparts to enter the inpatient psychiatric system (Daly and Walsh, 2013). Mental Health Reform (2012) highlighted the risk to the social and economic lives of people with poor mental health in Ireland and the social exclusion experienced by people with mental health difficulties. In the context of the economic crisis and austerity, mental health service -users in Ireland are acutely affected by poor housing, loss of employment and service cutbacks. The subsequent increased stress has had an adverse effect on family relationships, in some cases contributing to relationship breakdown and the onset or deterioration of emotional distress (Brosnan and Sapouna, 2015). The link between poverty, disadvantage and use of mental health services is certainly not a new phenomenon. Asylums and madhouses have historically been filled by poor people. Foucault's seminal work Madness and Civilization (1971) provides a critical insight into the social significance of the great confinement as a project of isolating the poor, the insane and other 'forms of uselessness' from society in order to protect social order.

International research indicates that the experience of injustice and inequality may be more damaging to mental health than the absolute levels of deprivation (WHO, 2009; Read et al., 2013). An influential contribution to this argument comes from the research of Wilkinson and Pickett (2009), which identifies the profound effects of living in unequal societies. Their research summarises multiple studies demonstrating that poverty leads to exclusion from community life and, from a sense of belonging and being valued, all of which result in people suffering 'social pain'. This argument fits in with other evidence suggesting that inequality and injustice feed into a sense of 'otherness', worthlessness and shame (Janssen et al., 2004).

Social justice can facilitate the consideration of other explicit experiences of discrimination and injustice such as sexism, racism, homophobia, ageism, and also more subtle experiences of being made to feel powerless or inferior. Within educational settings it is important to acknowledge the evidence from both Irish and international research on distress within ethnic minorities, migrant populations (Lakeman and Mathews, 2010; Fernando, 2011) and lesbian, gay, bisexual and transgender groups (Higgins et al., 2011). This research can provide a useful framework for student social workers to consider the experiences of people from marginalised and/or disadvantaged groups on the basis of the personal story of the individual in the social context of their lives. Such a framework can help students to think beyond individual methodologies towards community development and social action approaches with groups that have been traditionally excluded.

Nevertheless, while social workers focus on people's life contexts, they are not experts in people's lives. In that sense, it is vital to stress again that a binary between a 'coercive' medical model and a 'progressive' social model is unhelpful. Furthermore, a social approach is not in itself a meaningful alternative to biomedical hegemony. As Szasz (2008) warns 'nonmedical mental health and counselling professions are medicalisation cubed: as if to compensate for their lack of medical knowledge and qualifications, nonmedical mental-health "professionals" are even more deeply committed than psychiatrists to their claim of special expertise in the diagnosis and treatment of mental illness' (2008, p. 31). On a similar note, Manchester (2015) argues that social perspectives have been assimilated into the

prevailing bio-psycho-social paradigm and 'remain an adjunct to the view that people with mental health problems inevitably have some kind of pathological flaw that needs fixing, whether biological or psychological or both' (p.150). Rather than being preoccupied with the credibility of the social work role and perspective, it may be more helpful to take a grassroots approach in which survivors' language and narratives are the centre of education and practice.

Rethinking narrative, language and identity: Engaging with voice-hearing

In order to actively listen to users' meanings and stories, it can be important to engage with forms of expression and language which may be unconventional and perhaps unfamiliar to mental health professionals (Tew, 2002). In preparation for student engagement with such forms of expression our mental health curriculum includes methodologies of working with people who hear voices and/or have other unusual sensory experiences. A key premise of this approach is that voice-hearing experiences are not viewed as pathological symptoms but rather as emotional responses to traumatic life events. This approach challenges traditional biomedical practice and presents a new territory for mental health social workers who have been traditionally taught not to engage with 'auditory hallucinations' as such engagement may intensify psychotic symptoms.

Traditional psychiatric practice treats voice-hearing as a classic symptom of schizophrenia, a meaningless pathological phenomenon which is a product of genetic and cognitive brain faults. On this basis, professionals have nothing to offer to voice hearers who seek help other than medication to eliminate the voices (Corstens et al., 2008). However, the ground-breaking research of Dutch social psychiatrist Marius Romme and his co-researcher Sandra Escher pioneered a new approach to understanding voice-hearing experiences by firmly establishing that voices make sense in the context of the traumatic events that provoked them (Romme and Escher, 2005). In contrast to the traditional psychiatric approach which views voice-hearing as purely a pathological symptom, Romme and Escher's research with over 350 voice hearers has shown that between 70 and 80% of people who hear voices have had some traumatic experience which they connect with hearing voices (Romme and Escher 2000; 2005). As Dillon and Longden (2012, p.130) propose, 'hearing voices in

itself is a normal human experience that is often a reaction to a traumatic or intensely emotional event that has not been adequately resolved'. Voice hearers who come to the attention of psychiatric services are often stuck in destructive communication patterns with their voices. An alternative approach is based on helping people make sense of their voices and learning to cope with them (www.hearingvoicesmaastricht.eu). This radical shift from the pathologising language of *auditory hallucinations* to the ordinary language of *hearing voices* can be a tool to transform thinking and practice in mental health care. It also presents an opportunity for people who have been primarily defined through their diagnosis to reclaim new identities through exploring their experiences.

The Hearing Voices Network (HVN), founded over 25 years ago, is now an international movement and an influential example of people getting together as peers to share experiences and understandings of voice-hearing experiences. HVN (www.hearing-voices.org) aims to respect the ways in which individuals understand their own experiences of voices and Hearing Voices groups offer support by providing voice hearers with the space to talk freely about the issues which they feel affect them. As Tew (2011) argues '[j]oining the Network has enabled many people to reclaim their identities as no longer passive victims of a medical condition but active human beings who (sometimes) hear voices and have their own ways of dealing with any distress that may arise from this' (2011, p. 27). Discussing the contribution HVN approaches can make to mental health social work, Sapey and Bullimore (2013, p.624) suggest that social workers need to:

- Develop a different understanding of voices to the traditional view of biomedical psychiatry, that they are hallucinations, indicating an underlying illness.
- Develop positive attitudes to voice hearers, respecting their expertise and experiences as valid.
- Understand the role of childhood trauma, particularly abuse and neglect in the development of voices.
- Develop therapeutic skills so as to work with voice hearers and with voices.

Helping social work students to understand the relationship between individual history and psychotic symptoms is of crucial importance. Perhaps the most influential body of evidence that has emerged over the past two decades in relation to life events and psychiatric diagnoses is the research linking childhood adversity and psychosis, a condition that has been traditionally treated as a biochemical problem. 'Until very recently the hypothesis that abuse in childhood has a causal role in psychosis was regarded by many biologically oriented psychiatrists as heresy' (Read and Bentall 2012, p.90). In the past decade however there has been an avalanche of ground-breaking international studies showing that adverse life events, trauma, loss and neglect in childhood increase vulnerability to emotional distress. A recent meta-analysis by Varese et al. (2012) confirms this link between trauma and psychosis. In addition, many studies demonstrate the powerful relationship between all forms of child abuse and schizophrenia (reviewed by Read et al., 2004). People subjected to childhood physical or sexual abuse are more likely to be admitted to a psychiatric hospital; have earlier, longer and more frequent admissions; receive more psychiatric medication; are more likely to self-harm and to try to kill themselves; and have higher global symptom severity (Read and Bental, 2012, p.89-90). One of the most robust of these studies was a prospective study of 4,000 people in the Netherlands which found that those who had suffered 'moderate' abuse during childhood were 11 times more likely, and those who had suffered 'severe' childhood abuse 48 times more likely, to have 'pathology level psychosis' than people who had not been abused as children (Janssen et al., 2004).

These research developments are only significant if mental health professionals act upon them by asking people 'what happened' in their lives and responding respectfully to the stories they hear. Hammersley et al (2008) argue that '[t]he current approach which asks people what is wrong with you?' rather than 'what has happened to you?', misses the crucial point that all distress and behaviour, however seemingly bizarre, is a meaningful attempt to survive maddening experiences in what for some of us can be a crazy world' (Hammersley, Langshaw, et al., 2008, p.19).

Social workers, as a profession carrying psychosocial assessments, need to find a language to ask questions that haven't been asked before about people's lives including questions about abuse, bullying, neglect and loss (Read, 2013). Through such questions professionals can facilitate people to make connections 'between elements of experience that had previously seemed confusing or contradictory' (Tew, 2002, p.146) and take control of their own recovery.

Nevertheless, it is also important not to always assume the existence or denial of experiences of trauma and abuse. As professionals we can facilitate conversations about meanings, but we are not the makers of the meaning. As Tew (2002) argues, such an approach would require a commitment to hear and take seriously what people may have to say about their emotional distress, their life experiences, and the meanings, histories and hopes that they attach to them. Listening to people in their own terms and language has been identified as a missing component from current practice (Rogers et al., 1993; Hepworth and McGowan, 2012). This kind of listening can challenge traditions of biological psychiatry in which the voice of the service-user is primarily used to diagnose disorders and interpret experiences for people.

Professionals' willingness and ability to accept people's accounts of their experiences, including voice-hearing experiences can have a major influence on outcomes for people diagnosed with schizophrenia (Dillon and Longden, 2012). Practitioners who work with voice hearers suggest that 'in our experience, talking with voice hearers doesn't provoke psychosis... Most voice hearers find it liberating to be respectfully questioned about their voice hearing experiences and feel acknowledged by it. For some, only this kind of assessment produces profound change' (Corstens et al., 2008, p.321).

There is a need for social work students and practitioners to acquire the knowledge, skills and values to work with diverse voices. In Ireland since 2012 a number of voice hearers and professionals, including social workers, have participated in 3-day training programmes by Jacqui Dillon (herself a voice-hearer) on Hearing Voices Support Group Facilitation. Since then, over twenty groups have been set up in Ireland, both within and outside mental health services, with the Hearing Voices Network Ireland (hearingvoicesnetworkireland.ie) being officially launched in April 2015. Although recent in the Irish context, international experience

has demonstrated that hearing voices groups are effective communal solutions that enable people to make profound positive changes in their lives (Dillon et al., 2013).

This article argues that social workers should be active participants in seeking such communal solutions. This can be achieved by forming alliances with other voices of resistance, forward thinking stakeholders within and outside mental health systems to facilitate the development of critical spaces for rethinking the way we understand and respond to distress. The following section discusses the development of the Critical Mental Health Conferences in UCC and the Critical Voices Network Ireland (CVNI) as examples of such spaces which are also an integral part of social work education.

Rethinking Power; engaging with critical spaces

Over the past number of years, new approaches have emerged to address concerns about the current state of mental health services in Ireland. These approaches recognise that the bio-medical strategy in mental health care today will at best provide temporary symptomatic relief (which may be valid as a first step), but may compound, exacerbate and even cause further deep distress. Current responses to distress fail to capture the complexity of human experiences by ignoring the underlying grief, heartbreak and trauma in people's lives. These new approaches also recognise that the whole person needs to be centrally engaged in their own recovery (Gijbels and Sapouna, 2011).

Such approaches can be both critical and transformative as they question self-evident mental health knowledge and practice and construct new ways of knowing and understanding human experiences of distress (Sapouna, 2012). Such approaches break the silence of 'madness', moving it from nothingness to community engagement and visibility, often celebrating the 'gift' and 'normality of madness' (McCarthy, 2011). For example, Madpride Ireland's family fun days are a lively public event in a central park in Cork city. Madpride Ireland's founder, John McCarthy, says 'we believe that the best way to promote understanding of issues surrounding mental health is to engage the community through active participation in a fun environment. We do that by hosting family events that are inclusive, fun and suitable for children, teenagers, adults and families. These events do not bombard people

with pamphlets extolling the virtues of one approach over another. Rather they show the world that madness is an everyday occurrence that affects us and can be dealt with openly, lovingly and without fear. Have we opened the national debate on mental health? We sure have' (Madpride Ireland, 2012).

Key actors in the development of this new thinking are diverse but represent people who describe themselves in such terms as service users, survivors, patients, members of the mad community, carers, family members, practitioners, professionals, academics and the lay public, all of whom are dissatisfied with current forms of care and its underpinning bio-medical philosophy. In an attempt to provide a broader platform to discuss and debate concerns and share new initiatives and approaches, a series of annual critical perspectives conferences have been organised by the Schools of Applied Social Studies and Nursing and Midwifery, UCC, since 2009. Now at its seventh year the conference, attended by over five hundred delegates over two days, is considered one of the most significant events of its kind nationally and internationally, attracting speakers and delegates from across the continents. The critical perspective conferences are unique as they involve people from diverse backgrounds (self-experience, survivors, professionals, academics, carers) presenting, discussing and debating critical and creative perspectives in mental health. The Critical Voices Network Ireland (CVNI) emerged out of these deliberations 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 bio-medical model. This network now provides a democratic space with no hierarchical structures, open to everybody who wishes to join its discussions. An e-list and a Facebook page have been established for people to begin to share, debate and discuss issues of concern and different ways of working. These debates have been enriching, and have in many ways shaped new ways of knowing about mental health issues. Since early 2011 the network has held meetings which are open to all and have been organised around a series of round-table discussions, followed by a plenary session, focusing on creative approaches (e.g. setting up residential crisis and recovery facilities) and critical perspectives in mental health care (e.g. overuse of medication, forced 'treatment' issues, capacity legislation). Networking groups have been set up to undertake work in specific areas (Gijbels and Sapouna, 2011).

An important aspect of these developments is the beginning of a dialogue between stakeholders who have been separated in the past. Through the CVNI an environment has been created where different and sometimes conflicting voices and agendas can be heard and respected rather than silenced. Professionals, students, and people with self-experience have a free exchange as part of this forum. This is not always an easy exchange. Challenging mental health practice can be unsettling as it may require one's positions of certainty to be reviewed and possibly relinquished. But the transformative potential of this space can also encourage professionals to recognise that there are many truths, to shift from a position of certainty and to strive to understand the Other. Through these exchanges there is an opportunity to tell stories, to make sense of experiences and to reconstruct meanings, particularly previously silenced meanings (Sapouna, 2012). For the past seven years the critical perspectives conference has been an integral part of the mental health modules on both undergraduate and postgraduate social work programmes in UCC. The following section, informed by student evaluations and feedback, considers the student experience of engaging with critical mental health education.

The educational impact of critical perspectives; Opportunities and challenges

The feedback of social work students who have attended the critical perspectives conferences over the past seven years has been overwhelmingly positive, with many students saying that the 'conference is the best part of the mental health module'. Having such an event fully integrated in the educational curriculum provides students with opportunities to be in a space where different forms of knowledge- formation, learning and exchange take place.

Students appreciate the opportunity to listen to survivor, carer and professional perspectives and the diverse approaches and languages used in the deliberations. They also enjoy being part of an environment which has been described by participants as egalitarian and democratic, with a positive 'buzz' in the atmosphere, lively discussions in university corridors and over coffee. As one student said after last year's conference '*I was sitting next to someone and didn't know whether they are a professional or a service-user, it didn't matter and this was so*

refreshing'. Students also appreciate being in a space where survivor narratives are considered a valid way of learning about good practice. On the other hand, critical comments suggest that, at times, services and professionals are portrayed in a negative way and this can be discouraging for students who are about the enter the world of practice. Over the years a few delegates, including students, have said that they found the expression of emotion and anger towards mental health services uneasy and unsettling while others recognise that such emotions should be respected as real parts of the lives of people they will be working with.

Recognising the relationship between the emotional content of the issues debated and the capacity of dialogue within these spaces to achieve change is an important educational experience (Barnes, 2008). This process provides opportunities for capacity-building through learning to deal with complex issues of practice, learning not to avoid issues of injustice and oppression because they are emotionally changed. It is also an opportunity to be part of a process that models co-production as a tool to transform practice through a shift in power and control (Needham and Carr, 2009). In this shift, drawing from personal experience is central to the process of organising social movements and transformative practice as 'technical or expert knowledge alone is inadequate to the resolution of social problems, since the issues such problems raise are also political and ethical' (Barnes, 2008, p. 468).

Feedback on classroom-based learning follows similar trends while presenting some additional challenges. Overall, social work students tend to give positive feedback to the broader social perspective and the user-focused values embraced in the classroom, with many students describing the mental health module as 'thought provoking', an 'eye-opener', a course that generated an interest in area of practice they have not considered before. However, some students also question the extent to which this module prepares them for practice, by not covering enough 'mental health conditions' and by not providing enough information on the 'medical model'. For example, over the past four years of including more material on voice-hearing experiences in the classroom, some students have found that there was too much emphasis on psychosis at the expense of other conditions, such as 'depression' and 'anxiety'. These conditions are considered by students to be more common in

social work caseloads. Other critical comments suggest that the module does not provide a 'balanced' input between the medical and social approaches and, as a result, students may not be well equipped to work in predominantly biomedical practice setting.

The experience of UCC social work students who have undertaken a mental health placement has not been systematically researched. Through verbal feedback many students report that they benefited from the value-base they developed through the mental health module which allowed them to take an advocacy/human rights approach to practice. Other students argue that they struggled with what they described as 'a requirement to speak the medical language' and the need to know more about diagnoses in order to have a voice in the multidisciplinary team. Most student experiences of placement suggest that discussions about service delivery are dominated by biomedical frameworks, a trend evidenced in: clinical responsibility and leadership of the multidisciplinary team remaining with the consultant psychiatrist; criteria for intervention being based on clinical diagnosis; hegemonic views on mental 'illness' and subsequent 'cures' within the various disciplines; the use of medical terminology in contemporaneous case notes/discussions, case conferences, team meetings and ward rounds (Clifford, 2014).

Some social work students who have completed mental health placements report that their education is not perceived as 'balanced' by their practice teachers, some of whom view it as disproportionately favouring a 'social model'. The problem with this view of 'balance' however is that it assumes a binary between 'social and medical models' (often described as 'two sides of the story'), rather recognising that there are indeed many stories. As argued earlier, advocating the superiority of social model over a medical model fails to recognise that a model-based way of looking at human difficulties fails to capture the complexity of human distress (Bracken, 2007). In that sense social work education may be better framed as a *balancing* rather than a *balanced* act (Newnes, Holmes and Dunn, 1999; Read and Dillon, 2013), by providing a balancing view to the hegemonic expert models that dominate professional education and practice.

The participation of user-survivors in social work education is a key element of this balancing act which validates new ways of knowing about experiences of

distress and, therefore, contributes to a shift in power imbalances. Survivor narratives in our social work programmes are particularly appreciated by students as some of the following quotes suggest:

"As a social worker I would now look at the normal, everyday life of the service user"

"…what struck me was the emphasis on the normality of depression…they brought the subject to a more human level"

"…great insight into the road of recovery and what wellness means.."

"…it is important to look at clients' situation from a holistic point of view before subscribing supports that don't work…"

Survivor accounts through classroom, conference and video presentations have exposed students to some powerful stories. However, this presents its own challenges as the focus on and the curiosity about the personal testimony can endanger a culture of voyeurism (McFarlane, 2001, 2006). User involvement is more than a narrative, it is a value for a more democratic way of working and therefore the issue of power needs to be addressed. As argued by Cowden and Singh (2007, p.15-16) without addressing the issue of power 'the voice of the User becomes a fetish – something which can be held up as a representative of authenticity and truth, but which at the same time has no real influence over decision making'. With user involvement becoming increasingly mainstreamed in professional service provision and education it is important that social work education does not appropriate the user movement but recognises critical voices as essential contributors to transform the education process.

Finally, I would like to acknowledge that being at the interface of academia and survivor movements is a personally challenging task. Being an academic who works collaboratively with critically-minded survivors often requires me take a step back while creating a platform for user/survivor voices to be heard, an act of disappearance that Church (2013) describes as a political act. While such a discussion goes beyond the scope of this article it is important to say that co-teaching with survivors means that my work is not only complemented but also, at times, superseded by their dynamic, interesting and colourful insights. Over the years I am

learning to become more comfortable with stepping back and enjoying the privilege of co-production which has transformed my engagement with social work education.

Conclusion

This article considered the potential of social work education to transform dominant biomedical practice in mental health care. Within current practice contexts, social workers often find themselves powerless to articulate an alternative to the medicalisation of human distress and to challenge practices of coercion. Social work education needs to support students to embrace a critical approach to practice which views emotional distress as a meaningful response to problems of living, trauma and adversity rather than a chemical imbalance. This critical approach also addresses issues of injustice often experienced by mental health service users. In order to facilitate this process education needs to become a critical space where it is possible to:

- Rethink issues of knowledge- formation in mental health and recognise the importance of user/survivor knowledge in exploring the context and the meaning of human distress.

- Unlearn the language of symptoms and pathology; learn how to engage with people's unusual experiences and how to ask people 'what happened' rather that 'what's wrong' with them.

- Rethink issues of identity; move away from seeing people as 'patients' towards an understanding of the multiple and diverse aspects of their lives.

- Rethink issues and power; engage with critical spaces to consider different ways of responding to human distress and validate the emerging identities of users/survivors as equal partners in mental health practice.

As this approach to education challenges current mental health ideologies and practice, it is at times criticised for not preparing students for the 'reality' of service-provision. A further criticism of this approach is that it is 'not balanced', as it does not consider the medical model, often described as 'the other side of the story'. Moving beyond model-thinking, this paper proposes that social work education may be

better viewed as a *balancing* rather than a *balanced* act. This involves providing a balancing view to the hegemonic expert models that dominate professional education and practice.

A balancing act also implies that education is not an avenue for social workers to become the 'new experts' in the field of mental health but rather that the voice of users/survivors becomes central to all practice. By engaging in a paradigmatic shift and by forming meaningful partnerships with service-users, survivors and people with self-experience, social work can reclaim its social identity and respond to human distress in a way that is user-driven, respectful, context aware, and informed by human rights principles.

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Opportunities for social workers' critical engagement in mental health care

Co-authored contribution. Lead author, contributing 70% of formulation, execution, analysis, and publication.

Citation: Brosnan, L. & Sapouna, L. (2015) 'Opportunities for social workers' critical engagement in mental health care' in A. Christie, B. Featherstone, S. Quin, S and T. Walsh, *Social Work in Ireland. Changes and Continuities*, Basingstoke, Palgrave Macmillan, pp.159-177. (Reproduced with permission from Springer Nature).

Introduction

Mental health social workers in Ireland work in community and inpatient services as part of multidisciplinary teams (MDTs) aim to provide a 'holistic seamless service' and a continuum of care for mental health service users (Mental Health Commission, 2007). The structure of multidisciplinary service provision includes non-consultant hospital doctors, community mental health nurses, addiction counsellors, social workers, clinical psychologists, and occupational therapists led by a consultant psychiatrist. The unique skill social workers bring to the MDT is 'to take, as their primary perspective, a view of the individual in the context of their personal, family, cultural, and socioeconomic circumstances and to propose and carry out interventions in that context' (Mental Health Commission, 2006, p. 26). Mental health social work brings awareness of contextual/structural factors and interpersonal interactions through a diverse range of practices, including assessment of psychosocial needs, family work, counselling, advocacy, mobilizing community resources, community development, and social inclusion work.

Social work services in the Irish mental health context vary significantly. In many MDTs, social workers embrace, and often lead, a social recovery approach to practice, while in other MDTs social workers may find it difficult to promote a social perspective. The willingness of the consultant psychiatrist leading the MDT to support a social perspective is often quoted as the key factor in expanding or limiting possibilities for such practice. Given this inconsistent picture on the ground, this

chapter does not aim to provide a detailed overview of mental health social work practice in Ireland. Instead, we explore social work in relation to some key pillars of a social perspective in the context of current conceptual and policy transformations in Irish mental health.

The past decade has seen significant changes in the field of mental health that have impacted on social work practices. These changes go beyond the shift from institutional to community-care settings towards exploring experiences of human distress and recovery within a social context. The need to reform the Irish mental health services (MHS) is almost universally accepted as urgent (Sapouna, 2006; Higgins and McDaid, 2014). Key Irish policies, such as *A Vision for Change* (Department of Health and Children, 2006) and *A Recovery Approach within the Irish Mental Health Services* (Mental Health Commission, 2008), advocate a comprehensive, recovery-oriented, person-centred, biopsychosocial approach to MHS, as opposed to a purely biological orientation.

Despite the government's rhetoric of change, policy implementation has been slow and inconsistent across the country (Mental Health Commission, 2013). It has been argued that the economic crisis, with a range of cutbacks impacting disproportionally on MHS, is the main factor to have 'stalled' the process of change. However, in this chapter, we argue that by focusing on the lack of resources as *the problem,* professionals can fail to see that existing services are often experienced as unhelpful and/or damaging by people who use them. A preoccupation with the lack of resources tends to hide the problems that lie *within* the current MHS, including the attitudes and values of professionals, power imbalances between professionals and service users, and the hegemony of the biomedical model in defining and treating human experiences of distress. Despite a shift to the use of biopsychosocial discourses within MHS, the main responses to people in distress remain medical/pharmacological interventions (Bracken et al*.,* 2012).

Within this predominantly medical framework, social workers in Irish MHS often consider themselves powerless to develop a 'social' approach to emotional distress. Yet, research indicates (Brosnan, 2013) that service users want a social approach to practice that can make their contact with services more meaningful and 'human'. This requires a paradigm shift towards 'person-directed' practice (Quinn,

2013) and creating genuine partnerships between service users and professionals to facilitate a recovery process that service users direct. We are conscious that the terms 'recovery' and 'user involvement' are in danger of being assimilated within the current biomedical discourse and losing their transformative potential as a consequence. Therefore, this chapter offers a critical insight into the use of these concepts. We propose that social workers become critically engaged in mental health practice by:

- addressing the context of people's lives
- challenging medical hegemony through recovery-informed practice
- promoting meaningful service user involvement.

Addressing the context of people's lives

Social work is located at the interface between the person and their social environment and is therefore ideally placed to critically engage with the context of people's lives, a long-neglected element within the biomedical approach. While there are several examples of social workers in Ireland engaging with a social practice perspective, overall, the profession has yet to articulate a confident social approach to mental health. Many MDTs still operate without a full-time social work post, and within a predominantly medical hegemony, this limits the space for a broader holistic practice. Such practice is essential in recognizing the connections between people's emotional distress and life experiences.

Within interdisciplinary contexts, there is a tendency to view the primary role of social work as responding to practical concerns in people's lives, such as welfare benefits, housing, and employment. Responding to these concerns is important; however, this role does not in itself imply a broader understanding of emotional distress. We argue for a social approach to practice, which views emotional distress as a meaningful response to problems of living, trauma and adverse life experiences, rather than a 'chemical imbalance'. We propose a social approach in which context, relationships and meanings are put at the centre of our interventions (Bracken and Thomas, 2005). As Tew (2011, p. 2) states:

Fundamental to a social approach is the idea of being alongside people as they reclaim a life that is meaningful and satisfying to them – one that involves participating in the mainstream social world and taking roles that are valued within social, family, employment and other domains. As part of this, people may need help in making sense of what has happened to them – and how their social experiences may have contributed to their mental distress.

Social workers have distinctive practice capabilities in working alongside people and supporting them to overcome barriers to achieving their potential by adopting a community, as well as an individual, perspective. However, their potential to fully embrace this role can be seriously impeded by the way social work has developed over the past decade in Ireland, with practices being increasingly defined by managerial procedures and guidelines (Ferguson, 2010) that focus on individualized work and risk management. This definition of social work can limit the profession's potential to respond meaningfully to the unpredictable and complex situations of people's lives and address issues of injustice and discrimination.

In order to counteract these trends, social workers require a value base that is informed by the principles of empowerment, social justice, anti-oppressive practice, and genuine partnerships that recognize the expertise of people with experiences of distress. Social approaches are often considered to be lacking a coherent body of theory backed up by research compared to the medical perspective (Tew, 2011). Social workers need to be informed of the research evidence demonstrating the strong links between life adversity and emotional distress. Next, we highlight some key contributions in this area.

Injustice and adverse life experiences

A significant body of research challenges beliefs that 'madness' can be explained without reference to the context of people's lives and problematizes the excessive preoccupation with chemical imbalances and genetic predispositions as causes of human misery, including the conditions that are given the name 'schizophrenia' (Read and Dillon, 2013). Furthermore, the role of the pharmaceutical industry in promoting a narrow biomedical approach to treating human distress has increasingly been called into question (Rapley et al., 2011).

There is overwhelming evidence that life events and broader environments affect the likelihood of experiencing distress at some stage in our lives. Research confirms the relationship between inequality and poorer mental health, with particularly strong correlations between the incidence of distress and disadvantage, including unemployment, homelessness, lack of education, and being brought up in socially disadvantaged areas (Rogers and Pilgrim, 2010; Read et al., 2013). Furthermore, a considerable body of research has correlated membership of social groups that are subject to systematic experiences of oppression or disadvantage with higher rates of mental health difficulties (Fernando, 2011). A World Health Organization (WHO, 2009, p. iii) report concluded that:

> levels of mental distress among communities need to be understood less in terms of individual pathology and more as a response to relative deprivation and social injustice, which erode the emotional, spiritual and intellectual resources essential to psychological wellbeing.

Irish policy identifies poverty as a key risk factor for poor mental health (Department of Health and Children, 2006). Irish health statistics consistently show that people from lower socioeconomic backgrounds are up to seven times more likely than their middle-/upper-class counterparts to enter the inpatient psychiatric system (Department of Health and Children, 2006; Daly and Walsh, 2013). Mental Health Reform (2012) highlighted the risk to the social and economic lives of people with poor mental health in Ireland and the social exclusion experienced by people with mental health difficulties. In the context of the economic crisis and austerity, mental health service users in Ireland are acutely affected by poor housing, loss of employment and service cutbacks. The subsequent increased stress has had an adverse effect on family relationships, in some cases contributing to relationship breakdown and the onset or deterioration of emotional distress. The link between poverty, disadvantage and use of mental health services is certainly not a new phenomenon. Asylums and madhouses have historically been filled by people living in poverty. Foucault's seminal work *Madness and Civilization* (1971) provides a critical insight into the social significance of the great confinement as a project of

isolating the poor, the insane and other 'forms of uselessness' from society in order to protect social order.

International research indicates that the experience of injustice and inequality may be more damaging to mental health than the absolute levels of deprivation (WHO, 2009; Read et al., 2013). An influential contribution to this argument comes from the research of Wilkinson and Pickett (2009), which identifies the profound effects of living in unequal societies. Their research summarizes multiple studies demonstrating that poverty leads to exclusion from community life and from a sense of belonging and being valued, all of which result in people suffering 'social pain'. This argument fits in with other evidence suggesting that inequality and injustice feed into a sense of 'otherness', worthlessness and shame (Janssen et al., 2004).

A social justice framework can facilitate the consideration of explicit experiences of discrimination and injustice, such as sexism, racism, homophobia, ableism, ageism, and also more subtle experiences of being made to feel powerless or inferior. A consideration of identity and the intersectionality of oppression and discrimination, with consequent mental health challenges, is beyond the scope of this chapter. However, it is important to acknowledge the evidence from Irish and international research on distress within ethnic minorities, migrant populations (Lakeman and Mathews, 2010; Fernando, 2011) and lesbian, gay, bisexual and transgender groups (Higgins et al., 2011). Social workers need to consider the experiences of people from marginalized and/or disadvantaged groups on the basis of the personal story of the individual in the social context of their lives.

Childhood adversity and psychosis

Perhaps the most influential body of evidence that has emerged over the past two decades in relation to life events and psychiatric diagnoses is the research linking childhood adversity and psychosis, a condition that has traditionally been treated as a biochemical problem: 'Until very recently the hypothesis that abuse in childhood has a causal role in psychosis was regarded by many biologically oriented psychiatrists as heresy' (Read and Bentall, 2012, p. 90). However, in the past decade, there have been a number of ground-breaking international studies showing that

adverse life events, trauma, loss and neglect in childhood increase vulnerability to emotional distress. A recent meta-analysis by Varese et al. (2012) confirms this link between trauma and psychosis. In addition, many studies demonstrate the powerful relationship between all forms of child abuse and schizophrenia (reviewed by Read et al*.,* 2004). People subjected to childhood abuse:

- are more likely to be admitted to a psychiatric hospital;
- have earlier, longer and more frequent admissions;
- receive more psychiatric medication;
- are more likely to self-harm and to try to kill themselves;
- experience more severe symptoms (Read and Bentall, 2012).

One of the most robust of these studies was a prospective study of 4,000 people in the Netherlands, which found that those who had suffered 'moderate' abuse during childhood were 11 times more likely and those who had suffered 'severe' childhood abuse 48 times more likely to have 'pathology level psychosis' than people who had not been abused as children (Janssen et al., 2004).

Of particular interest is the work of Dutch social psychiatrists Marius Romme and Sandra Escher (Romme and Escher, 2005), who pioneered a new approach to understanding voice-hearing experiences. Traditional psychiatric practice treats voice-hearing as a classic symptom of schizophrenia, a meaningless pathological phenomenon that is a product of genetic and cognitive brain faults. On this basis, medical practitioners have nothing to offer to voice-hearers who seek help other than medication to eliminate the voices (Corstens et al., 2008). In contrast to this approach, Romme and Escher's (2005) research with over 350 voice-hearers has firmly established that between 70 and 80% of people who hear voices have had some traumatic experience that they connect with hearing voices. As Dillon and Longden (2012, p. 130) propose: 'hearing voices in itself is a normal human experience that is often a reaction to a traumatic or intensely emotional event that has not been adequately resolved'. Voice-hearers who come to the attention of psychiatric services are often stuck in destructive communication patterns with their

voices. An alternative approach is based on helping people make sense of their voices and learning to cope with them (www.hearingvoicesmaastricht.eu). This radical shift from the pathologizing language of *auditory hallucinations* to the ordinary language of *hearing voices* can be a tool to transform thinking and practice in mental health care.

Asking 'what happened' and listening to voices

These research developments are only significant for practice if professionals act on them by asking people 'what happened' in their lives and responding respectfully to the stories they hear. Social workers, as a profession carrying out psychosocial assessments, need to ask questions that haven't been asked before about people's lives, including questions about abuse, bullying, neglect and loss (Read, 2013). Through such questions, professionals can facilitate people to make connections 'between elements of experience that had previously seemed confusing or contradictory' (Tew, 2002, p. 146) and thereby take control of their own recovery.

Nevertheless, it is important not to always assume the existence or denial of experiences of trauma and abuse. Professionals can facilitate conversations about meanings, but are not the makers of the meaning. As Tew (2002) argues, such an approach would require a commitment to hear and take seriously what people may have to say about their emotional distress, their life experiences, and the meanings, histories and hopes that they attach to them. Listening to people in their own terms and language has been identified as a missing component from current practice (Hepworth and McGowan, 2012). This kind of listening can challenge traditions of biological psychiatry, in which the voice of the service user is primarily used to diagnose disorders and interpret experiences for people.

Meaningful listening is a key practice skill and requires a shift towards an active dialogue with the people concerned and their networks. An interesting example of dealing with psychosis through dialogue was developed in Northern Lapland by a group of innovative family therapists and has been piloted in some Irish MHS since 2012. The 'open dialogue approach', as it is called, works with people experiencing psychotic symptoms in their home with interventions involving the individual's social network. The general aim is to generate dialogue to construct

words for the experiences, which exist in psychotic symptoms. Open dialogue involves working in groups because psychosis is viewed as a problem involving relationships, rather than something that happens to an individual. Additionally, open dialogue values the voice of everyone in the process, most especially the person directly in crisis. The open dialogue project changed a mental health system that once had some of Europe's poorest outcomes for schizophrenia into one that now gets the best statistical results in the world for those beginning to show psychotic symptoms (Seikkula et al*.,* 2006).

In order to actively listen to service users' meanings and stories, it can be important to engage with forms of expression and language that may be unconventional and perhaps unfamiliar to social workers. Working with voices is a powerful example of this engagement. Professionals' willingness and ability to accept people's accounts of their experiences, including voice-hearing experiences, can have a major influence on outcomes for people diagnosed with schizophrenia (Dillon and Longden, 2012). Practitioners who work with voice-hearers suggest that:

> in our experience, talking with voice-hearers doesn't provoke psychosis ... Most voice-hearers find it liberating to be respectfully questioned about their voice hearing experiences and feel acknowledged by it. For some, only this kind of assessment produces profound change. (Corstens et al*.,* 2008, p. 321)

The Hearing Voices Network (www.hearing-voices.org) is an influential example of practice where voice-hearers have come together to develop shared understandings of voice-hearing experiences. In Ireland, since 2012, a number of voice-hearers and professionals, including social workers, have participated in three-day training on Hearing Voices Group Facilitation, facilitated by Jacqui Dillon (herself a voice-hearer). Subsequently, a number of groups have been set up within and outside MHS, with a number of mental health social workers being involved in them. Participating in this training enabled social workers to bring the principles of this approach into their individual and groupwork practice in Irish MHS. At an individual level, for example, social workers have started to work with service users around the meaning of voice-hearing. These practitioners report how people who were initially fearful to talk

about their voices have gradually opened up about their experiences and have been helped to make sense of what has happened to them. At a group level, social workers using the Wellness Recovery Action Plan (see below) have started to incorporate voice management techniques as part of wellness, relapse-prevention tools. It is of particular importance, however, that exposure to a different understanding of voice-hearing experiences has facilitated social workers and service users to have more open conversations about trauma regardless of the existence of voices. International experience has demonstrated that hearing voices support groups are effective communal solutions that enable people to make profound positive changes in their lives (Dillon et al*.,* 2013). Social workers can form alliances with service users and forward-thinking professionals within and outside MHS to facilitate the development of spaces that are conducive to the recovery process. Mental health recovery as a journey, but also as an ideology challenging the dominant medical hegemony, is discussed next.

Challenging medical hegemony through recovery-informed practice

Originally a user movement concept, recovery represents hopes and aspirations for the transformation of a paternalistic, coercive and institutionalized form of service provision. *A Vision for Change* (Department of Health and Children, 2006, p. 9), identified the need for MHS to adopt a recovery perspective and considered it a core principle to 'inform every aspect of service delivery'. While the concept of recovery in mental health is not a new one, there has been a redefinition during the past two decades involving a shift from the clinical understanding of recovery as the 'absence of symptoms', or equating it with a cure, to a process of 'recovering what was lost': citizenship, rights, meaningful roles, responsibilities, decisions, potential and support (see Bracken and Thomas, 2005; Mental Health Commission, 2008). In Ireland, *A Vision for Change* (2006) and the Mental Health Commission (2008) endorse a social recovery approach and emphasize the social inclusion aspect of recovery. Advancing Recovery in Ireland (ARI) is an initiative supporting Irish MHS in their efforts to implement a number of key concepts in *A Vision for Change*. ARI focuses on service-level structures, systems and practices that can maximize personal recovery opportunities and outcomes for service users. As Roberts and Wolfson (2004, p. 37)

argue, the current 'redefinition of recovery as process of personal discovery, of how to live (and to live well) with enduring symptoms and vulnerabilities opens the possibility of recovery to all'.

However, as Walsh et al. (2008, p. 251) observe, 'the shift from traditional psychiatry to recovery can be achieved on paper with a few deft strokes of a pen', but making a shift in organizational and cultural practice is altogether more challenging. Recovery as a concept and practice can contribute to a paradigm shift in mental health, in which the service user becomes the central driver of their own life, a life of their own choosing, in a community in which they are citizens with equal rights to all other citizens (Ryan et al., 2012). Mental health professionals can support or hinder this process.

There are common themes in recovery stories that are familiar to social work: enabling the voice of the service user, a commitment to anti-oppressive practice and social justice, and a focus on life contexts, systems, networks and relationships (Coppock and Dunn, 2010). At an individual level of practice, such themes can be acted on through hope-inspiring relationships, nurturing a vision of the life people want to live, being in charge of wellness, and focusing on strengths and resilience rather than pathology (Rapp and Goscha, 2012). In this process, social workers can use a social approach more as a basis of enquiry than as a way of giving expert insights. As Tew (2002, p. 151) suggests, social workers' 'most important role may be one of taking seriously and being the "enlightened witness" for the histories of trauma and powerlessness that may emerge, once connections start to be made'. At community and agency levels, such themes can be acted on through person-directed services, individualized self-management plans, service user-operated services, peer support and respect for 'experts by experience' (see Mental Health Commission, 2008). Moving beyond the focus on the individual, social workers are also in a position to acknowledge and act on the impact of distress on families, friends and social networks. By locating the experience of distress in a social context, social workers can have an important role in supporting renegotiations within family, social and agency networks and challenging patterns of oppression and exclusion within these networks (Tew, 2002). Furthermore, recovery-oriented practitioners can challenge the organizational and institutional barriers to creating environments

conducive to recovery, including professional attitudes and a resistance to 'let go' of the expert role.

An example of a recovery-focused intervention at an individual level is the Wellness Recovery Action Plan (WRAP). WRAP was developed by Copeland (2002), an American survivor, as a self-management tool offering 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 in Ireland, with many mental health social workers employing it as part of their practice. WRAP presents a format for people to detail how they are when well, as often professionals may not know them outside the context of acute services. It also encourages people to:

- develop a list of 'wellness tools', that is, daily routines and activities that help them stay well
- develop a circle of supporters
- identify triggers and warning signs
- make an action plan for when warning signs appear
- draw up an advance directive or, at minimum, a crisis plan, for example who might accompany the person to seek help from MHS, care for children, hold keys, and so on
- do a post-crisis review, to assess what went well and what can be improved.

A recent evaluation of WRAP Education Programmes in Ireland (Higgins et al*.,* 2012) identified the potential of WRAP to increase people's knowledge, promote positive attitudes towards recovery, and provide people with strategies to support mental health. While social workers in Irish MHS consider WRAP a central element of their recovery-oriented practice, much of this practice takes places within a highly medicalized culture. As Higgins et al.'s study identified, initiatives such as WRAP are only meaningful in the context of shifting the ethos of care from the current preoccupation with illness to one of wellness.

At a community/agency level, there are several examples of MHS that are seeking to reform their practices towards an ethos guided by a commitment to service user involvement, a recovery philosophy, a community development orientation and the importance of integrated partnership working. The Home Focus project in West Cork is one such example of a community-based approach providing outreach, home-based, individualized support for people with mental health difficulties in their own communities. Delivered by a team combining service user and professional expertise engaging in a diverse range of interventions, the project provided unique sources of support for its participants, resulting in reduction of hospitalization, individual gains, and, above all, a new experience of service provision where people felt respected, listened to and treated 'as a person rather than a symptom' (Sapouna, 2008).

A key dimension of the recovery philosophy is its organic link with the service user/survivor movement. For the survivor movement, recovery is about having a voice. As Bracken and Thomas (2005, p. 227) argue:

> through social action, the survivor movement has created safe spaces in which individuals can start the process of telling their own stories … the meaning of recovery is very closely tied to the struggle of survivors to have the right to tell their own stories in their own way.

Higgins and McGowan (2014, p. 64) state that first-person accounts of recovery, as well as highlighting resilience and overcoming adversity, are 'discourses of resistance', which advocate civil and human rights for those who experience mental health problems:

> Such accounts also advocate actively for a radical shift in how mental health practitioners frame and respond to people's experience of mental health problems urging a greater distribution of power between the institution of psychiatry and people using the services.

What does recovery mean for social work practice? In Brosnan's (2013) study, professionals practising on a 'recovery track' were described by service users as people who can act as allies, who come into meetings as human beings and leave their 'hats outside the door'. Brosnan, 2013, p. 135) also identified the prevalence of rhetoric about recovery in the absence of real change. As one participant put it: 'it's no good saying … we're a recovery-focused service but all that we're offering you is a psychiatrist and drugs'.

A meaningful recovery approach does not involve the implementation of technical measures within a predominantly medical framework of service provision. The recovery approach we are proposing requires a fundamental shift in understanding, responding to, and being with, emotional distress. In this shift, the voice of service users in defining their own recovery is central (Sapouna, 2008).

Promoting meaningful service user involvement (SUI)

SUI is considered to be a necessary component of good practice internationally (Kemp, 2010) and a feature of MHS planning and management for decades in many countries (Gammon et al*.,* 2014; Beresford, 2010). SUI in Irish mental health services first appears in the government policy *A Vision for Change* (Department of Health and Children, 2006). Chapter Three of this policy discusses SUI, asserting 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. It specifically recommends that service users be included in local management teams and that their perspectives inform national planning and regulatory bodies (Department of Health and Children, 2006, p. 27).

There are at least two directions for the impetus to include the voice of the service user (Beresford, 2002). The first is a push from top management committed to reform MHS. The second is the bottom-up demand of the user movement, inspired by civil and human rights movements. As social workers operate from within an increasingly managerial environment, there is a danger that collaborative working with service users becomes a 'tick box' procedure rather than a professional value. Meaningful involvement requires a change in the culture of professional superiority.

It is important, therefore, not to lose sight of the profession's commitment to human rights and social justice as the underpinning principle of SUI.

SUI can occur at strategic, operational or individual levels (Brosnan, 2013). SUI at the individual level, such as making decisions about their own care, ideally being in control of their own care, is highly significant for service users. This is to be distinguished from operational and strategic levels of involvement, which have more potential to influence the change of current practice and ethos. Rose et al. (2010, p. 393) list eight different forms of SUI:

1. Being consulted about staff recruitment, having a role in candidate selection or staff performance evaluations
2. Advising on local MHS in committee work
3. Involvement in research, usually consultation but increasingly service user-led and controlled research
4. User-led service delivery
5. Training of professionals
6. Employment in services as peer workers
7. Peer advocacy
8. Campaigning.

Some of these forms of SUI are evident in an Irish context (Brosnan, 2014), but due to space limitations, this chapter focuses only on peer advocacy and peer support.

Peer advocacy and peer workers

A Vision for Change (Department of Health and Children, 2006) makes a clear recommendation that advocacy should be provided as a right in all parts of the country. The Irish Advocacy Network (IAN), a prominent peer-run organization established in 1999, evolved from a vision to develop a critical mass of empowered service users who would use peer advocacy skills and training to demand respect, dignity and control over how they are treated (McGowan, n.d.). The IAN provides independent peer advocacy services at approved centres (that is, licensed centres to

detain people under the 2001 Mental Health Act) in all but one of the 26 counties of the Republic.

A similar yet distinct role to peer advocacy is that of peer support workers. In the past few years, peer support workers have been employed in the voluntary sector to work alongside a few pioneering statutory services. These peer worker projects are associated with the Advancing Recovery in Ireland (ARI) project. ARI is influenced by the Implementing Recovery through Organisational Change project in the UK (see www.imroc.org). Service user involvement is one of ARI's 10 organizational challenges. Also, as a result of ARI, Recovery Colleges have begun to emerge in Ireland where the emphasis is on co-production; peer educators and mental health professionals co-design a curriculum to support recovery. The ethos of Recovery Colleges is to move the emphasis from treatment to education and recovery.

Gosling (2010) describes in some detail how peer advocacy work and promoting self-advocacy can shift the balance of power and powerlessness in individuals' relationships with themselves, their peers and services. Other service user/survivor writers explain that peers best understand the support other service users need because they have been through the depersonalization and psychiatric mystification of the mainstream MHS (Dillon et al., 2013; Watts, 2014). Repper and Carter (2011) conclude that contact with peer support workers can result in many positive outcomes for those they work with, including increased self-esteem, self-management of difficulties, social inclusion and increased social networks.

The fact that no peer-led MHS, for example crisis houses, have emerged in Ireland to date, for reasons touched on elsewhere (see Brosnan, 2014), indicates the challenge to developing alternative models of care to the hegemonic statutory MHS. The Critical Voices Network Ireland emerged as a response to the lack of public space for debate 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 (Gijbels and Sapouna, 2011).

Challenges for service user involvement

There are many structural and cultural obstacles to the meaningful participation of service users: inadequate legal and policy-related support, complex, confusing

jargon-loaded organizational procedures and rituals, discrimination and stigma generated by professionals, and feelings of powerlessness, low self-esteem, scepticism or apathy towards SUI among many service users and carers (Carey, 2009).

Power dynamics are ubiquitous throughout the MHS, in the construction of knowledge, hierarchical structures, interprofessional status, and relationships between service users and service providers (Brosnan, 2013). A common theme that emerged in Brosnan's (2013) research into SUI is the low level of control available to service users over the processes they become involved with. The overall findings in this research indicate that service providers have much to learn from service users about the conditions of participation (Brosnan, 2013, p. 289). 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. By contrast, projects developed in real partnerships with user-led groups from the ground up, for example building capacity in local groups through human rights-based approaches (see McMillan et al., 2009), can be the beginnings of meaningful participation for service users (Brosnan, 2013).

Working collaboratively is an essential value base in social work. However, meaningful SUI does not come naturally within the current power structures of the MHS. Such an approach requires a shift from a preoccupation with professional roles and status towards recognizing the insights and expertise of people with lived experience of distress.

Conclusions

This chapter considers the opportunities for social work to contribute to a paradigm shift in Irish mental health care towards a context-sensitive practice in which the user is the central driver of their own recovery. This shift requires social workers to engage with critical questions about the way emotional distress is understood and responded to and to challenge the dominant biomedical model of thinking and practice. Critical questions reframe emotional distress as a meaningful response to problems of living, trauma and adverse life experiences. Such questions consider life stories, the impact of injustice and inequality in people's life contexts, including the

context of MHS where people often feel powerless. Considering these questions can enhance practice through conversations about 'what happened' in people's lives and through creating opportunities for people to articulate their experiences, hopes and expectations. It also involves engaging at a broader level of seeking structural change within and beyond MHS.

We also argue that a recovery approach, placing value on hope, choice and citizenship, is a key component in this paradigm shift. Social workers' knowledge and value base can facilitate the construction of environments conducive to recovery through hope-inspiring relationships, focusing on strengths and resilience, and negotiating relationships with family, social and agency networks. However, recovery is not a technical measure to be integrated in the existing culture of mental health care; it is a tool to transform it. In this transformation, the participation and involvement of service users is central. We then consider the importance of promoting meaningful user involvement, highlighting that the level of control service users have over the process, and to shape the agenda, remains a key concern if we are to move beyond tokenistic practices of involvement. A real risk remains that recovery and SUI, core components of the change that users and their allies demand of MHS, lose their transformative potential and are appropriated into cosmetic changes that sustain the 'bio-bio-bio' approach (Read et al., 2009).

Finally, while this chapter focuses on the contribution social work can make towards a social approach to emotional distress, we are not proposing that social workers become the 'new experts' in the field of mental health. We are not proposing a new 'social model' to replace the 'medical model' in order to establish some new domination in the way human distress is understood and responded to. As Tew (2002) argues, social work should approach this with humility and facilitate service users to understand their distress and recovery in the way that works most effectively for them. By engaging in a paradigm shift and forming meaningful partnerships with service users and people with self-experience, social work can reclaim its social identity and respond to human distress in a way that is user driven, respectful, context aware, and informed by human rights principles.

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The transformative potential of the arts in mental health recovery; an Irish research project

Co-authored contribution. Lead author, contributing 80% of formulation, execution, analysis, and publication.

Citation: Sapouna, L. & Pamer, E. (2014) The transformative potential of the arts in mental health recovery – an Irish research project, *Arts & Health: An International Journal for Research, Policy and Practice*, 8(1): 1-12.

This is an accepted/original manuscript of an article published by Taylor & Francis Group in Arts & Health: An International Journal for Research, Policy and Practice on 11 September 2014, available online: https://www.tandfonline.com/doi/full/10.1080/17533015.2014.957329

Abstract

Background: This article is based on the Arts + Minds (A+M) research project which investigated the experience of arts participation for mental health service users in Cork, Ireland, and the potential of integrating the arts into mental health care. *Methods:* Based on the principle of user-controlled definitions of recovery, the voice of service-users was central in this research. The authors used participatory observation methods and conducted qualitative interviews with project participants (service-users, artists and mental health staff) to explore the impact of arts participation on service-users and service structure and culture. *Findings:* The research demonstrated the transformative potential of the arts to create environments conducive to recovery through empowerment, connection-making, confidence-building, hope, story-telling and story-making. *Conclusions:* Moving beyond the general agreement on the positive contribution of the arts in mental health care, this article highlights some of the challenges of introducing creative forms of engagement and expression in traditional biomedical settings. It is argued that a meaningful partnership between the arts sector and mental health services is not just a technical measure but requires a radical shift in the way we understand, respond to and engage with human distress.

Key words: arts, mental health, recovery, creativity, cultural change.

Introduction and Background to the Research

It is increasingly recognised that arts participation by people experiencing emotional distress can offer a range of therapeutic benefits and facilitate the process of recovery through community inclusion and stigma reduction. This paper draws on qualitative findings from a research project conducted by the author (Sapouna, 2012), aiming to provide evidence of the value of the arts in mental health. Paticular emphasis is given to the potential of the arts to transform the current narrow focus of biomedical mental health care. The contribution of user-defined evidence of recovery in researching and capturing the changes that can be achieved through creative interventions is also highlighted.

Arts + Minds (A+M) was established in 2007 by Health Service Executive (HSE) mental health staff in Cork, Ireland, with funding and support from the HSE Cork Arts and Health Programme. It works across mental health settings in Cork City and County including acute, special care, continuing care, day care and community. A+M[11] seeks to facilitate service-users to participate more fully in the social and cultural life of the community, and to challenge the stigma faced by people experiencing emotional distress. A+M works with professional artists across all art forms including music, creative writing, visual art, dance and storytelling.

The A+M research project reported in this paper was set up to investigate the impact and potential of integrating the arts into mental health care. The project involved the planning, delivery and evaluation of art programmes (music and visual arts/animation workshops) to mental health service-users in three sites in Cork City and County: an acute inpatient unit (music project A); a day centre (music project B), and a city art gallery, with participants from two community mental health services (animation project).

The research took place throughout 2011. The arts projects were delivered over an eight to ten-week period between May and September 2011. 'Beyond Diagnosis: The transformative potential of the arts in mental health recovery', the report based on the research presented in this paper, was published in 2012 (Sapouna, 2012).

[11] For further information about Arts + Minds see www.artsandmindscork.com

The Irish Policy and Practice Context

The integration of arts into Irish mental health services is one element of a broader attempt to embrace creativity as part of recovery-informed, person-centred practice. *A Vision for Change* (2006), the Irish National Mental Health Strategy, identified the need for mental health services to adopt a recovery perspective and considered it a core principle to *"...inform every aspect of service delivery"* (p. 9).

While the concept of recovery in mental health discourse is not a new one (earliest articulations go back to Anthony, 1993; Deegan, 1988), during the past two decades there has been a redefinition involving a shift from a clinical understanding of recovery as 'absence of symptoms' or 'recovery to normality' to a process of 'recovering what was lost': citizenship, rights, meaningful roles, responsibilities, decisions, potential and support (Crowe & Taylor, 2006; Bracken & Thomas, 2005; Mental Health Commission, 2008). Recovery can contribute to a paradigm shift in mental health towards locating the service-user as the central driver of their own life, a life of their own choosing, in a community in which they are citizens with equal rights to all other citizens (Ryan, Ramon & Greacean, 2012). This shift from 'the patient' to 'a citizen' role can be a significant challenge to the hegemony of the medical approach by putting individual choices, social inclusion, citizenship and human rights to the centre of practice. As Roberts and Wolfson (2004) argue, the current "*redefinition of recovery as process of personal discovery, of how to live (and to live well) with enduring symptoms and vulnerabilities opens the possibility of recovery to all*" (p.37).

Arts and Mental Health Recovery

There is a growing body of evidence on the benefits of the arts for people experiencing emotional distress. Staricoff's (2004) extensive review of medical literature describes how various art forms can benefit general health and well-being, including mental health. This review highlights that mental health service-users' involvement with the arts stimulates creative skills and self-esteem, and improves self-expression and communication between service-users, staff/service providers and family. Studies exploring the benefits of arts participation have found that,

through art, mental health service-users have experienced a sense of empowerment (Hacking, Secker, Spandler, Kent & Shenton, 2008; Parr, 2005), improved self-esteem, greater confidence, a clearer self-image (Goldie, 2007; Hui & Stickley, 2010), motivation and an appreciation of having 'time out' from mental health concerns (Secker, 2011), enhanced general wellbeing and quality of life (Arts Council 2003; Bungay & Clift, 2010; Hacking *et al*., 2008; Moloney, 2005; 2007; White, 2008). Arts participation can facilitate people to take greater control of their lives and their recovery, (Van Lith, Fenner & Schofield, 2011), explore and understand feelings, develop alternative coping strategies when dealing with distress (Spandler, Secker, Kent, Hacking & Shenton, 2007; White, 2008), and feel more hopeful and better able to cope with distress (Spandler *et al*,. 2007; Stacey & Stickley, 2010). Further studies suggest that arts participation can lead to a reduction of stigma and social exclusion for people experiencing distress and their families (Parr, 2006b; Stacey & Stickley, 2010; Hacking *et al*., 2008) through expanding social networks, decreasing isolation (Parr, 2006a), creating a new identity as an artist and challenging the perceived identity of oneself as a user of a mental health arts project (Spandler *et al*., 2007). Arts participation offers people opportunities to give and receive mutual support, collaborate with others, develop a sense of belonging within the wider community (Spandler *et al*., 2007; Secker *et al*., 2007) and to connect with further opportunities within the community (Hui & Stickley, 2010).

Within the Irish context, Moloney (2005) and White (2008) document the experiences of services-users, staff and artists partaking in music workshops across a diverse range of mental health settings. Moloney's (2005) study concluded that the music workshops had a positive impact on service-users' self-confidence, concentration and perseverance, with positive experiences such as hope for the future, a sense of community and fun, a newly developed interest in art, improved communication and listening skills, learning new skills and realising new abilities. Positive impact has also been reported by staff and artists - benefiting from professional development, discovering new skills and realising diverse forms of communication with service-users (Moloney, 2005; O'Shanahan & Grehan, 2009).

Concerns have also been highlighted. Connecting with the wider community through the arts is not an unproblematic process. Parr (2006b) argues that being a

mental health service-user in mainstream artistic and cultural community settings may reinforce a sense of 'otherness', as one's contribution may be less understood or appreciated than in a protected mental health setting. Furthermore, the instrumental integration of the arts within mental health services can also be problematic. If the arts become a 'commodity' of mental health systems primarily focused on medication, containment and coercion (Stickley, 2012), their creative contribution may be compromised. Overall however, the literature on arts participation clearly suggests that arts and creativity can be an important element of the recovery process for mental health service-users.

Research Methodology

The choice of a qualitative methodology reflected the ethos of the A+M project, which itself is informed by principles of recovery and social inclusion. In a period where evidence-based practice is central to service development and delivery, the research methodology highlights the significance of evidence constructed by the narratives of people who have direct experience of mental health services (Higgins & McGowan, 2014; Faulkner & Thomas 2002). A qualitative methodology was therefore appropriate as it can empower individuals to tell stories which can aid our understanding of contexts, such as agency and community contexts, within which art initiatives have taken place (see Creswell, 2007). An interpretive framework was employed to consider the service-users' subjective experiences. This subjective dimension was particularly useful in exploring how project participants defined the significance of the arts as a care option within mental health care. Employing narrative-based methodologies in evaluating the contribution of the arts in mental health care raises questions about the nature of the evidence produced. Like other qualitative research on recovery (Wallcraft, 2005) and the arts (Stickley, 2012a), the evidence we (the authors) produced is primarily based on user-narratives and personal accounts rather than clinical outcomes. Such evidence can often be dismissed as 'unscientific' in the current evidence-based agenda. Furthermore, we are aware that in researching the integration of the arts into mental health care, the tensions between art as a form of creative expression and the dominant biomedical model of care, which has not traditionally encouraged creativity of expression, need

to be considered. Acknowledging these tensions, our paper concentrates on research findings that highlight the potential of creativity and the arts to transform the often coercive nature of mental health services and to help people engage with life-enhancing activities within and beyond mental health structures.

Participant observation and semi-structured face-to-face individual and group interviews with service-users, participating staff and contributing artists were the main methods of data collection in this study. The two researchers (the authors) actively participated in the music and animation workshops. All service-user participants were informed in advance by staff about the study and about the researchers' participation in the workshops. All were invited to participate in the study. The researchers explained the research aims, interview recording methods and confidentiality issues to all participants in the workshops and before the interviews. A total of thirty-five service-users were interviewed. Music project A was set in an inpatient unit which had a high turnover of user-participants (approximately forty) over the eight weekly sessions of the project. In this setting, individual interviews were held with twenty-one participants who volunteered to be interviewed after the music sessions. Music project B was set in a day-centre where individual interviews were held with five out of the ten regular attendees of the facility. Finally, all nine participants of the animation project were interviewed through three group interviews. Participating mental health staff and artists were informed about the study through their ongoing involvement with A+M. Interviews were held with all nine mental health staff involved in the workshops and the three artists who delivered the programmes. Prior to the interviews, all interviewees signed a consent form giving permission to record their experience of the project with the use of a dictaphone and to use the interview data for the purpose of the study.

Findings

Project participants had diverse experiences of mental health services, ranging from long-term inpatient engagement and receipt of intense support to first admissions and a minimum level of support at a community level. For the majority however, social isolation, the lack of stimulation, the lack of meaningful activities and boredom

were the common denominators. While this was particularly evident in the inpatient setting, people who lived in the community (both in hostels and in independent accommodation) also spoke about isolation and often having 'no reason to get out of bed in the morning'. In that sense, the opportunity to participate in the A+M workshops was particularly appreciated by service-users in both inpatient and community settings.

All thirty-five service-user participants described the art workshops as a positive choice to have as part of their care. This does not mean that *all* participants *always* enjoyed *all* the art sessions. People also spoke about struggling with interactions in a group, or about some aspect of music bringing up feelings of sadness and loss. However, they all appreciated the range of experiences they were offered through the art workshops.

Participants spoke about feeling good, enjoying themselves, experiencing and expressing emotions, having a sense of worth, developing a sense of collaboration and camaraderie, working towards an end result, developing concentration and focusing skills, realising they had skills they never thought they had, feeling respected and heard by both artists and mental health staff, and connecting with their communities. While only a handful of participants mentioned the word 'recovery', the majority spoke about arts facilitating the creation of an environment that is conducive to recovery. Based on the principle of user-controlled definitions of recovery (Higgins & McGowan 2014; Sapouna 2008), the voice of service-user participants has been central in this research. For the purpose of this paper we present a selection of key themes that emerged from the research and highlight the transformative potential of the arts within and beyond service provision.

Experiencing and expressing emotions

"Through singing I express beauty or hope" (music participant).

Participants spoke about both experiencing and expressing emotions through their involvement in the art workshops. This was, as one participant observed, not easy to

do within mental health services - "*...you know my biggest problem is… I still find it very, very hard to express myself in here* [inpatient unit]*"* (music participant).

Well over half of the participants appreciated arts as a way of non-verbal expression. For example, one participant said "*it's a way for quiet people to express themselves ...if you are quiet and you can play the drums you are expressing yourself, you know what I mean?"* Another participant, making reference to visual arts, said *"I suppose it gave one the freedom to... express oneself through painting or drawing, and you know what's nice is that you get the feedback...it puts us thinking about why we drew something or… what it means for us…".* The therapeutic effect of non-verbal expression was emphasised by A+M artists: "*…[P]eople can express themselves without having to put words on it …when you get to play instruments there's a great release from it, you just kind of forget everything, and you nearly get lost in just enjoying playing music*" (A+M artist).

Participants spoke about art evoking a range of emotions. While people primarily described the workshops as uplifting, energising experiences, four people also spoke about experiencing feelings of sadness, loss and frustration. For example, one person spoke about music evoking memories of loss, while an animation participant spoke openly about experiencing mixed feelings by saying that the project made him think about his life and his feelings and this had mixed results. This finding suggests that arts participation cannot be evaluated solely on the basis of evoking positive emotions but on the basis of (a) evoking a range of emotions which are integral to human nature and (b) providing people with the opportunities to express these emotions in a safe, accepting space.

Connecting with self, others and life

The majority of participants said that the art workshops provided a space to connect with themselves and their feelings. As one person said, *"...art is kind of connected with your soul, your sanity and if you are not connected you'd be like a zombie".* Participating in the workshops was also a way for people to 'get back some reality' in their lives. This was clearly articulated by one person who said *"...it was nice to get a beat and ...get something back, you know some bit of reality back you know"* (music participant).

Relationship-building with others is also a 'real life' situation. The workshops were experienced as a positive space for participants to connect with each other and to build relationships in a stress-free environment. As one staff member put it, "...*you can share stories like...this morning* [somebody said at the music workshop] '*oh I met my husband through this song'…You can tell your story in a sense and not be that big heavy kind of 'tell me about your life'...*".

Being part of the music group seemed to motivate participants to 'get on' with others in the inpatient setting. Over half of inpatient-care participants commented that, apart from smoking, there were limited opportunities for people to get together. *"It* [music] *helps me to link with other people... because I am a quiet kind of person"* (music participant). Participants said it was easy to mingle in the music workshops as they felt it was a friendly, family-like environment. Seeing another side of people was also identified as a way of building relationships by getting a different perspective on people. Participants spoke about how having fun, seeing other people having fun and enjoying themselves enhanced their wellness and helped them connect with others.

All nine participants of the animation project worked intensively in groups towards developing a story for the final product (animation feature). *"We were all on the same boat…we are connected through developing a story"* said one participant. Interestingly, this is not just a metaphor but it was meant literally, as one of the animation features included a boat journey through Cork city! Animation participants and artist spoke about developing a sense of camaraderie and co-working skills, as "…*the ability to co-operate is a skill that makes life easy*" (animation participant).

This does not mean that *all* workshop participants *always* enjoyed being together and co-working. People also struggled when being with others, for example one person spoke about the frustration of being part of a group: "*Sometimes it's hard, frustrating...trying to co-operate I am not enjoying it*" (animation participant).

Based on the earlier discussion, it can be argued that project participants were given opportunities to experience the benefits, limitations and challenges of 'being with others' and to connect with 'real life' situations, an essential process in mental health recovery.

Confidence-building; recognising strengths

Participants spoke extensively about getting a boost of morale and a sense of worth through partaking in the art workshops. Most interviewees said that they surprised themselves at what they had achieved, saying that they 'knew more', were 'able for more' and 'liked more' than what they thought. For example, one person spoke about how her confidence grew through the animation workshop as she had never taken a photograph in her life and then realised that she was able to make a short animation film - *"...these workshops opened up a creative side I didn't think I have…".* Staff also spoke about participants surprising themselves and others - "*...it's just amazing to see people with that ability and you think sometimes you would not see that unless they are in the music group..."* (staff). Seeing the "*finished product"* and *"your ideas become alive on a screen*" was very important for the animation group. *"We had a presentation in the end where we all watched it in the gallery, you know on the big screens ...it was brilliant"* (animation participant).

Approximately half of the participants spoke about their concentration suffering as a result of their mental health difficulties and the effect this had on their self-esteem. As a result, they appreciated the opportunity to work on their concentration through the arts projects. This was particularly relevant to the animation group who had to focus on story-making and film production. As one person put it, *"...it's brought out my concentration ...I don't feel worthless all the time".*

Furthermore, confidence acquired through the art workshops encouraged participants to make plans and pursue further interests by, for example, *"getting back into music and learn an instrument"* or "*joining a choir…"* (music participants).

It is important to stress the difference between skills-improvement through art and opportunities provided through art to acknowledge and realise existing skills. In other words, it is not necessarily the case that participants lacked concentration, focusing and problem-solving skills, but rather that they lacked opportunities to realise and demonstrate these skills to themselves and others.

Equalising power relationships

This research identified possibilities to equalise power relationships, through user involvement in decision-making and planning around the art workshops. Mental health staff actively engaged in the art workshops and this was appreciated by participants and artists. "*This made workshops an activity for all involved not just something for 'patients'"* (A+M artist). All staff spoke about service-user and staff relationships becoming more equal in the context of a joined activity where there is an opportunity to move beyond professional boundaries and just be members of the same group. This was also identified by about a third of user-participants. As one person observed, *"...the nurses got involved as well… just like us, they weren't like standing over there and just supervising, you know...there was no difference between* [us] *I didn't feel like a client".*

Participants also said they found it easier to approach staff in the context of the art workshops. As one person said, "*I don't know... the people here, the nurses and things like that - you can talk more to them".* This can have a positive effect on staff-user interactions outside the workshops. For example, one staff member said that after co-participating in A+M workshops, service-users have '*de-stigmatised us*'.

Seeing service-users as participants in art groups rather than 'patients' has also been a way to re-evaluate staff perceptions and practice. As one artist said, "*I think their relationships change a lot, especially in places where we would work in for a while... staff would have said to us that they see people in a different light or that they kind of said 'how did I not know that before', things about different members in their group that they would have never thought of it before".*

Changing relationships can also pose challenges to long-established power differentials between mental health staff and service-users. As a sense of powerlessness is one of the main barriers to the recovery process (Lilja & Hellzen, 2008; Tew, 2011), it is important that these new interactions can be transferred beyond the boundaries of art workshops to other areas of mental health care.

Beyond diagnosis

The A+M project provided opportunities for participants to see themselves and to be seen by others as individuals in different roles rather than as patients with a particular diagnosis. For example, people in the music workshops saw themselves and other participants as people having fun, sharing a joke, liking or disliking a particular kind of music. They also learned a bit more about one another's lives. Similarly, in the animation project participants met each other through different roles like story-tellers and story-makers, through trying new things together, and collaborating towards a common task.

As already discussed, mental health staff spoke extensively about seeing 'people' rather than 'patients' in the art workshops. Project participants also spoke about viewing themselves differently, as the following quote suggests: "*I think it's kind of different because you are not talking about your illness…. you are not talking about medication. You are just like any other person when you are in there, and you are just having a laugh … just like any other person"* (animation participant).

Artists acknowledged that people were going through hardship but stressed that the diagnosis is irrelevant when it comes to making art.

"... [M]y role is about having the creative environment for people to access, and if I began to know more about individual clients' reasons for being there I think it would take away from what I do".

"…]I]t's not about the condition…it's about … tapping into something that we all have, tapping into creativity…spontaneity and fun and …all of those things that are human".

(A+M artists)

This is quite a significant shift from traditional mental health practice where the diagnosis is central to professional thinking and provision of care.

Creating accepting and respectful environments

Research findings suggest that the arts can contribute to environments where people experience a sense of freedom, acceptance and respect. Almost all the participants said that in the art workshops they felt no pressure to perform, to 'be' or to express themselves in a particular way. As one of the music participants said, "*... everyone can be a part of it. So it doesn't matter if you can sing or can't sing, you can still have rhythm, and it's so relaxed".* Being in a place where people do not constantly doubt themselves is important, as the following quote suggests: *"...I am getting over a hurdle of playing music and seemingly nobody notices that you don't sing properly or something. I was very anxious before, anxious what this or this person thinks and now …I am over that, I …just don't worry if I miss a chord or something"* (music participant).

The majority of participants said that they felt respected and involved in what was going on, that their opinions counted, and that they were comfortable about making suggestions to their groups. In the animation group this involvement was manifested in the story-making and the production of the animation films. As the animation artist said, *"…*[my role] *is just to give the space for people to create their own stories".* In the music groups, user-involvement was manifested in the actual running of the sessions where the facilitators actively encouraged user-led music sessions.

The significance of feeling respected needs to be seen in the broader context of user experiences of mental health services. In this project, service-users did not speak about feeling disrespected by mental health staff; however, many expressed concerns about the lack of choice of activities and the infantilising nature of some of the other activities. One person drew a comparison between the experience of an arts workshop and another activity in the same setting where she felt as though she was being treated like a child. *"I love the art as well because...you know ...you could get that feeling... of warmth. At* [other activity] *sometimes…– it's like - you are put in a cage and you have a lot of kids and you tell them do jig puzzles or give crayons… I am paranoid that people think because you have a psychiatric illness that you are stupid".*

Being part of a social community-reducing stigma

Participants, staff and artists spoke about arts being a tool to combat isolation, break down barriers between service-users and the community and reduce stigma. For animation participants, being located in an art gallery, a 'normal space' in Cork city centre, was very significant. It signified involvement in the community not as a 'mental health group', as initially feared by some group members, but as an 'animation group'. This short conversation between two members of the animation group highlights this issue:

"So it's not like you're sitting with a nurse as such, or …a member of the mental health team – do you know what I mean…you're going to an Art Gallery…"

"You're going somewhere different… we've been bombarded with hospitals, we've been bombarded with medication"

"*It's great, I loved being in the gallery*"

"We've been institutionalised and it's completely the opposite of that is what we need".

Through the arts projects, participants living in the community engaged with facilities that they did not know about or did not have the confidence to use before. This exposure has also affected the way mental health service-users are now viewed in such facilities. As one staff member found out, "…*people who work in the community facilities view people with mental health issues differently having met them*". Community mental health staff also stressed the importance of meeting service-users in a mainstream community setting, a welcome shift from home visits and referrals to outpatient services.

Through arts participation, people had the opportunity to be part of the broader community and not just the mental health community. Four participants said that becoming involved in too many mental health groups can reinforce stigma and

a sense of 'being unwell'. As one animation participant said, *"...it's very important that we actually feel not...just people that are unwell …but we're just part of the social community".* A similar point was made by a staff member who argued that rather than becoming part of the service, arts would have to be brought into the community to create a broader network of people. This is not to deny the value and contribution of diverse groups within mental health care. Rather, it is about acknowledging that people need opportunities to engage with the world *outside* the mental health system rather than the mental health system *becoming* their world.

Discussion: Arts as a Tool to Embrace a Cultural Change in Mental Health

The Arts + Minds projects were experienced in a very positive way by participants in the three settings. In line with previous research, this study confirmed that arts in mental health care can create conditions conducive to recovery through the "*discovery of personal resourcefulness, meaning and growth, within and beyond the limits imposed by the 'mental illness*'" (MHC, 2008, p.7). Participation in the art projects also contributed to wellbeing and social inclusion by enabling participants to take on meaningful and satisfying social roles in their communities (Spandler, 2007; Hui & Stickley, 2010).

While participation in the arts workshops was clearly a way of breaking the monotony of life in inpatient care and the social isolation experienced by many in their communities, the transformative and therapeutic nature of creativity was also identified by participants in all three settings. Along the lines of other studies (Moloney, 2005; Spandler, 2007), it was found that arts in mental health care contribute a valuable space where creative expression is encouraged and where service-users can be acknowledged as people with potential, imagination and skills. The possibilities of achieving more egalitarian relationships between staff and users through art participation were also key aspects of our findings.

It is therefore important to develop strategic partnerships between the arts and the mental health sector, with arts programmes being another care option for people in distress. For arts to become a meaningful care option, the appreciation of multidisciplinary teams is required. Mental health professionals will need to expand their roles to embrace activities such as community development and fundraising for

art-related activities that have not traditionally been considered part of their brief. Furthermore, the role of education in preparing mental health professionals is significant. Including modules on arts and mental health in professional courses can certainly provide professionals with more tools to work creatively with people in a mental health setting. However, if arts are to be a meaningful care option, a broader recovery-focused, user-centred approach to mental health education and research is also essential.

However, integrating the arts into mental health practice is not an unproblematic process. This study has given a first-hand insight into the tensions between the creativity and freedom of expression embraced in artistic activities and the rigidity and passivity associated with the dominant biomedical model. For example, the majority of participants contrasted the art workshops with the regimental style of inpatient wards where they often felt 'observed', prevented from expressing themselves, and 'lacking a say' in their care. Artists and staff also identified resistance by some multi-disciplinary teams to the valuing of diverse types of engagement, including artistic engagement, as part of mental health practice. Therefore, if the integration of arts into mental health care is to be recovery-enhancing, it cannot be a mere instrumental addition to current services. This integration requires a more fundamental change in the current medically-focused model of care, which could be a challenging task. In other words, it is important that the contribution of the arts towards more creative, respectful and egalitarian forms of engagement does not operate in isolation (i.e. only within art workshops) but affects the overall culture of mental health care in a way that such care embraces creativity and provides opportunities for people to be seen beyond the role of the 'patient'.

Furthermore, our research has highlighted the risks associated with the assimilation of the arts into a mental health system which remains primarily focused on clinical rather than psychosocial interventions. Participant artists stressed the importance of the arts not losing their creative potential in a system that can often "*stop us from being as big as we can be*" (A+M artist). In line with other research, this study identified the distinct value of the arts in mental health as opposed to art

therapy (Levine, Perkins & Perkins, 2005). The focus of the art workshops has been on creative expression, which can have a therapeutic effect, but is different from art therapy where clinical goals are set. This is not suggesting that art therapy, or indeed other therapeutic interventions do not play a valid role in the recovery process. It is recognising the distinct contribution that arts can make in mental health which is about creativity, expression, experimentation, and play rather than treatment. The value of engaging with activities beyond the boundaries of clinical settings and connecting with a community beyond the mental health community was also identified as a key aspect of social inclusion and stigma reduction. In that sense, arts can be a tool to see people beyond their diagnosis, and as such can provide unique opportunities for recovery.

This qualitative study was informed by the narratives of people with first-hand experience of arts participation in mental health. The findings of the study have provided insights into how arts and creativity can contribute to a change of culture towards recovery-oriented mental health practice. Although this study did not adopt a user-led approach, user-led research is important, as this research can itself be a creative medium for such a change to be realised. In addition, research into arts participation in mental health would benefit from adopting broader sociocultural approaches and utilising creative media such as video, writing and story- telling (see Stickley, 2012), which can capture people's experiences and emphasise the users' voice as being central to research and evaluation.

Conclusion

The arts can be a medium for recognising people's resourcefulness and multiple skills, which are often lost when they become patients in a mental health service. In a broader sense, creativity in mental health care can contribute towards recovery, through enabling people to make connections, expand their experiences, take meaningful roles and experience a sense of worth and value.

Moving beyond the benign agreement on the positive contribution of arts to mental health care, this research has highlighted that such a contribution is not a mere matter of 'adding' arts programmes to the current mental health services. The broader conceptual and ideological framework governing mental health care poses

significant challenges to adopting a more creative approach to practice. This research has found that a meaningful partnership between the arts sector and mental health services is not just a technical measure but requires a cultural shift in the way we understand, respond to and engage with human distress. The arts in mental health care provide opportunities to see people in distress beyond their diagnosis and can facilitate such a shift towards embracing creativity of expression, nurturing strengths, and facilitating service-user care choices, both inside and outside mental health structures.

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Beyond Diagnosis: The transformative potential of the arts in mental health recovery

Co-autored contribution. Lead author, contributing 80% of the research design, methodology, research execution, thematic analysis of findings, report writing and publication.

Sapouna, L. & Pamer E. (2012) *Beyond Diagnosis; The transformative potential of the arts in mental health recovery*, Arts + Minds/University College Cork, Cork.

Open access available at:
http://www.artsandhealth.ie/wp-content/uploads/2012/11/Beyond-Diagnosis_lowres.pdf

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Executive Summary

Beyond Diagnosis explores the achievements and challenges of the Arts + Minds Action Research Project and locates both in the context of a literature and policy review of arts and health, mental health and recovery approaches.

Policy and Practice Context

The need for comprehensive, recovery-oriented and person-centred mental health care has been identified by key Irish policies and in particular the Mental Health Strategy *A Vision for Change* (DoH&C, 2006) and the *Recovery Approach within the Irish Mental Health Services* (MHC, 2008). "*The recovery approach acknowledges the person's rights to meaningful participation in community life and moves beyond the individual and organisation level to address the wider social, attitudinal and economic barriers to citizenship*" (MHC, 2008:10). Therefore, emphasis is placed on removing barriers to social inclusion, such as stigma and lack of access to suitable housing, education, work, friendships and meaningful activities (DoH&C, 2006; MHC, 2005 & 2008). This report explores the achievements and challenges of the Arts + Minds Research Project (2011) and locates them in the context of a literature and policy review on arts in health, mental health and recovery approaches.

The Arts + Minds Research Project (2011)

The Arts + Minds (2011) Research Project is funded through the Health Service National Partnership Forum (HSNPF) and the Health Service Executive (HSE) South. Arts + Minds (A+M) was established by HSE mental health staff in Cork in 2007. It includes staff from six mental health settings in Cork City and County[12], a representative from the Irish Advocacy Network, a mental health service user and a nursing student representative. Arts + Minds work across a range of mental health settings including acute, special care, continuing care, day care and community. The group works with professional artists across all art-forms including music, creative

[12] St. Stephen's Hospital; Cúnamh Day Hospital/Day Centre; South Lee Mental Health Unit, CUH; Togher/Ballyphehane Community Mental Health Service; Mahon/Blackrock Community Mental Health Service; St. Michael's Unit, Mercy University Hospital.

writing, visual art, dance and storytelling, and has delivered over 50 arts projects since its establishment.

The Arts + Minds research project was set up to investigate the impact and potential of integrating the arts into care planning. This action research model involved the planning, delivery and evaluation of art programmes (music and animation workshops) to mental health service users in three sites in Cork city and County: The South Lee Adult Mental Health Unit, Cork University Hospital (CUH); Cúnamh Day Hospital/Day Centre, Macroom, and Crawford Art Gallery, Cork, with participants from Togher/Ballyphehane and Mahon/Blackrock Community Mental Health Services. The A+M 2011 Research Project started in January 2011 and direct work with participants began in May 2011. All A+M art programmes took place over a period of eight weeks.

The Research

This evaluation research was an integral part of the A+M Research Project (2011) and was put in place from its onset. The design of the research was informed by the philosophy underpinning (a) current developments in mental health and (b) the development and delivery of the A+M Research Project (2011). In this philosophy, service-users play key roles in defining and taking charge of the changes they want to bring about in their lives. The approach to the evaluation needs to reflect the ethos of the project which is informed by principles of recovery and social inclusion. In a period where evidence-based practice is central to service development and delivery, this research highlights the significance of evidence constructed by the narratives of people who have direct experience of mental health services. Furthermore, this research acknowledges that despite the current changes towards recovery-oriented practice, mental health care, particularly in inpatient settings, remains primarily biomedical. In evaluating the contribution of arts in mental health care we cannot ignore the tensions between art as a form of creative expression and the dominant biomedical model of care which has not traditionally encouraged creativity of expression. While a detailed analysis of such tensions go beyond the scope of this research, it is important to acknowledge them and problematise them.

Key Findings

This research found that the arts in mental health are a tool to recognise people's resourcefulness and multiple skills which are often lost when they become 'patients' in a mental health service.

- A+M participants described the A+M workshops as a positive choice to have as part of their care and they appreciated the range of experiences they were offered through the project. Through these experiences people were given an opportunity to connect with 'real life' situations, an essential process in mental health recovery.

- Participants spoke about feeling good, enjoying themselves, having a sense of worth, developing a sense of collaboration and camaraderie, working towards an end result, developing concentration and focusing skills, realising they have skills they never thought they had, and feeling respected and heard by both artists and mental health staff.

- While few participants mentioned the word 'recovery', the majority of interviewees (participants, mental health staff and artists) spoke about arts facilitating the creation of an environment that is conducive to recovery by identifying the following themes:

    - Being part of a social community, building relationships, breaking isolation
    - Enhancing wellness though having fun
    - Experiencing and expressing emotions in an accepting environment
    - Feeling respected, heard and getting involved
    - Recognising resourcefulness and previously unrecognised skills and strengths
    - Confidence-building and boost of morale
    - Improvement in concentration and focusing skills

- Service user-staff relationships can be equalised in the context of a joined activity where there is an opportunity to move beyond professional and client roles and just 'be' members of the same group.

- Seeing service users as participants in the A+M groups has been a way to re-evaluate professional perceptions and practice; an opportunity to focus on strengths, talents and skills.

- The Arts + Minds project provided an opportunity for participants to see themselves and to be seen by others as individuals in different roles rather than patients with a particular diagnosis.

Recommendations

The Arts + Minds Research project provided clear evidence of the value of the arts in mental health in promoting individual wellbeing, recovery-oriented practice and social inclusion for people experiencing mental health difficulties. In order to maximise the positive contribution of arts in mental health care there needs to be (a) a strategic partnership between the arts and the mental health sector so that art programmes can become another valid care option; and (b) a cultural shift in mental health systems to embrace creativity and recognise the strengths and resourcefulness of people beyond the limits imposed by diagnostic categories.

Chapter One: The Arts + Minds Research Project 2011 in Context

1.1 Introduction and Background to Arts + Minds

Arts + Minds (previously known as the Arts and Mental Health Group, 2007-2010) was established by Health Service Executive (HSE) mental health staff in Cork in 2007. It is a cross-departmental, cross-agency group which includes staff from six mental health settings in Cork City and County[13], a representative from the Irish Advocacy Network, a mental health service user and a nursing student representative. Arts + Minds work across a range of mental health settings including acute, special care, continuing care, day care and community. The group works with professional artists across all art forms including music, creative writing, visual art, dance and storytelling, and has delivered over 50 arts projects since its establishment.

Arts + Minds aims to:

- enhance the wellbeing of mental health service users through engagement with the arts
- work in partnership with health/arts professionals and service users to develop high-quality programmes in line with national policy, strategies and research[14]
- facilitate mental health service users to participate fully in the cultural life of their community
- challenge and reduce stigma faced by people with mental health problems
- enhance the healthcare working environment and promote the value of arts in mental health care.

1.1.1 The Research Project

The Arts + Minds 2011 Research Project is funded through the Health Service National Partnership Forum (HSNPF) and the HSE South. The Arts + Minds 2011

[13] St. Stephen's Hospital; Cúnamh Day Hospital/Day Centre; South Lee Mental Health Unit, CUH; Togher/Ballyphehane Community Mental Health Service; Mahon/Blackrock Community Mental Health Service; St. Michael's Unit, Mercy University Hospital

[14] For example: A Vision For Change, the Mental Health Commission Quality Framework, and the NESF report Mental Health and Social Inclusion report, Participatory Arts Practice in Healthcare Context – Guidelines for Good Practice (2009, HSE South, Waterford, Healing Arts Trust), Arts Council Arts and Health Policy (2010)

Research Project started in January 2011and direct work with participants began in April 2011.

Projects aims and objectives:

The overall aim of the research project as set out in the funding application to the HSNPF and HSE South is to investigate the impact and potential for integrating the arts into patient care planning in mental health settings.

Specific objectives for the research project were identified as follows:

- To develop an arts programme in three research sites in consultation with service users, staff and artists
- To work with a team of professional artists to deliver in each site the arts programme
- To work with staff to integrate the arts programme into care planning in each setting
- To include a series of research evaluation meetings with service users, staff, artists, academics and relevant organisations in the community
- To investigate the impact and potential of integrating the arts into care planning
- To produce a final evaluation report and recommendation for best practice and future development.

Prior to the commencement of the evaluation of the Arts + Minds Research Project (2011), the School of Applied Social Studies, University College Cork was commissioned by the project committee to carry out the task. The report is based on the research findings carried out as part of the Arts + Minds research project.

1.2 An Overview of the Arts + Minds Research Project (2011)

The Arts + Minds project involved the delivery of music and animation art programmes in three different sites in Cork city and County. The specific mental health care settings are:

(a) South Lee Adult Mental Health Unit, Cork University Hospital (CUH): This service provides inpatient care through a professional multidisciplinary team for people with

mental health problems from Cork South and County Cork (Bandon, Kinsale). The inpatient unit consists of 46 beds - a 23-bed female ward and 23-bed male ward.
Delivered art programme: Music/The Flow Project

(b) North Lee Cúnamh Day Hospital/Day Centre, Macroom: Cúnamh Day Hospital is situated in the grounds of the Macroom Community Hospital and aims to provide a facility and care/support for mental health services in the local or surrounding area.
Delivered art programme: Music/ Éist Agus Faire

(c) Crawford Art Gallery, Cork with participants from Togher/Ballyphehane and Mahon/Blackrock Community Mental Health Services (South Lee): The Crawford Art Gallery is situated in the centre of Cork City. It is a national cultural and regional art museum. The gallery is dedicated to the visual arts, both historic and contemporary.
Delivered art programme: Animation/The Unfold Project.

1.2.1 Background to the Delivered Art Programmes

The Unfold Project (Animation)

The *Unfold Project* began in 2010 with a series of workshops which facilitated participants to engage with and creatively respond to the Crawford Art Gallery collection and exhibitions. A number of projects have taken place since then, and in October 2011 Arts + Minds and the Crawford Art Gallery featured the animation work of participants from Mahon, Blackrock, Togher and Ballyphehane. The films were created with visual artist Julie Forrester, who has supported the artistic development of the group since 2010.

The process, which culminated in the creation of the animation films, began with a walking tour of Cork with John Collins (WalkCork) in Spring 2011. On the tour, the group gained insights into the historic and legendary past of the city. While they walked, talked and listened members of the group documented the walk in the form of sketches, notes and photographs. These documents led to the development of

story-lines in subsequent workshops. A skilled raconteur, Pat Speight, was invited to join an *Unfold* workshop and he demonstrated how stories could grow from small beginnings.

Total number of project participants: 9

Weekly workshop average: 6

Flow/Éist Agus Faire (Music)

This Music & Health project built on previous work undertaken by musicians as part of the *Ceol le Chéile* project (2009) in South Lee Mental Health Unit at Cork University Hospital (CUH) and Cúnamh Day Centre in Macroom. The *Flow* project took place in CUH and the focus was on musical improvisation and creative expression. Participants were encouraged to use their voices, bodies and instruments to create new sounds and compositions, which were recorded at each of the weekly music groups. This exploratory way of working requires a high level of trust between the facilitating musicians and participants, which developed as the project progressed. On the conclusion of the project, the musicians produced a sound collage entitled *Flow* which featured the comments and musical sounds recorded. This recording was featured at the Crawford Art Gallery on October 10th 2011 as part of the World Mental Health Day celebrations.

Total number of project participants: 26

Weekly workshop average: 15

The *Éist agus Faire* (Listen and Look) project was based in Macroom and the title of the project was suggested by a participant in acknowledgement of the rich tradition of Irish as a spoken language in the nearby Muscraí Gaeltacht. This group had also recently worked with visual artist Charlotte Donovan and writer Denise Hall on a creative writing project (2010) which resulted in the publication of a number of *haiku*-style poems.

Éist agus Faire incorporated elements of Irish poetry and some of the *haikus* to create an original piece of music entitled 'Stars Flow Through Me' which featured the compositional, vocal and musical talents developed over the eight weeks of group

work in Macroom. This composition was also featured as the soundtrack for the 'Postcards from the Clouds' animation premiered at the Crawford Art Gallery on October 10th 2011.

Total number of project participants: 9

Weekly workshop average: 6

The musicians from MusicAlive who facilitated the groups are dedicated to refining methods of participation in musical activities that offer opportunities for exploration and individual self-expression, as occurred during these two innovative music and health projects.

1.3 The Broader Context of the A+M Research Project (2011)

1.3.1 Recovery-oriented Practice

A Vision for Change (2006), the Irish National Mental Health Strategy, identified the need for mental health services to adopt a recovery perspective and considered it a core principle to *"...inform every aspect of service delivery"* (p. 9).

Historically, mental health systems were based on a tradition of diagnosing and treating people with life-long psychiatric conditions with no hope of recovery or meaningful social life. The underpinning principle of this practice was that individuals with severe mental illness did not recover, and that the course of their illness was either a deteriorative or at best a maintenance course (Anthony, 2000, in Sapouna 2008).

While the concept of recovery in mental health is not a new one, during the past two decades there has been a redefinition of recovery involving a shift from the literal understanding of recovery as 'absence of symptoms' or 'recovery to normality' to a process of 'recovering what was lost': citizenship, rights, meaningful roles, responsibilities, decisions, potential and support (see Crowe and Taylor 2006, Bracken and Thomas 2005, Mental Health Commission 2008). As Roberts and

Wolfson (2004) argue, the current *"redefinition of recovery as process of personal discovery, of how to live (and to live well) with enduring symptoms and vulnerabilities opens the possibility of recovery to all"* (p.37).

This conceptualisation of recovery is primarily associated with Anthony's 1993 paper in the U.S., in which he argued that *"a person with mental illness can recover even though the illness is not 'cured'. Recovery is a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness*" (p.15). On a similar note, Deegan (1988) suggested that recovery is a process of taking control of one's life. This focus on the journey rather than on reaching its end is a metaphor which many users prefer (see Ramon *et al*., 2007).

While acknowledging the uniqueness of this journey, it is important to be aware of the common themes in recovery stories. At an individual level such themes include a sense of hope, a vision of the life people want to live, seeing and changing patterns, finding new ways and reasons, and being in charge of wellness (see Crowe and Taylor, 2006, Mental Health Commission 2008). At an organisational/societal level such themes include person-centred services, individualised self-management plans, service user-operated services, peer support and respect for 'experts by experience' (see Mental Health Commission 2005, 2008).

A key dimension of the recovery philosophy is its organic link with the service user/survivor movement. For the survivor movement, recovery is about having a voice. As Bracken and Thomas (2005) argue, "*through social action, the survivor movement has created safe spaces in which individuals can start the process of telling their own stories…the meaning of recovery is very closely tied to the struggle of survivors to have the right to tell their own stories in their own way*" (p. 227). A recovery approach does not involve the implementation of technical measures. It is a philosophy requiring a fundamental shift in understanding, responding to, and

being with mental distress. In this shift, the voice of the service users in defining their own recovery is central (see Sapouna 2008).

These themes have been reflected in the experience of A+M participants. The project was for many a process of empowerment, confidence-building, hope, story-telling and story-making. As discussed in section 1.4, the voice of the project participants has been central in this research. Chapter three presents these stories with direct quotations from individuals as the main evidence of the project's positive contribution to the lives of the participants.

1.3.2 Care Planning

The National Health Strategy, *Quality and Fairness: A Health System for You* sets out the key objectives for the Irish health system up to 2010 (DoH&C, 2001). In this document, the concept of care planning is defined as *"[a] plan formulated by a health professional in consultation with individual patients, their families and other appropriate professionals that describes what kind of services and care that person should receive"* (DoH&C, 2001, p. 201).

Likewise, in *A Vision for Change* (2006), a special emphasis is given to the need to involve service users, their families and carers at every level of mental health service provision. It further states that *"care plans should be written and agreed between all parties, and include a time frame, goals and aims of the user, the strategies and resources to achieve these outcomes, and clear criteria for assessing outcome and user satisfaction"* (DoH&C, 2006, p. 81).

In other words, individual care plans should reflect people's specific needs and its goals should maximise recovery, as highlighted in the MHC report *Quality in Mental Health - Your Views* (2005). This report, based a wide consultation process to inform Irish mental health policy, identified the importance of *"individualised care planning as one of its key aspects of holistic service delivery"* (MHC, 2005, p. 46). However, despite these recommendations the process of implementing care planning in the Irish mental health system is slow. For example, the *Annual Report* of the Mental

Health Commission (MHC, 2009) highlighted once more the fact that the area of care planning was lacking consistency in implementation and completion for inpatient mental health services. The Mental Health Commission's (MHC)[15] *Annual Report 2010* also noted over twenty areas of concerns regarding the current running of mental health services, including care planning.*"The existence and quality of individual care plans remains disappointing. In many cases, this is a mere 'paper exercise' and, in some cases, we found deliberate decisions not to implement the plans"* (MHC, 2010, p. 89).

Evaluating these gaps, the 2010 Mental Health Commission's report suggests that "*the absence of proper care planning is emblematic of the failure by a number of teams… to embrace the philosophical underpinnings of a modern mental health service. These are patient-centeredness, recovery, multi-disciplinary teamwork, and primarily community-based services*" (MHC, 2010, 89).

1.4 The Evaluation Process

This evaluation research was an integral part of the A+M 2011 Research Project and was put in place from its onset. The evaluative element of the research is concerned, in the first instance, with establishing the extent to which the original objectives of A+M 2011 have been achieved, how, and with what implications for future development. "*Evaluation research, as its name implies, is concerned with the evaluation of such occurrences as social and organisational programmes and interventions. The essential question that is typically asked by such studies is: Has the intervention (e.g. a new policy initiative or an organisational change) achieved its anticipated goals?*" (Bryman, 2001:40).

The A+M (2011) research project was originally set up to consider the impact and potential for integrating the arts into mental health care planning. However, through this research it emerged that understandings and practices of care planning varied

[15] The Mental Health Commission (MHC), established under the Mental Health Act 2001, is an independent statutory body. Its functions outlined under part 3 section 33(1) of this Act are to promote, encourage and foster high standards in the delivery of mental health care.

significantly among different stakeholders and mental health settings (see chapter 3.1.3). It was also recognised that simply considering the arts in relation to care planning would not provide a full appreciation of the arts in mental health. Therefore the emphasis of the research project broadened towards exploring the contribution and possible integration of the arts into the broader field of mental health care.

The design of the research was informed by the philosophy underpinning (a) current developments in mental health and (b) the development and delivery of the A+M 2011 research project. In this philosophy, service-users play key roles in defining and taking charge of the changes they want to bring about in their lives. The approach to the evaluation needs to reflect the ethos of the project, which is informed by principles of recovery and social inclusion. In a period where evidence-based practice is central to service development and delivery, this research highlights the significance of evidence constructed by the narratives of people who have direct experience of mental health services.

Furthermore, this research acknowledges that despite the current changes towards recovery-oriented practice, mental health care, particularly in inpatient settings, remains primarily biomedical. In evaluating the contribution of the arts in mental health care, we cannot ignore the tensions between art as a form of creative expression and the dominant biomedical model of care which has not traditionally encouraged creativity of expression. While a detailed analysis of such tensions go beyond the scope of this research, it is important to acknowledge them and problematise them.

1.4.1 Objectives of the Evaluation

The basis of this evaluation and the data collection were determined by the original objectives of the Arts + Minds 2011 Research Project outlined in section 1.1.1 The research was designed with the intention of focusing on both the *process* and the *outcomes* of the project, in order to provide a comprehensive discussion on:

- the impact of the project on (i) service users, (ii) agency/professional practice and (iii) the community

- the potential for integrating the arts into mental health care
- relevant national and international policy and research on the arts and mental health
- recommendations for best practice and future development

It is hoped that the evaluation process will also help to:

a. achieve clarity regarding progress, assess the strengths and weaknesses of the approach taken
b. plan the future development of the project
c. foster a capacity for ongoing self-evaluation
d. address some broader policy and ideological issues concerning the partnership between the arts sector and the mental health sector

1.4.2 Approach and Methodology

The main methodological tool employed was *qualitative* in nature. Participant observation (with *ethnographic* elements) and semi-structured interviews were employed to examine all individual components of the project. Applying a qualitative approach in the Arts + Minds research was considered appropriate and compatible with the ethos of the project as this approach is concerned with how people understand a certain topic, in this case the impact of the arts in mental health care. The strengths of the qualitative approach are:

- Researching people in natural settings
- Achieving a greater understanding of the respondent's world
- Stressing interpretations and meanings
- Humanising research processes by raising the role of the researched, allowing higher flexibility
- Presenting a more realistic view of the world (Sarantakos 1998:53).

As data was collected from the standpoint of the participants, an *interpretive* framework was employed to consider the service users' subjective experiences. This

subjective dimension was particularly useful in exploring how project participants defined the significance of the arts as a care option within mental health care.

Furthermore, as the researchers have been actively involved in the arts workshops, the research is also informed by elements of *ethnographic research* and *participant observation.* This is "*a distinctive qualitative research strategy which enquires into social life and behaviour through first-hand intensive observation in naturally occurring settings; such research is also participant insofar as the researcher …constitutes the primary research tool, participating in social activity in order to gain a close and unforced understanding of people's lived experience"* (Hall in Shaw & Gould, 2001:51). Using methods of participant observation, the researchers partook in both music and animation workshops where they introduced themselves, explained the aim of the research and actively participated.

1.4.3 The Evaluation Data

The data for this evaluation consist of:

1. Documentation and literature pertaining to the project's aims and objectives. This included:
    a. A broad review of documentation relating to the 'operational environment' (e.g. 'Vision for Change', 'A Vision for a Recovery Model in Mental Health Services', 'A Recovery Approach within the Irish Mental Health Services'), in order to locate the project in the broader context of service provision trends.

    b. A literature review on the areas of arts in health and mental health, social inclusion and recovery approaches in mental health.

2. Personal/group interviews with service users. The research was largely focused on the way participants described their experience of participating in the arts workshops;

3. Personal/group interviews with the staff team, some of whom are also members of the A+M Subgroup and Steering Group;

4. Personal/group interviews with contributing artists.

The following table presents the interviews with A+M participants and mental health staff by project and location. Interviews were held with five out of a mean average of ten participants of the *Éist Agus Faire Project* in Cúnamh day hospital/centre. As the South Lee Mental Health unit is an acute setting, there was high turnover of participants over the eight weeks of the A+M *Flow Project*. Interviews were held with a total of twenty-one participants of the *Flow Project*. Finally, all nine participants of the *Unfold Project* (South Lee Community Mental health Services) were interviewed.

Table 2: Arts + Minds Project - Interviews by Location

	North Lee Cúnamh Day Hospital/Day Centre Macroom ***Éist Agus Faire Project***	**South Lee Mental Health Unit** ***Flow Project***	**Crawford Art Gallery** ***Unfold Project*** **(South Lee Community Mental Health Services)**
Service users	5	21	9
Staff	3	4	2
Total	8	25	11

1.4.4 Ethical considerations, informed consent

The engagement of the researchers with the service users-interviewees in order to establish a trusting relationship is of crucial importance. The researchers were introduced to the participant groups as part of the Arts + Minds team. The consent was a continuous process. An explanation of the evaluation was given to each interviewee, outlining the reasons for the research and consulting them on the process. Recording methods and confidentiality in relation to data presentation were explained. All participant interviewees signed a letter giving permission to record their experience of the project. All interviewees agreed for the interview to be recorded with the use of a digital dictaphone. To protect confidentiality, data generated from the interviews with participants is presented using anonymous direct quotes to illustrate themes such as ‘connecting with self and others’, the transformative potential of fun’, ‘confidence-building’, and so on.

Chapter Two: Literature Review

This chapter discusses literature in the areas of arts and health, and mental health. The first section defines the concept and practice of creative/recreational therapy. The term 'the arts' is not used in the Irish mental health policy document *A Vision for Change* (2006); however a term that *is* used - 'creative/recreational therapy' - is commonly understood to encompass the arts. This chapter also considers the concept, guidelines, values and outcomes of good arts and health practice. The distinction between arts and health practice and the art therapies is also explored. The final section of this chapter focuses specifically on arts practice within mental health care settings.

2.1 A Vision for Change - Defining Creative/Recreational Therapy

Irish government policy on mental health is outlined in *A Vision for Change* (Department of Health and Children, 2006). The publication of *A Vision for Change* was *"in response to a widespread felt need"* for developing a broader approach to Irish mental health service delivery (p. 5). This policy has made recommendations for a person-centred, holistic, recovery- and community-based mental health service. To deliver this model of mental health care effectively, *A Vision for Change* (2006, p. 79) recommends an integrative multidisciplinary approach consisting of *"input from psychiatry, nursing, social work, clinical psychology and occupational therapy, and clinicians with specific expertise - for example addiction counselors, psychotherapists, creative/recreational therapists"*.

The term 'creative/recreational therapy' is not clearly defined in *A Vision for Change*. One way of defining creative/recreational therapy is through reference to the Oxford English Dictionary. The Oxford English Dictionary (2005) defines 'creative' as *"involving the use of the imagination or original ideas in order to create something*" and 'recreational' is defined as an *"enjoyable leisure activity"*. 'Therapy' is explained as a "*treatment of mental or emotional problems by psychological means" or "intended to relieve or heal physical disorder*". We can also define creative/recreational therapy by looking at the context of its practice. For example,

recreational therapy is defined by the United States Department of Labor as a profession of specialists who utilise activities as a form of treatment for persons with disabilities or illnesses through "*using art and craft, animals, sports, drama, dance and movement, music, community outings"* for improving the physical, social, cognitive or emotional well-being (Bureau of Labor Statistics, U.S. Department of Labor, 2010/2011).

2.2 Arts and Health

2.2.1 What is Arts and Health?

Arts and health is a broad term that embraces a range of arts practices which bring together the skills and priorities of both arts and health professionals. For the Arts Council of Ireland, *"[g]ood arts and health practice is characterised by a clear artistic vision, goals and outcomes. Alongside these, it aims to promote health and well-being by improving quality of life and cultural access in healthcare settings*" (Arts Council, 2010, p. 4).

Arts and health practice takes place in hospitals, residential units, daycare centres, primary care -centres and community settings, as well as in arts venues. It can involve health service users of all ages and abilities, their carers, visitors and healthcare staff. It can also involve any art-form or any genre within a particular art-form[16].

2.2.2 Distinction between Arts and Health Practice and the Arts Therapies

The Arts Council of Ireland makes a clear distinction between *"arts and health practice, where a key goal is the experience and production of art, and the arts therapies, where the primary goal is clinical*" (Arts Council, 2010, p. 5).

Arts + Minds, the group who coordinated the project on which this report is based, also make a similar distinction. Arts + Minds aim to enhance the health and wellbeing

[16] The Arts Act 2003 defines the arts as 'any creative or interpretative expression (whether traditional or contemporary) in whatever form, and includes, in particular, visual arts, theatre, literature, music, dance, opera, film, circus and artchitecture, and includes any medium when used for those purposes.'

of project participants through engagement with and participation in the arts, and to facilitate service users to participate fully in the cultural life of their community. They work in partnership with professional artists and arts organisations, mental health staff and service users, in order to achieve this. The focus of this work is on the experience and production of art as part of a broader, person-centred, recovery approach to mental health care. This process can have a therapeutic affect but it is distinctly different from art therapy as it involves creative rather than clinical goals.

Arts and Minds acknowledge the valuable work undertaken by arts therapists who have been working within the mental health care system for many years, and the potential that exists for shared learning and collaboration between the two approaches. Please see appendix 4, p. x for further information about the distinction between arts and health practice and the arts therapies.

2.2.3 Arts and Health Practice – Guidelines and Values

In 2009, Waterford Healing Arts Trust and the HSE South Cork Arts + Health Programme commissioned the Centre for Medical Humanities at Durham University to develop a series of guidelines for good practice for artists and health professionals engaged in participatory arts/healthcare practice. Participatory healthcare practice is a term used to reflect a way of *"working 'alongside' service user participants, who in many cases are involved in planning, development and in some cases, evaluation of projects, together with project staff*" (Goldie, 2007, p. 14).

In summary, the guidelines are:

1. **Participants come first**

Practitioners of participatory arts and health recognise the wellbeing of participants as paramount. They remain primarily attentive to this, irrespective of the arts activity's context, delivery, development and evaluation.

2. **A responsive approach**

The practitioner always attempts to draw out the creative potential of participants, challenging and motivating them whilst exercising professional judgment on the reasonable expectations from the activity.

3. Upholding values

A collective creative process is generated through the building of mutual trust between participants and practitioner, which generates a commitment from everyone involved to learning and experiencing together.

4. Feedback and evaluation

Practitioners recognise the importance of quality evaluation and their duty to contribute to it by encouraging honest feedback from themselves, participants and other staff.

5. Good management and governance

Practitioners commit to an ethos of good practice and adhere to the policies, protocols and ethical procedures of the organisations supporting the work, and of the institution or setting where the activity takes place (Centre for Medical Humanities at Durham University, Waterford Healing Arts Trust & Health Service Executive South (Cork) Arts + Health Programme, 2009, pp. 6-11).

In addition to the best practice guidelines outlined above, the Arts Council of Ireland (2010) developed the *'Arts and Health: Policy and Strategy'* document. This document lays out its key values underpinning the approach to arts practice in the Irish health care settings. Below is the summary of these values:

- A long-term strategic partnership and planning process across arts and health sectors
- Integration of good quality arts and health practice into the healthcare environment, which is planned by artists, service users, their carers and healthcare staff.
- Arts and health practice is committed to ongoing review of its directions/ purpose/process, and practice is evaluated.
- The wellbeing of participants is paramount throughout all stages of arts delivery and each participant's contribution should be valued (Arts Council, 2010, pp. 7-8).

2.2.4 Arts and Health - Outcomes

Staricoff's (2004) research report '*Arts in Health: A Review of the Medical Literature*' published by the Arts Council in England includes 385 references to studies relating to the effects of the arts in healthcare. The report highlighted different areas where the arts can play a role, including positive changes in clinical outcomes; improving communication between staff and clients; reducing drug consumption and shortening length of stay in hospital; improving mental health care, and developing practitioners' empathy across gender and cultural diversity (Staricoff, 2004, p. 10). These findings are in line with the Irish Arts Council (2003) that produced a report entitled '*Arts Health Handbook: A Practical Guide*'. This report suggests thirty different potential benefits from arts in healthcare settings. Below are the key points related to the benefits of arts in health.

Service user	Increased well-being/self-confidence, capacity for creative/critical thinking skills, developing a new talent
Staff	Improved working environment, stronger sense of community, increased creativity, enhanced awareness/ appreciation, better understanding of both service users and staff as individuals
Artist	Artistic/personal development, diverse audience/increased public understanding and appreciation of the arts
Community	Reduction in sense of intimidation or alienation from a public service, increased sense of ownership of a healthcare centre
Healthcare centre	Reduction in stress within workplace, positive experience of the healthcare environment (Arts Council, 2003, pp. 19-20).

A further report evaluates a year-long arts programme in five West Cork Community Hospitals in partnership with the West Cork Arts Centre. The data indicated similar

findings to those outlined above (Russel, 2007).

An interesting finding was highlighted in an Australian study on arts participation in relation to the participants' experiences of art facilitators. These study findings showed that participants viewed the role of facilitators as important in the way art sessions were provided. For example, participants appreciated a facilitator who *"offers choice and freedom, as well as opportunities with materials to expand one's potential... provides[d] guidance with skill development, yet is flexible to individual needs... encourages clients through their recovery journey by providing a sense of trust, openness and support"* (Van Lith, Fenner & Schofield 2011, p. 655).

2.3 The Arts in Mental Health

This part of the report discusses study findings on the contribution of arts in mental health. This section draws on a variety of studies to establish a rich and broad range of key findings.

2.3.1 Previous Research

There is a growing body of evidence on the benefits of arts for people experiencing mental health difficulties. Staricoff's (2004) study, mentioned previously, cited 385 peer-reviewed medical papers published between 1990 and 2004. This study highlighted the benefits of engagement with the arts (in this case creative writing, poetry, theatre, drama and visual arts, dancing/singing and music) for mental health service users:

- It improved the communication between service users, staff/service providers and family
- It stimulated participants' creative skills and enhanced self-esteem
- It facilitated individuals to discover new ways of expressing themselves (Staricoff, 2004, p. 8).

These findings are in line with two Irish reports, (i) *Music in Healthcare/Mental Health* by Moloney (2005) and (ii) *Ceol Le Cheile: Music Together* by White (2008). Both reports document the experiences of services users, staff and artists who were

involved in music projects in a diverse range of mental health settings in Cork City and County. Study findings show that the music projects had considerable personal, interpersonal, professional (for staff) and artistic benefits for service users and staff. For example, Moloney (2005) concluded that the music workshops had a positive impact on service users' mood, self-confidence, concentration and perseverance; the positive experience created hope for the future and a sense of community, it increased communication skills, and participants learned new skills. Staff and artists benefited from professional development, discovering new skills or new challenges and realising new ways of communicating with service users. These findings share similar outcomes with a different Cork-based music in mental health project (White, 2008). This project took place in five mental health settings including inpatient and community care. This study also confirms that for staff being part of the workshops *"it empowered them to engage with patients in a new way and complemented clinical intervention"* (White, 2008, p. 13).

Stigma and social inclusion

Further studies suggest that arts participation can reduce the stigma and social exclusion experienced by individuals with mental health needs and their families (Parr, 2006b; Hacking, Secker, Shenton & Spandler, 2006; Stacey & Stickley, 2010). For example, Parr (2006a) interviewed 30 mental health service users (referred to as 'project artists') and 5 paid project staff of two Scottish community arts projects - 'Art Angel' in Dundee and 'Trongate Studios' in Glasgow. In this study, the project artists identified a range of social benefits deriving from the arts projects. Some people described as a benefit the expansion of their wider social network which had *"a positive effect on my immediate circle. You know, the stone in the water effect. It ripples out, the effects on family"* (Parr, 2006a, p. 24). Others spoke about enhancing their self-esteem through having access to a weekly structure or routine, peer advice, acts of reciprocity, arts talk, networking with other artists or attending exhibitions. This led the researcher to conclude that both these community arts projects provided stability in participants' lives and contributed to the individuals' ability to relate to and communicate with others, which decreased their experiences of social isolation (Parr, 2006a, p. 25).

Another study by Secker, Hacking, Spandler, Kent, and Shenton, (2007a) focused on participatory arts projects in England for people aged 16 to 65 with different levels of mental health needs, using questionnaires and case studies. The quantitative part of this study showed statistical improvements in empowerment and social inclusion after six months of participation. The case studies included six diverse arts projects, and 34 participants were interviewed about their journey through the arts project. Some participants demonstrated experiences of feeling socially included. One comment by a participant was:

> *It's* [being part of an art project] *taught me a lot that I can interact with people... I've had friends and family saying to me that they've seen the differences. I'm responding to the world differently... I wouldn't have touched a course in the community, it's still a barrier to me but I'm making the circle bigger so it's positive... it's making the safety zone bigger* (Secker et al. 2007a, p. 35).

The findings by Secker *et al*. (2007a) concur with a different study that explored the role of arts participation in mental health services (Goldie, 2007). This study's findings indicated that arts participation provided a link to connect with other opportunities within the community. However, connecting with the wider community also poses some risks. Parr (2006b) argues that locating mental health service users in a mainstream artistic and cultural community contains the possibility that their contribution may be less understood or appreciated than in a protected mental health setting.

Personal development

Numerous studies exploring the benefit of arts participation have concluded that participants with different mental health needs experienced increased levels of empowerment (Hacking, Secker, Spandler, Kent and Shenton, 2008), improved self-esteem, greater confidence, and generation of a clearer-self image (Goldie, 2007, p. 23).

Similarly, a study by Van Lith, Fenner & Schofield (2011) in Victoria (Australia) concludes that creative activities enabled participants to take greater control of their lives, resulting in feeling stronger, more confident and more capable of taking control of their recovery. One participant reported that *"[i]n art making I become an active participant in taking charge and transforming my life"* (p. 656). Likewise, in a study that explored how arts mental health projects may facilitate a recovery approach, one participant explained, *"[i]t's actually given me back in my life some ambition to do something. Which is something that had been absent for a very long time"* (Spandler, Secker, Kent, Hacking and Shenton, 2007, p. 794).

General wellbeing, quality of life and new coping strategies

Literature also indicates that art participation promotes individuals' general wellbeing, quality of life (Arts Council 2003; Bungay & Clift, 2010; Goldie, 2007; Hacking *et al*. 2008; Moloney, 2005; 2007; White, 2008) and provides a medium to explore and understand feelings in developing alternative coping strategies when dealing with distress (Spandler *et al*. 2007; White, 2003). To capture the personal experiences of health benefits, below are some direct quotations taken from different studies:

> *Art making gets me into a routine of doing something productive and a reason to get out of bed which assists in creating a balanced life*... [a]*rt making is fundamental to bringing joy, pleasure and a sense of fun* (Van Lith, 2011, p. 656).

> *It helps that creative bit and that motivation bit, because the motivation with depression is obviously another symptom ... It's given me something to motivate me, to a better quality of life than just being ill* (Secker *et al*. 2007a, p. 35).

> *If you have anxiety you are tight in your body ... in a relaxed mental state you can manage your pain and put less pills in* (Secker et al. 2007b, p. 54).

> *Its sounds corny, but it's like a kind of magic [you] go into a sort of trance and I think it's a fantastic thing when it happens. It doesn't always happen ... but for me it was a way of getting out of depression* (Parr, 2006b, p. 156).

An Ireland-based strategic plan for arts and health entitled *HE+ART a Participatory Arts and Health Strategy for Sligo 2007-2012* evaluates three local arts programmes including (i) the Intergenerational Programme, (ii) Working Creatively with Older People Programme and (iii) the Arts Initiative in Mental Health (Moloney, 2007). The Arts Initiative in Mental Health was carried out in six mental health settings. The findings indicated that participants found that art participation made them happier, more positive, content and relaxed. Participants also spoke about having a sense of fun and they demonstrated more interest in art and new abilities (Moloney, 2007, p. 12).

A study undertaken in England is based on a practice approach called Arts on Prescription (AoP) (Eades & Ager 2008). The concept of AoP refers to a type of social prescribing, meaning *"a mechanism for linking patients in primary care with non-medical sources of support within the community"* (Friedli, Vincent & Woodhouse, 2007, p. 11). In other words, social prescribing is a referral process whereby GPs and staff in the social/health or voluntary/community sector, refer people with mental health difficulties (depression/anxiety) to an art service for additional support in their recovery. Self-referral is also an option. Generally speaking, AoP programmes are available throughout England and they provide a wide range of art activities. The three key benefits to AoP programmes' participants have been identified as: (i) improving mental health outcomes for individuals (ii) improving community wellbeing and (iii) reducing social exclusion (Bungay & Clift, 2010). Based on this AoP framework, a study found that *"64 per cent of the participants had greater self-confidence/self-esteem"* and one of the participant reported: *"I feel more relaxed about being myself in front of other people instead of just retreating into my shell"* (Eades & Ager, 2008, p. 65).

However, there has also been some critique of AoP programmes. The term 'social prescribing' has been criticised for its medical connotations and an alternative term 'community referral' has been suggested (Friedli, Vincent & Woodhouse (2007, p. 5). The referral process is another area of concern because not all professionals refer their clients to the programme. For example, in Nottingham (England) between 2008 and 2011, ten per cent of individuals were referred through primary care (e.g. GPs, public health nurses), fifty nine per cent by secondary care (e.g. acute care), twenty nine per cent by the voluntary sector, and ten per cent were self-referrals (Stickley, Hui & Duncan, 2011, p. 27).

In conclusion, the arts practice in mental health settings has demonstrated a variety of positive outcomes for people experiencing a range of mental health difficulties. There is evidence that engagement with and participation in the arts can contribute to the general wellbeing of mental health service users, can enhance quality of life and combat stigma and social isolation. Furthermore, it can improve or open up communication between service users, staff, family and wider society. Participation in the arts offers an opportunity for learning new skills and abilities and it has the potential for contributing to the process of recovery. The next chapter explores the experience of art participation in the context of the Arts + Minds Research Project (2011).

Chapter Three: Research Findings

This chapter constitutes the main body of the Arts + Minds research and is based on the fieldwork undertaken as part of this study. Research findings are discussed in two parts. The first part considers research findings on how participant service users, mental health staff and artists experienced arts within (a) their agency context; (b) the recovery approach underpinning mental health care and (c) care planning.

The second part discusses primary research findings on the impact of the Arts + Minds project on (a) participant service-users (micro-level) and (b) mental service and community culture and structure (mezzo- and macro-levels).

3.1 Experiencing the Operational Context

The first two chapters provided an overview of the operational context of the Arts + Minds project as well as a discussion on the conceptual, policy and practice frameworks within which the project emerged. The purpose of this section is to consider how these various contexts and concepts have been experienced and understood by those involved in the A+M research project.

3.1.1 Experiences of the Agency Context

The research project took place in a diverse range of mental health settings (acute inpatient care, day service, community mental health services), and project participants had a different range of experiences of the mental health system. These experiences varied from long-term engagement with and intense support by mental health services to first admissions and a minimum level of support at a community level.

It is not the purpose of this discussion to consider how people's diagnoses are affected by or affect their experience of the art workshops. On the contrary, this research has found that arts in mental health are a tool to move beyond diagnosis and to recognise people's multiple skills which are often lost when they become 'patients' in a mental health service.

However, when discussing people's experiences of art workshops we need to consider the service context where these experiences took place. In this regard, it is still relevant to highlight and acknowledge the difference between living in the community and being an inpatient - the latter still being for many an experience of institutionalisation.

Institutionalisation is not necessarily a theme of the past, or a product of long-term inpatient care. People who are in inpatient care for a short period of time can also become institutionalised if they feel they have little choice or control over the structure of their day and their life in general. As a study participant put it, it is ***not life as we know it:*** *"There's people stuck in here* [hospital] *and the night time is long and you know all they have is cigarettes, that's all they can look forward to, they can look forward to a cup of coffee coming out, everybody is queuing, you see the cycle in here is just amazing, the timing, it's just like I suppose like cattle... it's not normal, it's not life as I know it you know people, but it's – they're doing it – it's something to look forward to I suppose".*

A common denominator for the majority of participants was social isolation, the lack of meaningful activities and boredom. While this was particularly evident in the inpatient setting, people who lived in the community (both in hostels and in independent accommodation) also spoke about isolation and often having 'no reason to get out of bed in the morning'. In that sense, the opportunity to participate in the Arts + Minds workshops was particularly appreciated by service users in both acute and community settings.

The lack of stimulation was a shared concern among many participants in the inpatient setting who said the main activity was watching television and smoking. *"You know I've been joking with some of the other patients and we were saying like 'if the depression doesn't kill you in here the boredom would', because you know it* ***has*** *been boring you know, the weather hasn't been on our side either".*

…"and you know apart from the television or whatever there's really nothing to do here".

"A day in here feels like a week, it's long, it's tough, that's being honest".

Participants talked extensively about the need for more activities, such as art workshops, to be available throughout the year. Weekends were a particular concern for many inpatient participants; various therapies and activities are not available during that time and people experience weekends as a long and lonely time.

3.1.2 Experiencing Arts as Part of a Recovery Approach to Mental Health

"Art is an option of care and, as part of the recovery process, it takes the focus off the illness and the medical aspect of treatment" (staff member).

As discussed in chapter one, the Arts + Minds research project took place within a changing policy, and maybe culture, in mental health care. Through a recovery approach and a recognition that we need to look at mental distress beyond biomedical understandings, it has become possible to introduce arts as part of the activities offered in various mental health settings. As another staff member said, *"You know with the recovery mode,... we're really not talking about illness...I don't even think of what illness they have at the moment, I'm more thinking recovery, holistic, I'm thinking of…quality of life..."*

Project participants also articulated how they can now access a broader range of supports, in a broader range of locations.

"In the 80's my only contact [with services] *was a depo injection once a month now I am involved in 3 groups...there is camaraderie. You can tell people how you feel I can be myself I socialise more".*

"I feel in the last two years, since all of these groups have started, it's made it so much easier. Like I would be going mad if there was nothing happening in the next six months".

Through exploring how project participants, staff and contributing artists experienced the recovery philosophy underpinning mental health care, this research identified the following themes:

Changing attitudes in service provision: Staff and artists involved in the project recognised that staff of mental health services have gradually become more appreciative of creative and recreational activities. This is evident by their willingness to participate actively in workshops, whereas in the past they would have been more "*inclined to stand on the edge and look in*" (Arts and Minds artist). For example as one artist argued, "o*ver the last 5 years staff look at art more positively they are also getting involved in workshops : I think staff are more accepting of it… They're very open to you coming in and I think ...once they realise we* [artists] *have specific objectives that we want to achieve as well, they're very open to what we do and encouraging to the groups, and will get involved... when they come into a group session they're much more willing to get, you know, to pick up an instrument and get involved....".* While this quotation refers to nursing staff, artists also identified an appreciation of arts among a number of consultant psychiatrists who, over the past few years, have attended and "really listened" to presentations about music and spoke about the importance of these creative activities.

Making arts an integrated part of mental health care requires an appreciation from the multidisciplinary team. However, some staff members identified resistance in the multidisciplinary teams towards recognising arts as an aspect of care planning. As one staff member put it, *"…and it's hard, it is hard to get other colleagues to take it seriously… there's no doubt about it".*

Art as part of a partnership approach: Arts + Minds is a product of a partnership between various and diverse stakeholders with an interest in both arts and mental

health. This was seen as a strength by most staff and artist interviewees, as "*having different settings and stakeholders demonstrating an appreciation of arts in mental health makes the argument stronger, they can see the potential of all different arts [in mental health care]"* (Arts + Minds artist).

The value of this diversity was also stressed by a staff member who said *"… you have a group of different professions, you have a group of different ideas that brings different skills, it brings people that are good at something and not so good at other* [things], *it gives a greater sense of going to another powerful body and being recognised and given time and resources, it can produce educational data. It can produce research. It can produce fun. It can produce the music. It can answer to the needs of the community and the people*" (staff).

Mental health staff were particularly appreciative of community development and service user contributions to the project. These contributions were considered to provide a new, broader (than the mainly medical) perspective, "*something that makes you look at the problem in a totally different way"* (staff member on community development). *"And then we, we're looking at things from a community perspective but then maybe somebody else is looking at it from an inpatient perspective* (staff on service-user input).

Art as empowerment rather than therapy: This partnership approach gives a different tone to the various activity groups which are more about empowerment rather than therapy. This was a distinction made by all contributing artists who stressed the importance of moving beyond the mental health diagnosis to work towards creative rather than clinical goals. As one artist stressed, "*the idea of the partnership, the idea of the groups are...hopefully about empowerment.... we don't enter the groups as therapists...we can have musical objectives and creative objectives but we're not going with clinical goals".*

Mental health staff also made the distinction between arts and art therapy. As one person said, *"in art therapy you have depth of exploration while arts in mental health*

provide a broader spectrum of artists and art form. It is not art therapy". Staff also identified arts as something that offers people "*a choice, it offers them an alternative not necessarily another treatment*". In arguing for the value of arts in their own right, as opposed to therapy, one staff member spoke about the importance of moving away from a 'fixing culture' in mental health care and recognising the opportunities to consider a 'breakdown' as a 'breakthrough'. "*Maybe it* [art] *helps …to realise that there are no answers and that people don't need to be fixed... trying to fix someone else can be, for me, a bad job because I have not got any power or ability in fixing other people and sometimes a breakdown can be a breakthrough".*

Devolution of professional power: Changes towards a recovery, a more holistic approach to mental health, have also contributed to some service users feeling more 'in control' over their treatment and life. It is important to note, however, that these changes were mainly identified by interviewees who live independently in the community and describe themselves as 'being well' at the moment.

"*... it's getting **way** better. There's loads of work to be done still...in the past I would have had dealings* [with services] *when I was unwell, not in hospital but just unwell, where my family were taking the reins or a doctor was taking the reins, and almost collaborating without me even being there. That still is happening but I think… there's a lot more input from a patient now. And that… being labeled with depression or mental health of whichever form, it's not necessarily for life*" (A+M participant).

Participants also recognised the importance of the multidisciplinary team in improving communication and making more resources available to service users. As one participant said, "*the psychiatrists and the psychologists have less and less to do and that the nursing staff and all the other staff available to you, like the social services make **huge** contributions to us. Since they* [other staff] *took an active role and it's actually out of consultants' hands a bit, there's an awful lot more communication".*

Mental health staff also identified changes in their own practice regarding user-involvement. As one staff member said, *"I think the attitude is shifting that people have choices I think that consultants, nurses, and multi-disciplinary teams become more open to the patients having a choice".* Through engaging in a different relationship with service users, mental health staff also have the opportunity to re-evaluate established ways of working. For example, one staff member reflected on the changes in her thinking and practice: "…*I come from, a bit old school...because I don't want to admit that, but I did feel it wasn't a partnership [before], do you know? So it was very much like 'this is the care plan it's written on the care plan' - da, da, da, da - and I did it myself and then sometimes they signed it, sometimes they didn't, but that was it. I didn't really ask them 'what do you want?' But they didn't tell me what they wanted either, that's the way it was. So that has changed completely, and they are looking for something broader. They're not prepared to just have medication ad-hoc and no more. Community service…now they are looking for more and more*".

Culture and ideologies underpinning mental health care play a vital role in this discussion. In evaluating the contribution of arts in mental health care, we cannot ignore the tensions between art as a form of creative expression and mental health care which, because of the dominant biomedical focus, has not traditionally encouraged creativity of expression. While a detailed analysis of such tensions go beyond the scope of this research, it is important to acknowledge them. A meaningful partnership between the art sector and mental health services is not simply a technical measure but will also require a fundamental change of culture in mental health care. This research attempts to identify some of the ingredients of this cultural change.

3.1.3 Participants' Experiences of Care Planning

This study does not aim to provide an in-depth examination of care planning in mental health. Nevertheless, as the research project was originally intended to examine the possible incorporation of arts into care planning, experiences of care planning by participants, staff and artists merit some consideration.

The research found that the participants' degree of understanding the concept and practice of care planning was mixed. When asked about care planning, many interviewee participants initially said that they did not know what it meant. The question became clearer with probing, for example asking whether people had a key worker, as this was a concept with which most participants were familiar. However, for many it was unclear whether care planning and meetings with a key worker were the same activity. As a general observation, people who had had a long involvement with mental health services (i.e. over 10 years) seemed to know less about care planning compared to people who had engaged with services over the previous 3 to 5 years. Furthermore, the extent to which arts were considered to be part of a care plan varied significantly in the three research settings.

In examining experiences and understanding of care planning, the evaluation study identified the following key themes.

Content: *"They just kind of ask you, they ask you if you all right. They ask you if you have any problems and if you have you can talk about them. That's it really".* There were considerable differences in the experiences and articulations of care planning between participants in acute and community care.

For example in inpatient settings, medication management was a dominant feature of care planning. Some people talked about seeking 'privileges', such as access to their clothes and permission to go outside the hospital ward, as part of their care plan. Others saw care planning as a list of tasks instructed by staff… "*they say 'did you brush your teeth?' If you say you didn't they say 'brush your teeth every day, change your socks every day, have a shower every day, change your clothes every day, do the washing up. Do a bit of gardening a bit of painting'".* For one participant in acute care, care planning was an opportunity to make plans for their discharge from hospital, and to look at important practical issues such as finances and social welfare needs.

Others viewed care planning as an opportunity to 'come to terms' with their condition. For example, one person spoke about care planning as being a space to 'make sense' of his condition and to think about how best to respond to it. Another participant spoke about how through care planning he was able to open up to his family about being in hospital. Practical considerations, such as welfare and housing needs, were more part of care planning in the community - "*the key worker has an ear to the ground about what life is like for somebody with mental illness the practicalities the psychiatrist would like to know about medication there is more to life than medication"* (A+M participant).

Frequency and duration: The frequency and duration of care planning meetings varied significantly. Based on participants' feedback, care planning meetings took place more regularly in acute care. However, the frequency of these meetings varied; for example, one participant said that she met her key worker on a daily basis while others said that they had not met them for over two weeks. What is important to note is that for many participants it was not clear whether they referred to meetings with the key worker or to care planning sessions. As discussed earlier, this is a question of clarity about what care planning actually is.

One participant spoke about being introduced to a care plan on admission but not having met a key worker since then, which was 2 ½ weeks previously. *"I've come in, on the night I was admitted they had the care plan that yes I would take part in the therapies, and speak to nurses, and you know comply with medication and things like that, so that's obviously ongoing but there hasn't been any discussion since..."*

Staff availability for such meetings was seen as a key aspect of care planning by many participants. This is a concern particularly in inpatient settings, and service users talked about how they appreciate being approached by a key worker rather than having to seek them out themselves. One interesting point was made about the need for key workers to have 'protected time' to spend with service users: *"I suppose if we had a key worker to approach us when they had time, that they'd have protected time to approach us I suppose is what I'm getting at".*

One person who was approached by a staff member said "…*I know they're just extremely busy in there you know, it's very hard to get somebody, but I found that this nurse was kind of you know – she goes looking for you, and she'll find you, just to give you that five minutes, she's following – she followed up my medication wasn't organised the day the doctor put it up and I explained it to her that night and next day she'd seen to it I suppose and sorted it… it's nice just to have that*".

It is interesting that a number of participants commented on the lack of resources as an explanation for the limited availability of staff. "W*hat I would miss would be that I would have to have... a key worker to have more time to sit down with on a one-to-one basis... almost like a counselor... you know have some support and discussion along that lines, but the resources obviously aren't there for that".* On a similar note, a number of interviewees spoke about the pressure staff are under (in acute care) and expressed a concern about 'imposing' on their time if they requested a meeting -*"...you can see that they are running around all the time you know". De*spite the perceived time pressure on staff, most participants said they felt they could approach a staff member if they needed to.

Shared decision-making: The degree of user involvement in making decisions about their care differed considerably. The service context discussed earlier was an important factor in shared decision-making, with people living in the community feeling that they were quite 'in control' of care-related decisions. On the other hand, most participants who were in acute care said that decisions about their care were mainly in the hands of staff. Only one of the twenty-one service-users interviewed in acute care said that they made their own decisions. As one person said, "o*h, the nurse decides! We have no say in that".* Another participant stressed, *"they kind of make suggestions on your life. They discuss medications as well...Well, the nurses.... They decide and I suppose, the doctor really decides in the end like".*

For a number of participants in acute care, care planning was primarily about what they were 'allowed to do'. *"And little by little, once my mood goes up a bit...I'll be*

allowed to do more things". Another person said, *"at the moment no* [I don't have a say] *I'm being told what, what is happening, eh, but, I reckon once I get a little bit better I'll have a share in that".*

It was interesting that some participants viewed the expression of a request as something sounding 'demanding' and 'irrational'. For example, when a participant was asked if they would feel comfortable to request changes regarding the art workshops, the response was "*well no I could not say - well - I could not go to [nursing manager] and say I want the music therapy tomorrow because I want to sing a song. I can't do that at all!"*

On the other hand, the adoption of a 'softer' approach to care planning was acknowledged by one of the participants who had been involved in mental health services for over 20 years - "...*they [staff] say 'would you do' this rather than 'do it' you know what I mean?"*

Changes towards more shared decision-making were more evident among people who live independently in the community. As one participant put it, *"when I go to see the psychiatrist – before...I used to just take everything at their word, that you need medication yah you take it – no – I'm absolutely opposite of that now – complete opposite. I think myself I have a very strong role to play in my recovery... I just don't allow them to give me a prescription... and I would say 'look I've been well for X amount of months, why isn't it being decreased rather than increased constantly' so, I think for those reasons I would* ***definitely*** *have to have a very independent say in things"*. This view was also supported by mental health staff working in the community "…*and they [service-users] have huge input into their care plan. What they want, what they don't want, and they get it and it's great*".

Furthermore, this research found that people who live in the community experience more choice of therapies and interventions in care planning rather than exclusively relying on medication. Two participants particularly appreciated meeting a diverse group of staff in the community (for example one person's key-worker is an occupational therapist). The same people also valued 'normal' community spaces for

meetings with mental health staff. Meeting in the service user's home, a pub, a café or a local HSE office helped to reduce the stigma, according to one participant who said "*it doesn't feel that you're in a mental health ward or the stigma that goes along with it and so this to me is like an office that I can*…[making reference to a community based HSE office] *be anyone".*

Arts in care planning; None of the project's participants spoke explicitly about arts being part of their care plan. While participation in the art workshops was greatly appreciated by the service users involved, it was mainly perceived as an 'extra bonus' rather than as an integral part of their care plan.

As already discussed, this is not a surprising finding. This needs to be understood within the long-established culture in mental health care where medication remains the key care provision and where additional activities, while starting to be more appreciated, remain peripheral to care planning.

Mental health staff stressed the importance of having a wide range of resources to respond to the needs and interests of service users. As one staff member said: *"The more variety you have the more service users you will catch in the net and… that… things won't go stale from doing them over and over again…people want to be careful with not to be doing the same things all the time".*

Mental health staff also stressed that including arts in care planning creates more options beyond purely medical responses. For example, one staff member said that "*not everything should be medically orientated*…[art is] *a non-threatening, non-invasive* [activity] *and it's a great communicator, socialising factor*"… Another staff member concurred with this view by stressing that "…*it can't be all about medication it's very much the social side of it and I suppose intellectual as well for the client …"* On a similar note, another staff member said that "[art is] *as important as the medication as the counseling … The service users love it. I mean I have seen them absolutely blossom since we have got involved".*

Staff also noted a significant reduction in the frequency of outpatient appointments (e.g. from fortnightly to two-monthly) among people who participate in community art projects as they can find support in other places through engaging in activities which are meaningful for them. As one staff member argued, "…y*ou know, and it's not as reliant on the nurse …or on the psychiatrist again, that they have found something that they like..."*

The artists in this study stressed the significance of arts in care planning as part of a package that enables people to deal with their mental health difficulties. An important opportunity provided through art is to see people in different roles, for example as a participant of a music workshop rather than a 'patient'. From a care planning point of view, it is important for mental health staff to be aware of the impact of art on participants, for example to notice how less anxious a person can be at the end of a music workshop, or how they may interact well within a music session while not interacting outside the music group. It is an opportunity to look at strengths, talents and abilities which are often lost when a person is exclusively viewed as a 'patient'.

3. 2 The Impact of Arts + Minds

This part of the report discusses service users' experiences of their participation in the Arts + Minds project. The first section outlines the participants' motivation to partake in the workshops, as articulated by them. Then, the impact of the art workshops on (i) individual participants (micro-level) and (ii) service/community culture and structure (macro- and mezzo-levels) is considered. The discussion is informed by interviews with Arts + Minds participants, mental health staff and contributing artists.

3.2.1 Motivation to Participate and Choice to Continue the Workshops

"It sounded good to me …A reason to get out of bed at the start of the week" (animation project participant).

Many project participants spoke about the workshops being a way of dealing with boredom, particularly in acute care, a reason to get out of bed, a way of improving their mental health - *" ...you know, I suppose to reawaken the mind because I suffer from depression and the mind closes down and stops thinking. Just to you know become more creative and more sociable"* (music project participant). Others were simply curious about the activities, while some participants also spoke about hoping that they would have fun. As one participant said: "*I hope after a session to be able to sit back and say: What a lovely evening we had!".*

The idea of participating in an activity in the city centre was appealing to many participants of the animation project. "*I liked the idea of working in an art gallery, the atmosphere around there... it's right in the centre of the city"* (animation project participant).

Participants' previous experience of art workshops was mixed. Most day care participants had previous experience of music workshops, had enjoyed them and knew what to expect. In acute care the experience was mixed. For many project participants it was a first or second admission, while others who had been in the service for longer had experienced less input from the arts in the past. Three of the animation workshop participants had done animation work with the same artist before and enjoyed it, hence they decided to participate again.

People's perceptions of mental health care also affected their willingness to participate in the workshops. For example, one person did not want to participate initially because of stigma and because of viewing such activities as 'pointless'. "*There is a bit of a stigma attached to it and you know when you're not used to it and trying to come to terms with it or understand it ...so and that's why I kind of I suppose a bit ignorant maybe or I just didn't want to take part in some of the activities here. You know out of tiredness some days or just lack of interest or just feel probably that it's pointless".*

This research found that, apart from enquiring about people's motivation for joining the art workshops, it is also important to consider why people continued to participate in the workshops. Most participants spoke about staying in the workshops being their own choice, while one person who was ambivalent about staying in a group said: *"I haven't given up because [staff name] thinks it's good for me as occupational therapy".*

Project participants appreciated having choices in participating, walking in and out of sessions, engaging little or a lot with the group, introducing their ideas to the group, and changing their minds about participating. For example, one person spoke about the music workshop. *"They've been asking me to go to it for weeks and … I've been looking at them and saying like, 'how, how'. I knew I was going to be in here with a crowd playing instruments or whatever, I didn't know what was involved. I just thought it would be like putting a load of 4-years olds into a room and giving them saucepans and spoons banging you know, that was my perception you know – I suppose very ignorant but that's just being honest..."*

Another participant said: "*Yeah - I slowly but surely got drawn into it (music) which did not happen the last time. I think, I actually got up and left the last time. .... I found it very therapeutic today".*

This was also confirmed by the artists who delivered the workshops - *"...if a person doesn't want to sing would they like to say a poem or would they like to use some other way of expression...And you know by the end of the group...it's not that everyone has to engage or, often for the first week people don't but then after two weeks or three weeks they engage a little more" (Arts and Minds artist).*

This brief conversation among project participants gives a good insight into the experience of having choices:

- *"And again that your opinion again very much counts. That if you do try out a class of 10 weeks and after the first or second you just say 'oh definitely not me at all' that you can just leave it to somebody else."*

- *Exactly yah. And try something new if there's something else comes up, that's what I like…"*

- *"Having the choices,* [is] *very important..."*

3.2.2 Micro-level; Impact of A+M Workshops on Participants

All interviewee participants described the art workshops as a positive choice to have as part of their care. This does not mean however that *all* participants *always* enjoyed *all* the art sessions. Some people for example spoke about struggling with interactions in a group, or about some aspect of music bringing up feelings of sadness and loss. However, they all appreciated the range of experiences they were offered through the Arts + Minds workshops.

"I think it's essential...I just think it's essential for giving people different things to get involved in, open your mind to different things, meeting different people, ***love*** *the idea that there's men and women, love that idea, that it's not just one group of men or women, love diversity and things...as many different things that could be related to the arts as possible"* (animation project participant).

"*I think it's about - respect, dignity, views, alternatives, it* [art] *can give a person a sense of being freed up, a sense of being connected with the soul, their gut - their heart.* [Arts] *can ground people, it can take people out of sometimes the block they get int*o..."(staff).

Participants spoke about feeling good, enjoying themselves, having a sense of worth, developing a sense of collaboration and camaraderie, working towards an end result, developing concentration and focusing skills, realising they had skills they never thought they had, feeling respected and heard by both artists and mental health staff.

While few participants mentioned the word 'recovery', the majority of interviewees spoke about arts facilitating the creation of an environment that is conducive to recovery by identifying the following themes:

Being part of a social community

…*"it* [arts] *gives... a sense of not being cut off, it's integrated with our culture, the everyday stuff that they do in communities and the outside world..."* (staff).

A+M participants, staff and artists spoke about arts as a 'care tool' to combat isolation. *"... [S]ocial isolation is the hardest thing to combat. And sometimes there's a tendency to say ok they're not ill so they don't need anything, you know, but social isolation is crippling. And I think that would be somewhere where the arts can certainly slot in and ultimately I would like to see some of our clients...moving into community dance groups or moving into community arts groups..."(*staff).

For animation workshop participants, being located in an art gallery, a 'normal space' in Cork city centre was very significant as it was seen as a way of being involved in the community.

Again, this is a short conversation between two members of the animation group highlighting this issue:

- *"So it's not like you're sitting with a nurse as such, or do you know a member of the mental health team – do you know what I mean so and even going to the Crawford Art Gallery you know like it gives you - you're going to an Art Gallery …"*

- *"You're going somewhere different. It's – for anybody that's been in long-term mental health care it's absolutely – we've been bombarded with hospitals, we've been bombarded with medication"*

- "*It's great, I loved being in the gallery"*

- *"We've been institutionalised and it's completely the opposite of that is what we need".*

Community mental health staff also stressed the importance of meeting service users in a mainstream community setting and developing new relationships with them in a different context. This was considered a welcome shift from a pattern of care primarily involving home visits and referrals to outpatient services.

The symbolic significance of a community space was also articulated by the animation facilitator who said: "*I think coming into somewhere like the Crawford Gallery and using this space is a really important part of it...it's inclusive in that way, and claiming the territory as well*".

The *Unfold* (animation) *Project* involved a historic walk around Cork city, which was something that none of the participant service users, staff and artist had done before. It was a new shared experience for all and "*it opened up the city in a new way for all of us, and made it a more interesting place to be..."* (animation artist).

A sense of a social community was also developed in both acute and day care settings through the music workshops, where participants spoke extensively about opportunities to 'be with' people in a fun, relaxed environment, to see 'patients' in a different light, to have a sense of belonging.

"The atmosphere is different, everybody is enjoying it its more relaxed it's separate from the hospital, it is out of the atmosphere in the hospital it's different it's separate from it..."

"Well it made me feel part of a group, belonging, accepted, you know as opposed to being scorned at, put down... it was good for me, it was good fun for my self-esteem I felt my confidence was better...I do get periods of giddiness ...but I am always afraid

like that something is not going to last or that someone is going to take this away from me. I did not feel like this in the music today."

(music workshop participants)

Connecting with self, others and life; opportunities and challenges

A number of participants said that the art workshops provided a space to connect with themselves and their feelings. As one person said, *"...art is kind of connected with your soul, your sanity and if you are not connected you'd be like a zombie".* Another participant also spoke about how art "...*makes me think about myself, my life, my feelings".*

Participating in the workshops was also a way for many people to 'get back some reality' in their lives. This was clearly articulated by one person who *said "... it was nice to get a beat and ...get something back, you know some bit of reality back you know. I like music, I listen to it a lot but I've lost interest in it lately and you know I just found that I was able to get a small bit of rhythm back in my own"* (music workshop participant).

Relationship building with others is also a 'real life' situation. This research found that art workshops were experienced as a positive space for participants to connect with each other and to build relationships in a stress-free environment. As one staff member put it, "...*you can share stories like ... this morning* [somebody said at the music workshop] '*oh I met my husband through this song'. You... can share stories with... the music and the arts. You can tell your story in a sense and not be that big heavy kind of 'tell me about your life'...*"

"I think this helps everyone to be together this is a good thing you know" (A+M participant).

As one artist put it, *"it* [music] *is a way of establishing relationships with people who often find it very difficult to communicate with people...and the fact that it's non-*

verbal, again often it seems to happen without people realising, and... you see a totally other side to people. And you see a side where people have potential..."

Being part of the music group seemed to motivate participants to 'get on' with others in the acute setting. Many participants commented that, apart from smoking, there were limited opportunities in acute care for people to get together. Participants said it was easy to mingle in the music workshops as they felt it was a friendly, family-like environment. "*In what way that music enliven the hospital better? I suppose it brings kind of – more family orientated but more people get closer a bit you know, patients as well I think"* (music workshop participant).

"*It makes me feel interested in getting on with people... it's group therapy you know what I mean..."* (music workshop participant).

"It [music workshop] *helps me to link with other people... because I am a quiet kind of person"* (music workshop participant).

"It's easy to mix with music...it's enjoyable to be with people when singing" (music workshop participant).

Mental health staff made similar observations on arts as a medium to enhance communication and interaction. "*I think one of the strengths of the project...is communication it's about connections – it's about more than just communications, it's like the unspoken"* (staff).

"... a forum for people to interact and to develop- that's how I see music" (staff).

Fun and enjoyment were mentioned by many music workshop participants as ways of connecting with others. One person said "*well I have a good craic I am looking forward to getting out - interact like. They mock me, I mock them. Its good fun like".* Another participant stated: "*I don't know being with a group, being with a group of people... it helps me relax a bit and when I play I kind of enjoyed it. It's like playing*

and I enjoyed all the people I am with, people singing singsongs. I enjoy it really more than anything else".

Seeing another side of people was also identified as a way of building relationships by getting a different perspective on people "....s*urprised me – ...I was just looked around the room and I've seen you know other people kind of making an effort and you know I suppose just able to let go a small little bit then as well*" (music workshop participant).

In the *Unfold* (animation) *Project*, people worked intensively in groups towards developing a story for the final product (animation feature). *"We were all on the same boat ….we are connected through developing a story"* said one participant. Interestingly, this is not just a metaphor, but it was meant literally, as one of the animation features included a boat journey through Cork city!

Animation project participants spoke about developing a sense of camaraderie and co-working skills. As a member of this group said, "...*the ability to do something, to co-operate is a skill that makes life easy*".

The *Unfold Project* facilitator also commented on the development of a collaborative spirit among workshop participants - *"... the teamwork just fell into place in a very fluent way, and it was never pointed out you're going to do this or you're going to do that, but people gravitated towards the things that they enjoyed doing and because they enjoyed doing them they were good at those aspects. So somebody who liked telling stories was the person who wrote the script, and somebody who liked technology was the person who did the computer, but at the same time people who'd never used the computer before, were also exposed to the opportunity to do that, and they were very focused, but very unpressurised way... I think teamwork was brilliant and having a bit of fun and a bit of a laugh as well, because things go wrong and they laugh, things go right and they laugh*".

This does not mean that *all* workshop participants *always* enjoyed being together and co-working. People also struggled when being with others, for example one person spoke about the frustration of being part of a group: "*Sometimes it's hard, frustrating...trying to co-operate I am not enjoying it maybe I am not supposed to enjoy it*" (animation workshop participant). Another participant spoke about not always enjoying the music workshops … "s*ometimes I don't [enjoy it] - it's not that I don't like people but sometimes I am kind of too depressed to… I don't know too nervous maybe to play sometimes or to sing".*

Based on the discussion above, it can be argued that project participants were given opportunities to experience the benefits, limitations and challenges of 'being with others'. Through this experience people were given an opportunity to connect with 'real life' situations, an essential process in mental health recovery.

Changing interactions and perceptions

Mental health staff actively engaged in the Arts and Minds workshops and this was appreciated by participants and artists. "*This made workshops an activity for **all** involved not just something for 'patients' or people who are ill"* (Arts and Minds artist).

Some participants said they found it was easier to approach staff in the context of the art workshops; as one person said, "*I don't know... the people here, the nurses and things like that - you can talk more to them".* This can have a positive affect on staff-user interactions outside the workshops. For example, one staff member said that after co-participating in A+M workshops, service users have '*de-stigmatised us*'. Another staff member said "*...they see me differently as well. It's all so positive. Now when they have a problem with their mental health...they actually will ring me up or contact me very privately and talk about it"*.

Staff and some participants spoke about service user-staff relationships becoming more equal in the context of a joined activity where there is an opportunity to move beyond professional boundaries and just be members of the same group. As one

participant said, *"... and the nurses got involved as well, do you know what I mean, that was the thing as well like – [names of staff] got involved just like us, they weren't like standing over there and just supervising, do you know... it was like we were all – there was no difference between me [names of staff] I didn't feel like a client".*

Mental health staff also spoke about equalising relationships as it is evident in the following dialogue.

- *"And it changes your relationship because...[if] you've somebody at home, you're coming to the patient and illness is what you're dealing with...Into an animation group for example into an art gallery and you're part of the group and they're part of the group, and the relationship has changed. Your relationship is on, is on a level...All are participants in a group, rather than a nurse and a patient".*

- *"Yeah, that's what I actually find. And the word 'facilitating', I mean I came in as a facilitator initially, I'm not a facilitator anymore".*

- *"No".*

- *"I'm actually participating".*

- *"Another participant!"*

Seeing service users as participants in art groups has been a way to re-evaluate staff perceptions and practice. As one artist said, "*I think their relationships change a lot, especially in places where we would work in for a while... staff would have said to us that they see people in a different light or that they kind of said how did I not know that before, things about different members in their group that they would have never thought of it before".*

"*And nurses, the nurses who come into the groups often comment again that they're surprised how people interact with us. That it's different. I think the choices would be part - there's no pressure put on people… people can come in whatever way that they want to interact, and the way we set up the groups … allow people to achieve something small and then maybe move on"* (Arts & Minds artist).

The following comment from a staff member highlights the opportunity to review perceptions and to improve staff-user relationships. *"I actually didn't think they could do, but ...it [art project] is a place for them to tap into their creativity...their imagination, all of that... and I think they feel also equal to me in every way. So it's a very good working relationship we have established. My relationship with them has improved".*

One artist, drawing from previous experience, said *"we've heard staff comment that they were absolutely amazed at how people could interact within the group, and one staff member once said something like 'it almost makes you feel, God yeah, we're really underestimating these people'. So in that sense there is a definite impact on staff. It makes staff re-evaluate themselves at times... Oh God maybe there's more ways of interacting with people".*

Changing relationships can also pose challenges to long-established power differentials between mental health staff and service users. As one artist said, *"... in the group* [A+M], *everyone is the same level...some people really embrace that, and some people can find it unsettling because there is this outstanding relationship and this is the way it's always been".*

Beyond diagnosis; from service users to creators

"I didn't feel like a client" (animation workshop participant).

"*I see them as people in every way now and not talking about illness...at all, and to me that's what life is about*" (staff).

The Arts + Minds project provided an opportunity for participants to see themselves and to be seen by others as individuals in different roles rather than patients with a particular diagnosis. For example people in the music workshops saw themselves and other participants as people having fun, sharing a joke, liking or disliking a particular kind of music. They also learned a bit more about each other's lives. Similarly, in the animation project participants met each other through different roles like story-tellers and story-makers, and through trying new things together, collaborating towards a common task.

As highlighted in the previous section, mental health staff spoke extensively about seeing people rather than patients in the art workshops. As one staff member observed, *"they were not diagnosed or necessarily clinically looked at; it was a different angle so it gave a different aura about it".*

"…And you're definitely not thinking of illness I don't mind if they have a history of schizophrenia or bipolar whatever that's not the issue anymore" (staff).

Project participants also spoke about viewing themselves differently, as the following quote suggests: "*I think it's kind of different because you are not talking about your illness. You are not discussing that - you are not talking about medication. You are just like any other person when you are in there and you are just having a laugh and -- just like any other person. I think this is more positive because you can forget your problems"* (animation project participant).

An interesting point was made by one of the artists who stressed the value of not knowing about people's diagnoses. *"I think it* [art] *would be a really dynamic way of working with those people and – fun – and something that…. involves them not as service users so much but as people who are creators themselves. It's not… that here I am being a consumer, I'm being a creator - which is a huge leap…It's really good to change that around and say well actually no I'm not* [a victim] *I'm somebody who is in charge with the mental illness".*

Arts were also identified as a way to creatively address the consequences of mental health problems such as low self-esteem, lack of self care and low confidence, rather than merely the clinical symptoms. *"You can't just say depression is the problem. It's what comes with that. So again if we are thinking of care plan, maybe they* [service users] *were not interacting well* [with others] *and we knew that they found enjoyment in music it would be the right thing to put them into the music group"* (staff).

Fun has transformative and therapeutic potential

"It's very serious a lot of the time in [name of service] *and I like when ye come in and just have a bit of craic*" (comment of participant to one of the artists).

"It was good to see people happy in that situation" (workshop participant).

While taking part in an art workshop was clearly a way of breaking the monotony of life in acute care, the transformative and therapeutic nature of fun and enjoyment were also identified by participants in all three settings. Many workshop participants spoke about how having fun, seeing other people having fun and enjoying themselves enhanced their wellness. For example, one person who was initially reluctant to get involved in the music workshops said *"...but surprisingly it was nice to see some people enjoying themselves, there's a bit of craic and there's a small bit of communion about it ...you know just for the people that are there".*

"I enjoyed it.... I looked around the room and everybody – even the ones that kind of looked bored - they were still rattling the rattles" (music workshop participant).

"Well the music itself is uplifting people. People enjoy singing it gives them a chance for a boost" (music workshop participant).

"That's far more beneficial than anti-depressant medication (laugh). *Did I say that?"* (staff).

The therapeutic potential of an accepting environment

The findings from the interviews suggest that having fun can be therapeutic and transformative when people are in an environment where they feel there is no pressure to perform, to 'be' or to express themselves in a particular way. Effectively this is an environment where people experience a sense of freedom and acceptance. As one of the contributing artists said, *"I think it comes down again to the creativity side of things, that people have that opportunity, again non-verbally there's no pressure... you don't have to come up with a masterpiece but you get to say what it is that you want to say without having to put any words on it. If you want to just have a little tip away on an instrument and play very quietly you can do that. Or if you want to really let go you can do that too. So there's that freedom* [it] *is important that there's no right or wrong".*

On a similar note, one of the music workshop participants said "...*well, everyone can be a part of it. So, it doesn't matter if you can sing or can't sing, you can still have rhythm, and it's so relaxed, and there is a lot of laughter in it".* Being in a place where people do not constantly doubt themselves is important, as the following quote suggests: *"... I have over a hurdle of ...doubting myself. I am getting over a hurdle of playing music and seemingly that nobody notices that you don't sing properly or something. I was very anxious before, anxious what this person or this person thinks and now I have learned I am over that, I am relaxing and just don't worry if I miss a chord or something. So it's kind off, it's an effect...People accept and I get on with people better since I have started getting back into music".*

"I suppose looking at it it's a non-invasive form of therapy. It's not threatening, it's non-invasive, but it's very creative" (staff).

Feeling respected and being involved

Many participants said that, in the A+M workshops, they felt respected and involved in what was going on, they felt that their opinions counted, that they were comfortable to make suggestions to their groups. In the animation group this involvement was manifested in the process of story-making, as well as the participants' contributions in the design of the feature animation films. As the animation artist said, *"I suppose [my role] is just to give the space for people to create their own stories".*

Commenting on people's involvement in the making of the animation features, the artist/facilitator highlighted that it "*fell into place very naturally, and everybody was able to bring something of their own, everybody…some of the participants know a lot about Cork history and had a lot to contribute in a way that was refreshing for everybody, and others had different skills".*

Community mental health staff also commented on the user-centred nature of art groups.

"And back to it again with participation in arts groups, people are not as passive, the longer they participate in a group, the less passive they become".

"And of course client input, servicer input has changed massively".

In the music groups, user-involvement was manifested in the actual running of the sessions. The musicians were responsive to the various contributions/requests made by participants but they also moved beyond that to create an environment where user initiatives were facilitated and encouraged. As a staff member observed, "*my expectation would be that at the beginning people would sit back and let the musicians carry on and entertain them but it wasn't working at all like that. It was interlinked with the service users and some days it would be very led by the service*

users they would insist that they wanted to do that or and the [musicians] *would take that on board as well. It was great!"*

As one the artists said, "*it's not us calling the shots... they're having an influence on what happens, and what is to, you know, if it's a regular group that comes together that they're having an influence on what happens in the coming groups*".

The significance of feeling respected needs to be seen in the broader context of user experiences of mental health services. In this project interviewees did not speak about feeling disrespected by mental health staff; however, some expressed concerns about the lack of choice of activities and the infantilising nature of some available activities. One person drew a comparison between the experience of an arts workshop and another activity in the same setting where she felt being treated like a child. *"I love the art as well because I think a lot depends on the people who are doing it as well...you know ...you could get that feeling... of warmth. At* [name of other activity] *sometimes I feel like – it's like - you know you are put in a cage and you have a lot of kids and you tell them do jig puzzles or give crayons. I feel it's a bit like being treated - solvent intelligence. I am paranoid that people think because you have a psychiatric illness that you are stupid".*

Feeling better: Relaxing and mood-improving effect of creativity

"I find it [music] settles me down a bit. I feel good after".

…"[music] *helps time to pass more easily, more pleasantly, more joyfully, it helps pass the day so I can get to sleep at night. When I get to sleep at night my problems get solved during the sleep."*

(music workshop participants)

"*They talk about it* [music] *the following day and it totally lifts their spirits"* (staff).

Participants spoke about the relaxing and mood-improving impact of the Arts and Minds workshops in different ways. Animation workshop participants spoke primarily about the relaxing affect of the actual project: *"I put some effort... the actual work relaxes me"* (animation workshop participant). On the other hand, the majority of music workshop participants spoke about music helping them to 'get out of themselves', to forget about their problems and their 'illness', to 'let go'.
These are some of the comments of music workshop participants, staff and artists:

Getting out of oneself:

"It's relaxing like. It gets you out of your own head and it gets you doing something apart from lying in the bed. I mainly like it because it gets you out of yourself".
"I suppose it gets you out of yourself and when you sing you feel happy. It's a happy inducing exercise, so for depression it is I think a positive therapy".

"I like percussion it brings me out of myself".

"It [music] *gets me out of myself. I won't be thinking all the time and it gives me a break from myself really and I think that's impacting on my mood because I am not always thinking. So, my mood has gone up a bit"*(music workshop participants).

"*I think when you have music over a period...you see people grow for that 8 weeks. Their confidence grows, their self-esteem, the way they interact with other people. If you think mental illness, depression, schizophrenia a lot is about isolating oneself, going away from interacting whereas music brings that out in people...that's what I think arts can contribute it's for the patient bringing them out of themselves*" (staff).

Letting go:

"Music has a way,...it's something that everybody lives with, everybody has a beat, everybody you know it takes something out, you know and it kind of there's a bit of flow in it, there's just energy in it".

Forgetting problems:

"[Music] makes your mental health better anyway...it makes you happy, you forget about problems".

"Well it takes people out of their problems, it lifts their spirits. You know they can forget about why they're in hospital for a while".

"It is fun it takes my mind of my illness".
"Just it takes my mind off and worries and sometimes I can be very [worried]".
"It's taking my mind of things. I take my mind off myself a bit as well. It is enjoyable as well. It helps the mental health in that way as well. I am less worried, less anxious..."

"*I think the mood totally lifts when they are singing or when they are doing something different to just talking about health matters*" (staff).

The anxiety-reducing impact of the workshops was also identified by participant artists - *"... it's kind of interesting even people's voices or how fast they speak you often get a very good idea of where someone is at. You know sometimes people come in and they can, they talk so quick that it's, you know, it's like this anxiety that comes through, and sometimes at the end of a music group they've actually almost slightly - a little bit more organised in themselves*" (musician artist).

Experiencing and expressing emotions

"Through singing I express beauty or hope" (music workshop participant).

"Art is another option, a non-threatening, non-invasive means of communication self-exploration and phenomenal self-expression" (staff).

Project participants spoke about both experiencing and expressing emotions through their involvement in the art workshops. They also spoke about difficulties they experienced in finding ways to express feelings and vent anger within some agency contexts. As one participant stressed, "...*you know my biggest problem is I still find it very, very hard to express myself in here".*

Many participants appreciated arts as a way of non-verbal expression. For example one participant said "it's *a way for quiet people to express themselves ...if you are quiet and you can play the drums you are expressing yourself, you know what I mean? If you do art and you draw a pretty picture is good...."* Another participant, making reference to visual arts, said *"I suppose it gave one the freedom to... express oneself through painting or drawing, and you know what's nice is that you get the feedback...you know it puts us thinking about why we drew something or you know what it means for us or our thoughts around it when we're drawing...".*

The therapeutic effect of non-verbal expression was emphasised by Arts and Minds artists: ".. *sometimes you don't want to talk about things, and there's a lot of talking therapies already existing. This is completely non-verbal. And I think that that's what people like, is the fact that they can express themselves without having to put words on it and even for myself sometimes when you get to play instruments there's a great release from it as well, in that you just kind of forget everything, and you nearly get lost in just enjoying playing music*" (musician).

One participant made an interesting distinction between venting and releasing - *"the art does not vent, it might release I feel, because.... I used to do some drawing myself, it takes you away from you know, it can distract..."* - and stressed the need to have spaces to 'vent' in an acute setting.

Project participants spoke about art evoking a range of emotions. While people primarily described the workshops as an uplifting, energising experience, some also spoke about experiencing feelings of sadness, loss and frustration. Below are some of the comments made after the music workshops:

"...it makes you feel good...I suppose it can make happy anyone who liked music"

"... it's nice that people get the opportunity to sing and it's good for one's confidence. The other thing is the making of the music is quite nice, it's creative and the harmony and that, and it's uplifting,..It gives energy or something"

"It cheered me up...It is good"

"It's you can see people smiling instead of just frowning all the time or being upset with themselves all the time".

One person spoke about music evoking memories of loss: *"...it cheered me up but it kind of upset me as well because music was a big thing to me and to my grandfather who passed away. So music upsets me sometimes..."*

Another participant of the music group expressed a concern about getting elated though music by saying, "*...it calms me down but maybe I do get carried away with music. I might get a little bit high".*

A participant of the animation group spoke openly about experiencing mixed feelings by saying that that the project made him think about his life and his feelings and this had mixed results: "...*I got a sense of worth but I also got frustrated".*

The findings of this research suggest that the contribution of arts to mental health cannot be evaluated solely on the basis of evoking positive emotions but on the basis of (a) evoking a range of emotions which are integral to human nature and (b) providing people with the opportunities to express these emotions in a safe, accepting space.

Cognitive affects: Improving concentration

A number of project participants said that their concentration had suffered as a result of their mental health difficulties and the lack of stimulating activities in their mental health care. As a result they appreciated the opportunity to work on their

concentration through the arts projects. This was particularly relevant to the animation group who had to focus on producing a story and a feature animation film. "*I think because it takes a lot of focus and you are really using both sides of your brain doing animation, it's very kind of logic but it's also very kind of spatial and creative as well, so particularly animation utilises both sides, and integrates your ideas and the creative and the logic gets very integrated within that*" (animation artist). As one project participant put it, *"...it's brought out my concentration ...I don't feel worthless all the time".* Another person said *"...your mind is* ***completely*** *focused on what you're doing, on what you have to think about*".

Music workshop participants also spoke about being able to focus through music… *"...you know I have an iPod with me and I have* ***not*** *been able to concentrate on music, I'm just skipping every song... I'm very into music, I love music....But I've lost interest in all that kind of stuff...but I actually enjoyed that* [being able to concentrate in music] *today".*

An improvement in concentration and engagement was also identified by artists and staff. As one of the music artists said, *"...staff has said then they found that sometimes in the music groups people were very different, they were more capable than they might have thought they would have been for, you know, outside the music group they'd be surprised that people could follow instruction or try to hold a melody..."*

What needs to be clarified here is the difference between skills improvement through art and opportunities provided through art to acknowledge and realise existing skills. In other words, it is not necessarily the case that participants lacked concentration, focusing and problem-solving skills but rather that they lacked opportunities to realise and demonstrate these skills to themselves and others. As one participant artist stressed, *"I think they just need permission to do that* [cope with challenges] *and if you have the space...for creating an environment for people to be people, give themselves the permission".* This is further discussed in the next section.

Confidence building; recognising strengths

"You can use your imagination, there is no limit to it" (animation workshop participant)

"Art gives an opportunity to succeed at something this is important in mental health"

"What is achieved in the art group is the start of a bigger process of walking a bit taller, of realising that people can do things in their lives".

"I think it's very satisfying to create something out of nothing, so it's very good for someone to be seen to be able to create something in the first place no matter what it is.

(Arts + Minds artists)

Project participants spoke extensively about getting a boost of morale and a sense of worth through partaking in the art workshops. Most interviewees said that they surprised themselves at what they had achieved, saying that they 'knew more', were 'able for more' and 'liked more' than what they thought. For example, one person spoke about how her confidence grew through the animation workshop as she had never taken a photograph in her life and then realised that she was able to make a short animation film - *"...these workshops opened up a creative side I didn't think I have…".* Another animation group participant said "*I realised I had imagination",* while a music workshop participant spoke about realising that they liked rhythm *"...because I have never really played an instrument, I think I like rhythms actually drums and – I didn't realise that before that I liked rhythms …"*

Staff also spoke about participants surprising themselves and others. "*Sometimes they [staff] think patients, because they are patients, they don't have that ability or skill and they do. We had patients in there they played the guitars, they can do lots of singing, some of the voices we've heard are wonderful. ..it's just amazing to see*

people with that ability and you think sometimes you would not see that unless they are in the music group..." (staff).

Seeing the "*finished product"* and *"your ideas become alive on a screen*" was very important for the animation group. *"We had a presentation in the end where we all watched it in the gallery you know on the big screens so do you know ...it was ...was brilliant"* (animation workshop participant).

This study found that confidence acquired through the art workshops encouraged participants to make plans and pursue interests. Some people spoke about pursuing interests related to the music workshops:

> *"It got me thinking about when I do leave here that I do really want to get back into music and learn an instrument".*
>
> *"And maybe you know something it instilled in my mind would be maybe to join something like a choir at home or something like that".*
>
> *"...it's just trial and error do you know and like I'd definitely be interested in as well, like yourself now and I've a guitar at home for six years that I've never learnt to play, and I'd love to learn to play it but it's hard to motivate myself, but if there was a group that was teaching music or something do you know.*
>
> (music workshop participants)

A significant impact of the art workshops for many participants was this gradual move from apprehension to 'trying new things' and exploring other interests. As one person said, "...*here...music gives you a chance to kind of enjoy yourself and you are encouraged in what you are able to do. You know your interests, they encourage you to keep up your interests or find new ones".*

This is a key step towards independence. As one of the artists argued, people realise that "...*if I can do that in the music group maybe I can do a little bit more outside...so*

maybe using an instrument first and then by the end maybe using your voice or, you know, and, then sometimes people take the leap and just start to do their own thing".

3.2.3 Mezzo and Macro-levels: Implications for Service/Community Culture and Structure

This research found that arts in mental health care can create conditions conducive to recovery and wellbeing. Arts in mental health care contribute a valuable space where creative expression is encouraged and where service users can be acknowledged as people with creative potential, imagination and skills. It is important however that this contribution does not operate in isolation (i.e. only within in art workshops) but affects the overall culture of mental health care in a way that such care embraces creativity and provides opportunities for people to be seen beyond the role of the patient. Therefore, the incorporation of arts in mental health care is not just a technical matter of adding activities to current services. It requires a more fundamental change in the current, medically focused model of care, which can be a challenging task. The research has attempted to identify some key ingredients of this change concerning (a) service and community culture and (b) service and community structure.

Service and Community Culture:

A space where the diagnosis is irrelevant: As already discussed, art workshops were experienced by participants as places where they could move away from 'being a patient' to 'being a person' with creativity and skills. Artists acknowledged that people were going through hardship but stressed that one's diagnosis is irrelevant when it comes to making art. As one of the contributing artists said, "... *my role is about having the creative environment for people to access, and if I began to know more about individual clients reasons for being there I think it would take away from what I do"*.

"…it's not about the condition, the mental condition, it's about … tapping into something that we all have, tapping into creativity…spontaneity and fun and …all of those things that are human".

"… the whole idea of creativity is that everybody can do it… the more we kind of pigeon-hole people the less fluid that becomes".

(A+M artists)

This is quite a significant shift from traditional mental health practice where the diagnosis is central to professional thinking and provision of care.

A space where the unexpected is valued: Project participants appreciated the sense of freedom they experienced within the A+M workshops. Part of this sense of freedom was the openness of workshops to accommodate, enjoy and work with the unexpected whether it was a tune, a story or a photograph. As one of the artists said, "*too much structure around the sessions…doesn't really allow for unexpected things to happen, and I think it's the unexpected things that actually bring it along*".

Moving beyond therapies: This research found that a distinction needs to be made between arts in mental health and art therapy. The focus of art workshops has been on creative expression, which can have a therapeutic affect but is different from art therapy where clinical goals are set. This is not suggesting that art therapy, or indeed other therapeutic interventions do not play a valid role in the recovery process. It is recognising the distinct contribution that arts can make in mental health which is about creativity, expression, experimentation, and play rather than treatment. Seeing people beyond their diagnosis provides unique opportunities for recovery.

Equalising power between service users and mental health staff: As discussed in the previous section, mental health staff and service users were co-participants in music and animation groups. In these groups, staff had an opportunity to see a different side of service users which is often lost when dealing with a 'patient'. This research identified opportunities to equalise power relationships, through user involvement

in decision-making and planning around the art workshops. It is important that these new interactions can be transferred beyond the boundaries of art workshops to other areas of mental health care.

Spaces to experience and express emotions: Project participants appreciated the opportunity, through the A+M project, to both experience and express a range of emotions. This highlighted the necessity to provide more opportunities, outside the art workshops, for creative expression of emotions, including frustration and anger.

"People want to vent, people want to vent. People are very frustrated you know and when you're depressed or when you're stressed out you need to vent. But there's nowhere in here to go to do that [let go]. You have, you know everybody's tip toeing around and being quiet you know...." (A+M participant).

Stigma: A number of participants said they had initial concerns about the art group being perceived as another mental health group. As one participant said, "*....I actually was once or twice going into the Crawford Gallery... and you'd see a group of people and you'd often just say just to yourself 'God I wonder what are that group doing now'... And I thought once or twice to myself I wonder how* [name of artist] *would have labeled us as a group. Were we the mental health group that came in to do art or were we just a group?"*

Such concerns were quickly alleviated; participants said that they appreciated that the focus of the project was on the art rather than the diagnosis and that they were not labeled as 'mentally ill' by the artist facilitating the workshop. Within the Crawford Art Gallery they were the 'animation group' rather than the 'mental health group'.

Breaking down barriers within the community: Through the arts projects, participants living in the community engaged with community facilities that they would not have known about or they would not have had the confidence to use before. This exposure has also affected the way people with mental health difficulties

are viewed in such facilities. As a staff member found out, *"…people who work in the community facilities view people with mental health issues differently having met them".*

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"I know myself people who work in community settings are ***very*** *surprised that the people coming in are just like everybody else, you know. It certainly breaks down barriers".*

"I suppose they're now part of their community. They have a sense of belonging that I felt they didn't have before I got involved in this". (staff)

Service and Community Structure

Strategic planning: Arts as an integrated option of care rather than an 'add on': Mental health staff welcomed opportunities to include arts as part of mental health care activities. Staff members were enthusiastic about the project and took active part in the Arts and Minds workshops. This was greatly appreciated by artists and participants.

However, at a structural/organisational level there is a piecemeal provision of arts in mental health. Artists primarily respond to services when they are invited to deliver a workshop and, as a result, it is difficult to plan ahead and to integrate arts into mental health care. There is a need for a strategic partnership between mental health services and the art sector: "...*I mean ideally we would work as they do in France with partnerships with healthcare settings where we would know over a year that we will work in this setting for this length of time...that it would be more integrated again and that we would be involved in...trying to develop a language...putting the value on it so it would help drive it forward..."* (artist).

Nevertheless, concerns were also expressed by one artist about arts becoming part of mental health structures. This may lead to arts losing their creative potential by being part of a system primarily focusing on mental illness. As this artist put it, "…*I*

think a lot of the time with mental health problems the structures are the things that crowd us in and stop us from being as big as we can be. We become claustrophobic".

Quality of engagement rather than art form: This research found that the form of art was not particularly relevant in making a project 'successful' and a positive experience for its participants. Of particular significance however were the opportunities provided, through the art form, for people to grow in confidence, self-esteem and to tap into previously unrecognised strengths. In this process, the quality of engagement between artists and service users is of crucial importance. This research found that service users felt respected, appreciated, listened to by the artists: *"I love the art as well because I think a lot depends on the people who are doing it as well...you know ...you could get that feeling... of warmth"* (A+M participant).

Artists were respectful of the pace, mood and choices of project participants. As one staff member commented, there was an understanding of confidence issues "...*and not pushing people to it. They were not over-enthusiastic forcing people to do things what people did not want to do*". Another staff member said *"they* [artists] *know what they are doing. You can see that in a group. You can see that they pre-thought what they were doing before they come in..."*

The production of 'good art' was also considered important in promoting people's confidence in their skills, capacities and in achieving an outcome they are proud of. The screening of the *Unfold Project* in the Crawford with the soundtrack of the *Flow* and *Éist Agus Faire* music projects on October 2011 was indeed an event where people felt proud of their involvement and achievements.

Implications for the multidisciplinary team: Mental health staff stressed that having arts as an integrated part of mental health care requires an appreciation of arts, by the multidisciplinary team, as a valid component of care planning. A number of staff spoke about resistance among their nursing colleagues to recognise arts as part of their work in mental health care and to get actively involved in fundraising, planning

for and implementing art projects. "*I'm working with the team. So I want team-playing as opposed to... my own pushing this* [arts] *or* [me] *being there* [at the art projects] *all the time, and I love being there, but I would still like a bit of help from my colleagues*" (staff). The need to engage with other disciplines was also identified. "*We want more staff, multidisciplinary, I want nurses but I also want other disciplines"* (staff). This can be particularly challenging at a time when there is a shortage of staffing across all health sectors. As a student nurse pointed out, "*I could see ...people being pulled like with* [name of staff] *she or people in the community being pulled from other services* [to be involved in art projects]".

This raises questions about whether such activities are considered as an integral part of professional role or a mere luxurious addition. The complexity of the staff role, when taking arts on board, was also highlighted: "*We have to fundraise, we have to come up with the venues, we have to get groups together, we have to get consent, we have to, the nature of the condition means that you have to keep reminding people, sometimes they turn up, you'll always have a bit of worry about that, that you'll run something that nobody will turn up"* (staff).

There have also been positive experiences of staff engagement, particularly in teams with good communication between the various disciplines: " ...*my peers, my ADON* (Assistant Directors of Nursing) *DON* (Directors of Nursing) *would [be supportive] and the consultant actually...is open to the arts because I update them. I tell them, which is a form of communication and the end result like of this will be launched and may be able to get a group of people together to get that information out there"* (staff).

"*Staff need to become curious, interested involved*" was argued by one staff member. This has implications for the education and training of health and social care professionals. One staff member made recommendations for the creation of an 'arts in mental health' module in undergraduate psychiatric nursing education. It was also stressed that learning is a mutual process and should not only focus on what arts can offer to mental health but also on the contribution of mental health to the arts: "*I think that equally mental health has a lot to offer to the arts. I think we as*

professionals and artists have an awful lot to learn from the people with the mental health. I think it needs to be a two way, I don't think the arts can just come and give you know, I think any much giving there is as much receiving to be done". Achieving this mutuality requires a shift in the culture of expertise dominating the current mental health system. User involvement in the education of health and social care professionals, and medical education in particular, is of key importance in this process.

Finally, a strong argument was made by staff for the role of an arts coordinator if arts are to be integrated in mental health care: "*We could not function without an arts coordinator".* An arts coordinator can integrate perspectives from the arts, community development and mental health, and the integration of such skills was identified as very important by staff.

Move outside the mental health system: It is also important to give people an opportunity, through the arts, to be part of the broader community and not just the mental health community. Some participants highlighted the fact that becoming involved in too many mental health groups can also reinforce stigma and a sense of 'being unwell'. As one person said, "...i*t's very important that we actually feel not...just people that are unwell or have been unwell but we're just part of the social community".* Another participant commented "*..because stigma is still there and it's probably always going to be there but I think just to reduce it by getting involved in all do you know – regular things not just mental* [health activities]*".*

A similar point was made by community mental health staff who argued that rather than becoming service-centred, arts would have to be brought into the community. "*We don't want to contain the project to one group of people (e.g. attending a particular service) but rather create a network of people through arts"* (staff). It was also pointed out that a good network of community-based activities is more cost-effective than service-based activities and can lead to a reduction of service demand, with significant cost-cutting benefits. This is not to deny the value and contribution of diverse groups within a mental health setting. Rather, it is about acknowledging

that people need to have opportunities to engage with the world outside the mental health system rather than the mental health system becoming their world.

Chapter Four: Conclusions and recommendations

This research found that the Arts and Minds project was experienced in a very positive way by participants in the three research settings. The project contributed to conditions conducive to recovery through the "*discovery of personal resourcefulness, meaning and growth, within and beyond the limits imposed by the 'mental illness'*" (MHC, 2008:7). The project contributed to conditions for wellbeing and social inclusion enabling participants to take on meaningful and satisfying social roles in their communities in line with the national Mental Health Strategy *A Vision for Change* (DoH&C, 2006) and *A Recovery Approach within Irish Mental Health Services* (MHC, 2008).

Arts in mental health care can provide an environment where creative expression is encouraged and where service users can be acknowledged as people with creative potential, imagination and skills. Most importantly, arts in mental health provide an opportunity to re-consider the culture of mental health care in a way that such care embraces creativity and provides opportunities for people to be seen beyond the role of the patient.

Strengths of the project

- A+M provided a space where participants could achieve something positive, work towards small changes that can be transferred to other areas of their lives.

- A+M participants spoke about having a sense of purpose, becoming more confident in themselves, 'surprising themselves', discovering strengths, resourcefulness, skills and interests.

- A+M provided a space where participants felt part of a social community and had opportunities to connect with themselves and others.

- A+M provided a space where participants and staff were members the same group; this co-participation has the potential to create an environment for different interactions, for example:
  - to equalise staff-service user relationships
  - to embrace social roles beyond being a 'patient' '
  - to facilitate staff to see people in a more holistic manner
  - to recognise previously unacknowledged service user strengths
  - to promote user-involvement in care planning

- A+M provided a space where fun had a therapeutic and transformative potential.

- A+M participants felt respected, involved and heard during the workshops.

- A+M participants felt easy, relaxed and accepted in the space of the workshops.

- A+M participants spoke about the workshops having a positive impact on their mental health, and mental health professionals identified a considerable reduction in the frequency of outpatient appointments for people in the community who are actively involved in art projects.

Challenges

As arts are not currently an integrated part of mental health care, the manner in which arts programmes are introduced into different agencies is *ad hoc* and subject to the commitment and enthusiasm of mental health professionals at a local level. This *ad hoc* nature affects the continuity of arts programmes as it makes it difficult to plan for on a long-term basis.

The current resource constraints in the health sector have undoubtedly impacted on the funding of arts programmes. Furthermore, staff shortages make it harder for mental health professionals to get involved in fundraising for, organising and

delivering such programmes. A lack of appreciation of arts in mental health by multidisciplinary teams makes it difficult to consider art-related activities as part of the professional role, as it is often viewed as a 'luxurious extra'. Furthermore, unless arts projects are viewed as another care option by professionals, such projects will not be fully utilised in the mental health sector.

However, the key challenges to adopting a more creative approach to mental health care are posed by the broader conceptual and ideological framework within which this care is located. This research has found that in evaluating the contribution of arts in mental health care, we cannot ignore the tensions between art as a form of creative expression and mental health care which, because of the dominant biomedical focus, has not traditionally encouraged creativity of expression. While this discussion does not aim to provide a detailed analysis of such tensions, it is important to acknowledge them and problematise them. This research argues that a meaningful partnership between the arts sector and mental health services is not just a technical measure but will also require a fundamental change of culture in mental health care. The research identified as key ingredients of this cultural change a mental health system that:

- Embraces creativity;
- Equalises power relations between service users and staff;
- Provides opportunities for people to write their own stories;

and ultimately:

- Sees people in distress beyond their diagnosis.

Recommendations

- **Strategic partnership between the arts and the mental health sector** with arts programmes being another care option for people in distress rather than a 'bonus add-on'. For arts to become a meaningful care option, the appreciation of multidisciplinary teams is required. Mental health professionals will need to expand their roles to embrace activities such as community development and fundraising that have not traditionally been

considered part of their brief. Having designated members of the multi-disciplinary team, liaising with various arts projects can help the development of this broader role. Furthermore, the position of an arts coordinator is essential for a partnership between arts and mental health care: "*We could not function without an arts coordinator"* (staff). An arts coordinator can integrate perspectives from the arts, community development and mental health, and the integration of such skills was identified as very important by professionals involved in the A+M project.

While this strategic incorporation is desirable, this report argues that arts should not become a part of mental health structures which are still primarily focused on the treatment of illness. The creativity and freedom of expression that arts contribute to the human experience can be incompatible with the current biomedical focus of mental health care. It is important that arts will not lose their creative potential in a system that often can "*stop us from being as big as we can be*" (A+M artist).

- **Education of health and social professions.** In order to utilise arts as another care option, it is important that mental health professionals are prepared to consider arts as such an option. Education plays a crucial role in shaping our understanding of mental health issues and ways to respond to people experiencing distress. Including modules on arts and mental health in professional courses can certainly provide professionals with more tools to work creatively with people in a mental health setting. Again, such an initiative can have a limited affect within an otherwise biomedical approach to mental health education. If arts are to be a meaningful option in mental health care, a broader recovery-focused, user-centred approach to mental health education for *all* mental health professionals, including psychiatry, is also essential.

- **Continuation both inside and outside the mental health system**. Through participants' positive experiences of the A+M project, a number of unmet needs at both community and inpatient levels were identified. Social isolation

is a key concern for people experiencing mental health difficulties in the community. Lack of stimulation and meaningful activities is a key concern for people in inpatient care. For many project participants the A+M project was the main way to connect with a social community and break a circle of loneliness, isolation and boredom. This does not suggest that the A+M project or any other arts project are the only or the best ways to respond to these needs. However, this research identified some ways of providing opportunities for meaningful activities and pursuing of interests both inside and outside the mental health system. For example many participants, having experienced the opportunities provided through the A+M projects, said they would like such projects to continue as the period of eight weeks was found to be too short. Others spoke about having opportunities to pursue new interests further after the completion of an A+M group, as many people realised they had interests and skills they were not aware of. Finally, it is also important to give people an opportunity, through the arts, to be part of the broader community and not just the mental health community. This will require enhancing links with the community through a community development approach.

- **Community development.** In line with previous research (see chapter two) the A+M project was found to be a way of reducing stigma and social exclusion experienced by individuals with mental health difficulties. A community development approach, which was also part of the A+M partnership, is essential in shifting the responsibility for mental health to the community, recognising the contextual factors that contribute to well-being and combating the stigma associated with mental health problems. The partnership approach adopted by the A+M research project is a good model of collaboration between various actors, which allows for a more holistic response to mental health difficulties and better utilisation of community resources.

- **Ultimately a cultural change!** Moving beyond the general agreement on the positive contribution of arts to mental health care, this research has

highlighted that such a contribution is not a mere matter of 'adding' arts programmes into the current mental health services. A meaningful partnership between the arts sector and mental health services is not just a technical measure but will also require a cultural shift in the way we understand, respond to and engage with human distress. This is a shift towards embracing creativity of expression, nurturing strengths and facilitating service-user care choices, both inside and outside mental health structures.

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Appendix 1

Interview Questions for Arts and Minds participants (music & animation)

1. How long have you been using:
   a. the service you are currently attending (name of service)?
   b. mental health services in general?
2. What kind of activities do you do here?
3. Care planning:
   a. Do you meet a key worker/nurse to discuss your care?
   b. How often do you meet?
   c. Who decides when to meet?
   d. What kind of things do you look at?
   e. How do you make decisions about your care plan?
4. Do you have any previous experience of art workshops (including music/animation)?
5. Why did you decide to participate in this (music/animation) workshop?
6. Experience of this (music/animation) workshop:
   a. Likes
   b. Dislikes
   c. Things that could be done differently?
7. How does this (art work) compare with previous dealings with/experience of mental health services? (Please expand)
8. What were you hoping to achieve through participating in the art workshops?
   Probes: What changes do you want to see happening in your life?
   Anything else you hope to achieve?
9. Do you think the arts should be part of care planning in mental health? Why?
10. Any other comments?

Thank you!

Appendix 2

Interview Questions for Mental Health Staff

1. What is your role in the *Arts and Minds* project?
2. What is your previous experience:
    a. in the area of mental health?
    b. in the use of arts in mental health (if any?)
3. What do you think arts can contribute to:
        a. mental health care?
        b. service users of your agency? (For example what was the impact of previous art projects on participants?
    c. care planning in particular?
4. What are your expectations of the A+M project (music/animation)?
5. In your opinion what are the strengths of the project?
6. In your opinion what may be the areas that need to be further developed?
7. At this point do you think that you have:
        a. adequate in-service and other training?
        b. appropriate support in your position?
        c. adequate resources to do your job as you think it should be done?
8. Current mental health policy recommends more options/alternatives in service delivery.
        a. Can you talk a bit more about the impact of these recommendations on care planning?
        b. How do you think these recommendations are manifesting in the practice context?
9. How do you think A+M *(music/animation)* has impacted:
        a. on the clients of your service?
        b. on mental health service delivery in your agency?

10. *Arts and Minds* is a product of a partnership approach between various stakeholders. What are the benefits of the partnership? What are the possible limitations?
11. At the end of the pilot programme:
    a. what would constitute a successful outcome?
    b. what would constitute failure?
12. Are there any other points concerning *Arts and Minds* that you would like to make?

Thank you!

Appendix 3

Interview Questions for A+M Artists (music & animation)

1. What is your role in the *Arts and Minds* project?
2. What is your previous experience (if any) in the use of arts in mental health?
3. What do you think arts (music/animation) can contribute to:
    a. a mental health setting?
    b. service users in the particular settings (names of settings)? (For example what was the impact of previous music/animation projects on participants?)
    c. care planning in particular?
4. What were your expectations of the A&M project?
5. How is the project going so far? Have these expectations been met?
    a. In your opinion what are the strengths of the project?
    b. In your opinion what may be the areas that need to be further developed?
6. At this point do you think that you have:
    a. adequate in-service and other training?
    b. appropriate support in your position?
    c. adequate resources to do your job as you think it should be done?

7. Current mental health policy recommends more options/alternatives in care planning and service delivery.
    a. Can you talk a bit more about the impact of these recommendations on the role of arts in mental health?
    b. How do you think these recommendations are manifesting in the practice context?
8. *Arts + Minds* is a product of a partnership approach between various stakeholders. What are the benefits of the partnership? What are the possible limitations?
9. At the end of the pilot programme:
    a. what would constitute a successful outcome?
    b. what would constitute failure?
10. How do you think *Arts + Minds* has impacted on mental health service delivery in (names of settings)?
11. Are there any other points concerning *Arts + Minds* that you would like to make?

Thank you!

Appendix 4

Key summary of the difference work aspects between arts practice and art therapists adopted by Brett & McHarg, (2010 cited in Broderick, 2011, p. 96)

	Art practice	**Art therapists**
1. Practice	- Free-lance workers – short-term contracts - Individuals can decide for themselves - Working relationship begins without any prior knowledge and develops over the course of a project	- Are staff members and work as part of a professional team - Individuals are referred to therapist after assessment - Working relationship is defined in advance; therapist is focused on providing a service
2. Duty and Care	- No clinical duty of care and has no access to medical records/confidential information	- Has clinical duty of care regarding who is referred to whom and has access to medical records/confidential information
3.Supervision /support	- Without collegial professional support tends to work in isolation	- Is professionally supervised
4. Aesthetic vs. Therapy	- Makes comment on art piece being made, makes aesthetic judgments and influences process/outcomes - The produced art work stands on its own	- Makes no comments/judgments on the produced artwork - Therapist and client use artwork interpretatively and symbolically as a tool

Michel Foucault (2001) Madness and civilization; a history of insanity in the age of reason, Routledge Classics, London

Citation: Sapouna, L. (2012) Classic texts: Foucault, Michel. Madness and Civilization: A History of Insanity in the Age of Reason, *Community Development Journal*, 47 (4):612-616. (Reproduced with permission from Oxford University Press).

My first encounter with the key ideas of Michel Foucault's (1926-1984) classic text, Madness and Civilization, was during my social work studies in Greece in the late 80s. It was the time of the so-called psychiatric reform in Greece, fuelled by the exposure of the horrific conditions of Leros Psychiatric Hospital. This institution was located on a remote island and its purpose was to contain all patients from Greek psychiatric institutions who were deemed untreatable to a single space of confinement. My undergraduate dissertation was focused on the Greek psychiatric reform and the deeply imbedded institutional practices in the country. Foucault's Madness and Civilization provided me with a framework to conceptualise confinement as a process of exclusion and 'silencing of the mad'. In the case of Leros, for example, it was possible to move beyond condemnation of the appalling physical conditions and to identify the unspoken consent of Greek society to abandoning people in this institution. This consent was part of a process of exclusion, relegating people to a state described by Foucault as a state of 'non-existence'. The key ideas of the text also helped me to consider issues of professional power and resistance to changing long-established practices within psychiatric institutions. As such, the text enabled me to argue that a meaningful process of de-institutionalisation cannot be achieved unless issues of control and professional power are addressed.

I revisited and studied the full text during my Master's research on community mental health in Ireland in the early 1990s. I was then faced with a rather different situation - large institutions were closing down as part of the then national mental health policy (DH, 1984); however, mental health care appeared to evolve, both physically and ideologically, within institutional grounds. It was important then to ask further questions about the processes that justify the continuous exclusion

and silencing of those who experience mental health difficulties. One such question lies in a key idea underpinning the text, which is that the constitution of madness as an illness has brought it into silence. Foucault argues that during the Middle Ages and the Renaissance, madness was part of everyday community life and was not excluded from society. He talks about a dialogue between the 'sane' and the 'mad' in earlier historical periods, with the mad having a culturally significant role to play in society. It is during the Classical period that madness ceases to have a place in society and becomes a manifestation of non-being. "Confinement merely manifested what madness, in its essence, was: a manifestation of non-being; and by providing this manifestation confinement thereby suppressed it, since it restored it to its truth as nothingness" (Foucault, 2001, p.109).

Within this nothingness the mad fall into silence and the language of psychiatry emerges as 'a monologue of reason about madness'. Through this analysis it is possible to argue that the debate on institutional vs. community care, as a debate of exclusion vs. inclusion, can be rather meaningless. As long as 'madness' is defined and interpreted by the language of medicine, or indeed by any other 'expert language' such as psychotherapy, those experiencing distress will be silenced, non-existent.

Madness and Civilization considers issues of power, exclusion, marginalisation and the nature of knowledge, all of which are central to understanding the operation of mental health systems. Foucault's historical account highlights the significance of the context; he clearly considers the confinement of the mad as a consequence of moral, economic and socio-political factors rather than a scientific development. "What is constitutive is the action that divides madness, and not the science elaborated once this division is made and calm restored" (Foucault, 2001, p. xii). Current biomedical mental health strategies are based on the self-evident science of psychiatry and regularly disregard the significance of the context. However, the recognition of context is important at both macro- and micro-levels. It involves (i) the acknowledgment of mental health care as a socio-political act (macro-level) and (ii) an appreciation of how experiences of distress are connected with the context of people's lives (micro-level).

The text provides a clear account of how the science of psychiatry has established its authority as the expert system for defining and treating human distress within the institutions of confinement. Indeed Foucault, more than any other modern social theorist, helps us understand the rules and processes enabling experts in any field to practise their discipline. His work provides an enlightening account of how the ideas that guide professional practices come into existence and how they acquire power (see Chambon, Irving and Epstein,1999). Madness and Civilization moves beyond concerns about marginalisation and power to problematising what has become self-evident in psychiatric knowledge and practice. Foucault's investigations into the nature of knowledge in psychiatry can be described as both critical and transformative. The critical aspect of Foucault's deliberations offers the opportunity to see how mental health professionals exercise power over users of the system by imposing a particular 'expert truth' (e.g. diagnostic categories). However, the transformative potential of such deliberations provides the opportunity to see it as 'one truth among many'. This brings us to a significant development in the field of mental health, which is the rise of the service user/survivor movement and the increasing articulation of different 'truths' by people with self-experience of distress. Critical and transformative perspectives are not the monopoly of enlightened academics and professionals. Such an assumption would perpetuate patterns of silence and invisibility through yet another monologue about human distress. These perspectives have been shaped by the growing voices of people directly affected by the mental health system. To highlight the emergence of these different truths, I will consider some recent developments in articulating critical and transformative perspectives in mental health care in Ireland.

Grassroots movements constructing new ways of knowing in mental health[17]

Over the past number of years, new approaches have emerged to address concerns about the current state of mental health services in Ireland. Such concerns include the inhumane physical conditions in hospital units, over-reliance on and excessive use of medication, lack of meaningful community-based alternatives to

[17] This section draws from the ongoing work of the Critical Voices Network Ireland.

hospitalisation, involuntary treatment, abuse of professional power, and lack of information and choice in relation to 'treatment' options. These approaches recognise that a bio-medical strategy in mental health care today will at best provide temporary symptomatic relief (which may be valid as a first step), but may compound, exacerbate and even cause further deep distress. Furthermore, there are concerns that current responses to distress fail to capture the complexity of human experiences by ignoring the underlying grief, heartbreak and trauma in people's lives. These new approaches also recognise that people need to be fully engaged in all aspects of their own recovery (see Gijbels & Sapouna, 2011).

Such approaches can be both critical and transformative as they question self-evident mental health knowledge and practice and construct new ways of knowing and understanding human experiences of distress. Such approaches break the silence of 'madness', moving it from nothingness to community engagement and visibility, often celebrating the 'gift' and 'normality of madness' (see McCarthy 2011). For example, Madpride Ireland's family fun days are a lively public event in a central park in Cork city. Madpride Ireland's founder, John McCarthy, says "we believe that the best way to promote understanding of issues surrounding mental health is to engage the community through active participation in a fun environment. We do that by hosting family events that are inclusive, fun and suitable for children, teenagers, adults and families. These events do not bombard people with pamphlets extolling the virtues of one approach over another. Rather they show the world that madness is an everyday occurrence that affects us and can be dealt with openly, lovingly and without fear. Have we opened the national debate on mental health? We sure have" (Madpride Ireland, 2012).

Key actors in the development of this new thinking are diverse, but represent people who describe themselves in such terms as service users, survivors, patients, members of the mad community, carers, family members, practitioners, professionals, academics and the lay public, all of whom are dissatisfied with current forms of care and its underpinning bio-medical philosophy. In an attempt to provide a broader platform to discuss and debate concerns and share new initiatives and approaches, a series of annual critical perspectives conferences have been organised by the Schools of Nursing and Midwifery and Applied Social Studies, University

College Cork. These conferences are unique as they involve people from diverse backgrounds (self-experience, survivors, professionals, academics, carers) presenting, discussing and debating critical and creative perspectives in mental health. The Critical Voices Network Ireland (CVNI) emerged out of these deliberations 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 bio-medical model. This network now provides a democratic space with no hierarchical structures, open to everybody who wishes to join its discussions. An e-list and a Facebook page have been established for people to begin to share, debate and discuss issues of concern and different ways of working. These debates have been enriching, and have in many ways shaped new ways of knowing about mental health issues. The network holds quarterly meetings which are open to all and have been organised around a series of round-table discussions, followed by a plenary session, focusing on creative approaches (e.g. setting up residential crisis and recovery facilities) and critical perspectives in mental health care (e.g. overuse of medication, forced 'treatment' issues, capacity legislation). Networking groups are being set up to undertake work in specific areas. (see Gijbels & Sapouna 2011) .

An important aspect of these developments is the beginning of a dialogue between stakeholders who have been separated in the past. Through the CVNI an environment has been created where different and sometimes conflicting voices and agendas can be heard and respected rather than silenced. Professionals, students, and people with self-experience have a free exchange as part of this forum. This is not always an easy exchange. Challenging mental health practice can be unsettling as it may require one's positions of certainty to be reviewed and possibly relinquished. But the transformative potential of this space can also encourage professionals to recognise that there are many truths, to shift from a position of certainty and to strive to understand the Other. Through these exchanges there is an opportunity to tell stories, to make sense of experiences and to reconstruct meanings, particularly previously silenced meanings.

Concluding remarks

Madness and Civilization provides a framework to problematise in a systematic way mental health thinking and practice. The text helps us to think about professional power, to question the construction of knowledge on which the diagnosis of 'normality' is based, and to acknowledge the value of new ways of knowing which are emerging from the voices of people affected by mental health care. At a time when questions about resources to enhance existing mental health strategies dominate, Foucault's writing encourages us to ask questions about the nature of what we do in mental health care. This is an opportunity to critically engage with questions about the nature of interventions addressing human distress rather than to merely promote more of the same interventions that have often been proven unhelpful or indeed damaging. It is an opportunity to stop and think about what we take for granted in psychiatry, particularly the self-evident medicalisation of human troubles. Such questions can be unsettling. Meaningful discussions between those who are traditionally considered as 'experts' in mental health and those considered as 'mentally ill' can be uncomfortable and we often get requests for a 'balanced debate' between the 'two sides' - a debate that 'doesn't only focus on the negatives' of the mental health system. Foucault's work provides a space in which to recognise that there are no two sides, to acknowledge that there are many sides and that people experiencing distress are entitled to be in charge of writing and interpreting their own story. Shaking the certainty of professional expertise and truths can be uncomfortable and unsettling. However, shaking this certainty also provides an opportunity for transformation towards a more democratic, person-centred, respectful response to human distress. It provides an opportunity to begin a new dialogue with people whose voices have been traditionally silenced and marginalised.

Dedication

This contribution is dedicated to the memory of John McCarthy, mental health activist and founder of Madpride Ireland, who spoke about the 'normality of madness' and started a debate on mental health in Ireland.

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Having Choices: An evaluation of the Home Focus Project in West Cork

Citation: Sapouna, L. (2008) *Having Choices: An evaluation of the Home Focus Project in West Cork,* Department of Applied Social Studies & HSE, University College Cork.

Open Access, available at:
http://www.hse.ie/eng/services/Publications/services/Mentalhealth/havingchoices.pdf

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Executive Summary

Policy and Practice Context

The need for comprehensive, accessible, community-based mental health services has been identified by key Irish policies and in particular the Mental Health Strategy *A Vision for Change* (DoH&C, 2006), the *Vision for a Recovery Model in Irish Mental Health Services* (MHC, 2008) and the *Primary Care Strategy* (DoH&C, 2001). *Vision for Change* proposes a fundamental shift in the location of mental health services and the philosophy underpinning their provision. The strategy advocates the promotion of a holistic, person-centred, recovery-oriented, community-based service.

This evaluation study explores the achievements and challenges of the Home Focus project and puts them in the context of a literature and policy review on mental health, community and recovery. This will allow a consideration of the wider implications of this innovative approach which, it is hoped, will contribute to a debate on how (a) to achieve the changes recommended by Vision for Change, and (b) to evaluate innovative services for people suffering with mental health difficulties.

The Home Focus Project

Home Focus is a pilot project funded under the *Enhancing Disability Services Project Funding* (EDS) of the Department of Justice, Equality and Law Reform. The funding is administered by Pobal, a not-for-profit company with charitable status that manages programmes on behalf of the Irish Government and the EU. The project is based on a collaborative approach between National Learning Network West Cork, West Cork Mental Health Services, the Irish Advocacy Network, HSE Disability Guidance Services, Work Start West Cork and West Cork Community Partnership.

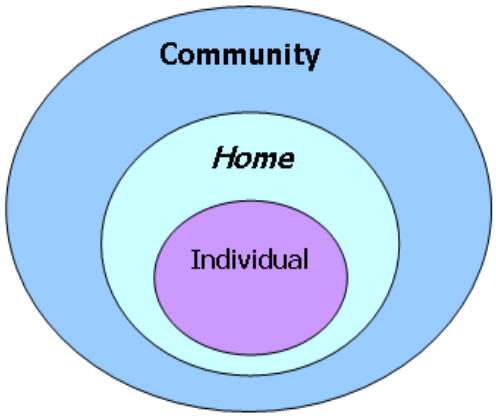
Home Focus provides outreach, individualised support to people with mental health difficulties who are isolated because of their inability or unwillingness to access traditional, centre-based models of service delivery.

The aim of the project is to deliver a service to this group of people in their own homes and communities in the West Cork area, enabling them to enhance their mental health and wellbeing, independent living skills, levels of connection to their own communities, access to training, education and employment opportunities, improved quality of life and future planning.

The Home Focus programme is delivered by a team combining diverse service-user and professional expertise. The staff team includes a rehabilitative training instructor, an outreach nurse, a recovery support worker and a recovery resource worker.

The participants were primarily those identified by the West Cork Mental Health Services. Between September 2006 and March 2008 the Home Focus team worked with 35 individuals for an approximate duration of between 3 and 18 months, depending on the needs of each participant.

Based on the individual participant's needs, the project was delivered at three levels:



Underpinning Philosophy

This innovative model of service delivery is based on community, outreach and home-based interventions, combined with the involvement of users of mental health services in programme design and delivery. Throughout its formation and delivery, the Home Focus project has developed its own unique identity. This identity is a constellation of variables including the philosophy informing mental health provision in West Cork, the diversity of the staff and management teams, and the geographical and social characteristics of the target area. This distinct identity is evidenced in:

- The application of creative, strength-based engagement strategies
- The provision of a holistic, non-medically driven service
- The provision of a service in a rural context where issues of isolation and limited access to services is pertinent to the experience of service users.

The Evaluation Study

An evaluation process was put in place from the onset of the project. The design of the study was informed by the philosophy underpinning (a) current developments in mental health and (b) the development and delivery of the Home Focus project. In this philosophy, service-users play key roles in defining and taking charge of the changes they want to bring about in their lives. The approach to the evaluation needs to reflect the ethos of the project, which is user-centred and recovery-oriented. In a period where evidence-based practice is central to service development and delivery, this evaluation study highlights the significance of evidence constructed by the narratives of people who have direct experience of mental health services.

Key findings

The broad range of experience and expertise pooled by the Home Focus project ensured a holistic approach to participants' needs and a high-quality, flexible and balanced programme. Key findings of this study include:

- ***A significant reduction in hospital days*** (47%), over a period of 12 months for participants who engaged with the Home Focus project. This also represents significant savings on hospital admissions.

- ***Specific gains achieved by participants*** include health and social gain; improved social engagement; linking with community groups and support organisations; improved mental health; improved independent living skills; employment; further training and certification.

- ***A new unique experience of service provision.*** Participants spoke extensively about how the project provided them with a hopeful vision for their future, how they felt respected, listened to and were treated 'as a person rather than a symptom'. They appreciated being met in their own environment, having choices and the time and availability of the staff team. They also identified striking differences between this and previous, predominantly negative, experiences of services. As many of the participants experience social isolation, they valued the social contact and relationship-building opportunities offered through the project. Many participants also talked about their improved mental health and their increasing sense of control over their mental health difficulties.

- ***A contribution to new approaches in service provision.*** The Home Focus project demonstrated the possibility for/viability of a flexible, user-centred service which is community-based and recovery-oriented. The project also provided a valuable additional resource to West Cork and, as it is based on a partnership, it contributed to improved relationships between various services and community organisations. Furthermore, the partnership demonstrated a positive way forwards for service provision to people who suffer from mental health problems, shifting the responsibility of care from mental health services to the community.

- ***Articulating a community development approach to mental health.*** Through the partnership and the engagement with community groups, the project demonstrated a commitment to a community development approach. Through this approach it is possible to address the broader contextual factors contributing to mental distress, normalise mental distress by providing support within mainstream community services, and develop an educational component which will help the reduction of stigma associated with mental health.

Recommendations

The Home Focus project provided a unique resource in enabling the provision of a quality, flexible service to people with mental health difficulties in West Cork. In order to continue and maximise its contribution, the project needs to be (a) mainstreamed and (b) part of a broader network system of community-based resources.

Chapter One

The Home Focus Project in Context



Lost in my community (Dick Page 2008)

1.1 Introduction and Background to the Evaluation Study

Home Focus is a pilot project funded under the *Enhancing Disability Services Project Funding* (EDS) of the Department of Justice, Equality and Law Reform. The funding is administered by Pobal, a not-for-profit company with charitable status that manages programmes on behalf of the Irish Government and the EU. The project provides outreach, individualised support to people with mental health difficulties in their own environment. *Home Focus* is based on a collaborative approach between National Learning Network West Cork, West Cork Mental Health Services, the Irish Advocacy Network, HSE Disability Guidance Services, Work Start West Cork and West Cork Community Partnership. The project started in May 2006 and direct work with participants began in September 2006. The project's funding through Pobal came to an end in March 2008, however Home Focus will be supported through internal funding until June 2008.

The group of clients for this project are people with mental health difficulties who are isolated because of their inability or unwillingness to access traditional, centre-based models of service delivery. The aim of the project is to deliver a service to this group of people in their own homes and communities in the West Cork area, enabling them to enhance their mental health and wellbeing, independent living skills, level of connection to their own communities, access to training, education and employment opportunities, improved quality of life and future planning.

The evaluation process was established from the beginning of the project. Early in 2006 the Department of Applied Social Studies, University College Cork was commissioned by the project's management board to carry out this task. This report is based on the research carried out as part of the evaluation of the Home Focus project.

This evaluation study is concerned, in the first instance, with establishing the extent to which the original objectives of the Home Focus project have been achieved, and the implications for future development. Furthermore, this study considers the

broader operational context of the project and therefore provides a conceptual and policy analysis of community-based, recovery-oriented practice in mental health. Finally, as the main objective of the study is the consideration of 'evidence of recovery', the question of 'what constitutes valid evidence' is central in the design of the evaluation. The author proposes an evaluation framework which reflects the innovative approach of the Home Focus project through the development of participative methodologies, and the generation of outcome indicators based on service-user experiences.

1.2 The Operational Context

1.2.1 Local Context

Partner organisations

The design, delivery and management of the project are based on a partnership approach, which is one of the unique aspects of Home Focus as it provides the basis for a holistic and comprehensive community-based mental health service provision. The partner organisations to the Home Focus project are:

- Health Service Executive (HSE) South:
  - West Cork Mental Health Services: A multidisciplinary team provides acute hospital-based and community-based services. This includes residential services, out-patient services respite care and elements of primary care. The West Cork Catchment area has a population of 53,445 (CSO, 2006) which is divided into three sectors: (a) Skibbereen/Schull, (b) Bantry/ Castletownbere and (c) Clonakilty/Dunmanway (see map on page …) The overall ethos of West Cork Mental Health Services is to create an empowered partnership with the client through promoting good mental health and to provide a high quality service which is equitable, empathetic and respectful.

- Disability Guidance Services: This service is composed of three main elements: (a) Guidance and Advice, (b) Monitoring and Rehabilitative Training, and (c) New Developments. The service is applicable to all people with physical and sensory, intellectual and mental health disabilities from the ages of 16 to 65.

- National Learning Network (NLN): A non-Governmental training organisation, part of the REHAB Group. NLN offers vocational and rehabilitative training programmes which carry nationally and internationally recognised certification and are designed to lead directly to jobs or progression to further education.

- Irish Advocacy Network: A user-led organisation aiming to provide information and support to fellow mental health service users and to empower them to speak up and take control of their lives.

- West Cork Community Partnership (WCCP): A community development organisation with a mission statement to "develop the social, economic, environmental and cultural resources of West Cork for the purpose of improving quality of life and creating full and equal participation of all sections in the community".

- Work Start West Cork: A FAS-funded Supported Employment organisation which helps people with learning, mental health, physical and sensory disabilities find work in the open labour market. Work Start West Cork covers the whole of West Cork with offices in Bantry, Skibbereen, Clonakilty and Bandon and services from Castletownbere through to Kinsale.

Needs identification

Following a broad and inclusive consultative process including service providers and service users and informal discussions between the partner organisations, the need for a programme that would address the needs of a particular group of individuals who have mental health difficulties became apparent. This is a group of people who

have severe and enduring mental health issues and who do not effectively engage with the traditional or current services provided by the partnership organisations or other community services. These people will not utilise the traditional service models of training and support, which are predominantly centre-based. As a result of their disengagement from services and community activities, these individuals have little or no social, occupational or leisure outlets.

The following extract from the Southern Health Board (now HSE) "*Focussing Minds*" report (2002) indicates that statistics for levels of mental illness in the West Cork area are as follows:

Prevalence of Mental Health Difficulties in West Cork Population		
	Prevalence	***No. of Population***
Adult Population >= 16 yrs		36,341
All Mental Disorders	20%	7,268
Depression: (Any Week) (Lifetime)	10% 55%	3,634 19,988
Anxiety Disorders	5%	1,817
Alcohol Dependence	5%	1,817
	2%	727

Drug Dependence		
Schizophrenia	1%	363
Bipolar Affective Disorder	1%	363
Source: Focussing Minds 2002 Note: Total Population 2006: 53,445		

The combined experience of the partner organisations in this project has led to a realisation that the group of individuals with the highest level of need (i.e. people with enduring mental health difficulties) is currently the group in receipt of the lowest level of support and intervention. In particular, four of the six organisations have had direct experience of seeing the emerging need that is being addressed by this project. The following is a description of this experience.

The National Learning Network (NLN) has been providing services to people with mental health difficulties in the West Cork area for over 20 years. Traditionally NLN training programmes have been partly or wholly delivered in Centre. In the past number of years NLN has also developed employer-based and home-based training programmes as well as delivering training programmes in outreach locations within communities. Much of this experience has resulted in the successful engagement of individuals with mental health difficulties with NLN services, and as a consequence, it has also resulted in high levels of community integration and successful outcomes for these individuals. However, it has become apparent over a period of time that there are a substantial number of individuals with mental health difficulties who would benefit from engagement with NLN services, yet their degree of mental health difficulties makes it extremely difficult for them to engage in a consistent and

meaningful way with existing programmes. For example, some individuals say that although they would be interested in attending training programmes and feel that such programmes would be of benefit to them, they would find it awkward and difficult to participate for a variety of reasons, as follows:

- Fear of change in daily routine
- Reluctance to leave the security of the home environment
- Inability to be part of a group
- Not accustomed to using means of transport, necessary to travel to a training centre
- Inability to get up in the mornings
- Lack of motivation
- Lack of confidence needed to interact with other course participants or staff
- Would prefer a service in familiar surroundings – home or local community.

There are a number of students who commence training programmes but who subsequently discontinue for many of the reasons listed above. In nearly all cases, these individuals, who have high levels of need, return to their homes and do not have access to any further rehabilitative training service.

West Cork Mental Health Services have identified a group of their clients whom they find are difficult to engage, reluctant to attend current services, some of whom may be socially isolated and with significant disability. These people have been identified by Mental Health Services through Mental Health teams. They require a more intensive, tailor-made, individualised and home-based intervention than currently available. This intervention would be best delivered utilising the team-approach. Mental Health Services believe that this approach will result in improved mental health for the individuals, thus enabling them to engage with existing community projects and services.

HSE – Disability Guidance Services – West Cork would have very similar experiences to that of National Learning Network and Mental Health Services – West Cork, insofar as identifying a group of people with mental health difficulties who have extra needs. On an ongoing basis, they meet people in guidance interviews who are then referred to a particular service, but who then never engage with that service for many of the reasons mentioned above.

The Irish Advocacy Network **(IAN)** was commissioned by the then Southern Health Board to carry out a survey on the needs of users of mental health services in Cork and Kerry. Through 163 in-depth interviews held with service users in Cork and Kerry, it became increasingly obvious that a change of approach towards community, home-based services was called for. This is evidenced by the following extracts from service user comments:

"A move in the right direction would be treatment at home".

"Need more information on alternative treatments".

"Lack of support, such as Welfare Officers or Community Psychiatric nurse to keep in touch with you".

"Would prefer if I had proper care in the community and did not have to come into hospital. I work 3 days a week and find it very difficult to go back to the community and work after a spell in hospital. I feel as if I have psychotic patient written all over my forehead and everyone knows".

"Do not know what is available in services. Better information needed on illnesses".

"Activities needed to relieve boredom, computer to work with, visits maybe once a week to cinema".

"Would like more support after discharge from hospital".

"Would like the doctors to go through drugs with me to get a drug to help with the problem and to involve me in that decision".

Contributions from voluntary groups were also included in the same study, and a sample of these comments are included here:

"Additional staffing required, together with more training".

“Need to develop improved links between hospitals, GPs and voluntary groups”.

“7 –day services needed on a 24 hour basis”.

“Multi-disciplinary teams needed”.

“Counselling services required”.

“Home-based services”.

“Alternative treatments – not just medical model”.

1.2.2 National Context; Mental Health and Primary Care Policy

The Home Focus project clearly echoes the recommendations of national guidelines for primary and mental health care.

Primary Care

The need to work with individuals and communities to improve their health and social well-being through a primary care approach is advocated by the 2001 Health Strategy on Primary Care. The strategy sets out a new direction for primary care as the central focus of health and social services in Ireland. The aims of the proposed developments are: to provide (a) a strengthened primary care system which will play a more central role as the first and ongoing point of contact for people with the health-care system, (b) an integrated, inter-disciplinary, high quality, team-based and user-friendly set of services for the public, and (c) enhanced capacity for primary care in the areas of disease prevention, rehabilitation and personal social services to complement the existing diagnosis and treatment focus.

“*The primary care team will work with local populations and other agencies to identify health and social needs*” (DoH&C, 2001:26). Broadening the focus of primary care means the shift of responsibility to primary care teams for services which are currently provided in specialist care settings but which may require less extensive specialist input (ibid). This has significant implications for the re-allocation of mental health care within broader community-based services. This approach is consistent with the current directions in mental health policy and service delivery.

Mental Health Policy

The need for comprehensive, accessible, community-based mental health services has also been identified by key Irish policies and in particular the new Mental Health Strategy "*A Vision for Change*" (2006). This policy builds on previous community care policies to advocate a person-centred, holistic, community-based, recovery-oriented mental health service. Overall, "*A Vision for Change*" proposes significant changes and improvements in mental health, with increased reliance on community-based services.

"*The vision embodied in this policy is to create a mental health system that addresses the needs of the population through a focus on the requirements of the individual. This mental health system should deliver a range of activities to promote positive mental health in the community; it should intervene early when problems develop, and it should enhance inclusion and optimal functioning of people who have severe mental health problems. Service providers should work in partnership with service users and their families, and facilitate recovery and reintegration through the provision of accessible, comprehensive and community-based mental health services*" (DoH&C, 2006:14).

The Home Focus project is based on principles of assertive outreach and home-based care, two of the four community- based intervention programs proposed for the effective delivery of community-based care.

Proposed Community-Based Intervention Programmes

1. Home-base care
2. Crisis intervention
3. Early intervention
4. Assertive outreach

Vision for Change 2006

Home Focus is also underpinned by a recovery philosophy, discussed in chapter two, which is a key recommendation of *Vision for Change*. The Mental Health Commission's Discussion Paper "*A Vision for a Recovery Model in Irish Mental Health Services*" also provides a foundation for the development of a recovery approach in mental health care. The principles informing the delivery of the Home Focus project are also identified in the "*Quality Framework*", another key document by the Mental Health Commission (2007). The "*Quality Framework*" is based on a broad consultation with stakeholders and identifies the following fundamental eight themes to mental health service provision:

1. Provision of a holistic seamless service and the full continuum of care provided by a multidisciplinary team.
2. Respectful, empathetic relationships are required between people using the mental health service and those providing them.
3. An empowering approach to service delivery is beneficial to both people using the service and those providing it.
4. A quality physical environment that promotes good health and upholds the security and safety of service users.
5. Access to services.
6. Family-chosen advocate involvement and support.
7. Staff skills, expertise and morale are key influencers in the delivery of a quality mental health service.
8. Systematic evaluation and review of mental health services underpinned by best practice will enable providers to deliver quality services.

It must be noted however, that while "*A Vision for Change*" has been a welcome development in promoting long-awaited changes in mental health care, there are serious concerns about the process of 'making it happen'. Over two years after its publication, the pace of its implementation has received heavy criticism from user groups, doctors, psychiatrists, health professionals and mental health campaigners.

The Irish Mental Health Coalition (IMHC), a coalition of NGOs working in mental health, outlined some of these concerns at a press conference on 23 January 2008. The IMHC highlighted a number of recommendations of "*A Vision for Change*" which have not been acted upon, including the abandonment of the promised National Directorate for Mental Health; the fact that catchment areas have not yet been finalised; delays between the allocation of resources and recruitment of staff, and the fact that the implementation plan for "*A Vision for Change*" has not been published two years after the launch of the policy.

Of particular concern is the redirection of assets deriving from the sale of mental hospitals as these assets were ring-fenced for community-based developments in the mental health sector. According to "*The Lie of the Land"*, a report by the Irish Psychiatric Association (IPA, 2008) there was a "*systematic shredding of assets …with both lands and buildings in mental health services either being given away or sold for under the market cost without any benefit to mental health services…The political system is clearly complicit in this process, either directly or more often, by silence and indifference*".

These concerns make the contribution of the Home Focus project even more significant as it is one of the few initiatives, after "*A Vision for Change*", providing evidence of a recovery, community-oriented, person-centred mental health service.

1.3 An Overview of the Home Focus Project

Participant profile

The Home Focus team was set up to work with people who have severe and enduring mental health issues and who typically do not effectively engage with the traditional or current services provided by the partnership organisations or other community services. The participants were primarily those identified by the West Cork Mental Health Services. The Home Focus team received a total of 49 referrals between September 2006 and March 2008. Out of these referrals, 35 individuals were suitable

for and willing to engage with the programme. The table below presents the gender and age profile of the project's participants.

Home Focus Participants – Gender and Age details		
	Male	**Female**
16-20	2	0
20-40	11	1
40-60	12	3
60+	5	1
Total	30	5

Project's aims and objectives

The programme aimed to enable participants to enhance their mental health, independent living skills, level of connection to their own communities, quality of life, access to training, education and employment options and future planning.

Specific objectives of the home focus project included:

- The delivery of a high-quality, intensive service to 40 people with mental health difficulties.
- The involvement of users of Mental Health Services in the design and delivery of the programme.
- Assimilation of learning from the project to inform future design and delivery of services for people with mental health difficulties
- Reduced admission to Mental Health Acute Services.
- The expectation that as participants will progress to training and employment, they will become net contributors to the State and this will result in a reduction in the burden on Social Welfare payments.
- The hope that that the project will have a positive influence on service users' expectations of Mental Health services.

Stakeholders' expectations

During the evaluation research, members of the partner organisations and the Home Focus team had the opportunity to expand on the project's objectives and to articulate their expectations of the project on three different levels: (a) service-users (micro-level), (b) service provision (mezzo-level), and (c) the community (macro-level).

(a) For service users

"*That for people who have been isolated or have experienced difficulties with relationships it* [Home Focus] *will open up ways that they can experience positive encounters and that in some way that will help them to move on in their lives; perhaps help them to stay out of hospital, perhaps help them to get involved in a meaningful activity with other people that they couldn't access prior to the service*" (member of management board, June 2006).

A central expectation of the project was the provision of a service that is client-centred rather than service-centred. Stakeholders from management and staff viewed that as a way to meaningful empowerment of service users, who are considered as active participants in their care plan.

The issue of a bottom-up approach to making choices is also very important. Many interviewees stressed that both 'the need to change' and 'the kind of changes to be brought about' have to be identified by the participants themselves rather than the professionals working with them, which has been the traditional way of working in mental health. The need to recognise that expectations for every individual participant were different was also stressed.

Stakeholders also identified the contribution of the project to breaking social isolation, forming new relationships and making informed choices about use of available help and resources.

(b) For service providers

The opportunity for the Home Focus project to impact on service provision in the West Cork area was also identified. The project is considered as an opportunity to develop a holistic approach to mental health, by learning to support users to make their own choices, and by having greater co-ordination and respect between service providers.

Home Focus can provide a different model of service provision, shifting the focus from hospital care. "*The service idea is that intensive work takes place at the hospital, that the hospital is at the centre of the activity of the service. What needs to happen is that we move away from that, that the community is the area of high activity and intensive working and that hospitals are places for respite care*" (management board member, June 2006).

Home Focus was also seen as an additional resource, providing intensive service to clients who have disengaged from existing services. The contribution of the project to assisting the development of knowledge at a local level and of policy at a national level was also recognised.

(c) For the community

Home Focus was considered as an opportunity to bring the community to the centre of mental health care provision. This can be done by recognising the role of the social environment in mental distress, reducing stigma and normalising the process of seeking help. The role of the recovery support worker, outlined in the next section, was seen as particularly important in engaging with the community, promoting awareness and therefore ensuring that the community is more likely to be supportive of people with mental health difficulties.

The Home Focus Team

A multidisciplinary team including a Rehabilitative Training Instructor, a Recovery Support Worker and an Outreach Mental Health Nurse deliver the programme directly to the service users. A Recovery Resource Worker is also a member of the

team and works with the community, raising awareness and supporting community development initiatives. A broad range of staff from all the partner organisations including psychiatrists, psychologists, managers, administrators and programme development officers support the Home Focus staff team.

The Home Focus Team

- Rehabilitative training instructor
- Outreach mental health nurse
- Recovery support worker
- Recovery resource worker

A partnership approach

The programme is based on a collaborative approach between the partner organisations listed in section 1.2.1. The broad range of experience and expertise pooled by this approach ensured a holistic approach to participants' needs and a high-quality, balanced programme. The catalyst for programme development was the organisations' experiences of the needs on the ground and an examination of best practice approaches that have been adopted internationally to address similar needs. This innovative model of service delivery is based on community and home-based interventions, combined with the involvement of users of mental health services in programme design and delivery.

Referrals system

For the duration of the pilot project all the referrals have come from the Mental Health Services through the Team Coordinator. These referrals originate with the Multidisciplinary Mental Health Team (Community Mental Health Nurses, Psychiatric Social Workers, Psychiatrists, Occupational Therapists, In-Patient Staff). The Home Focus Team then assesses the referrals and appropriate actions are taken.

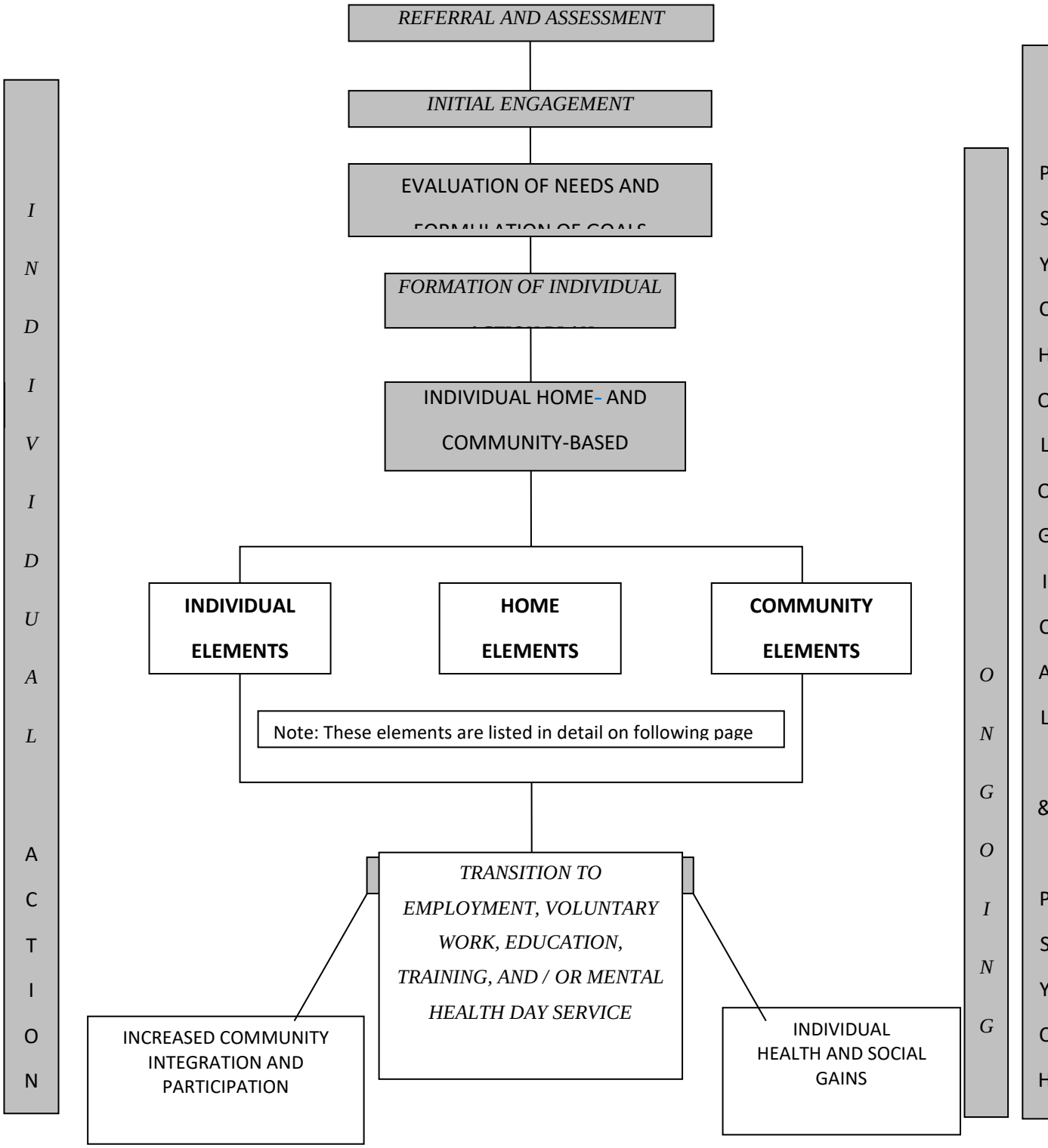
Engagement and project delivery

The service delivered consists of a home and community-based intervention, which has an approximate duration of between 3 and 18 months, depending on the needs of each participant. Following referral of individuals to the programme, there is a period of engagement between the staff team and the individual, during which trust and relationships are established. During this initial stage of the programme, there is an identification of the individual's needs, strengths, supports, goals, desires, interests and barriers to achieving their future plans. Also, there is an assessment of areas such as access, transport, health, support and opportunities with a view to enhancing the success of engaging the individual in their community. Following this evaluation of needs, an Individual Action Plan is drawn up collaboratively between the individual and the staff team. The participant will then begin to work on the elements (Individual, Home, and Community) of their Individual Action Plan with the team. A continual and systematic review and revision of the plan ensures that each individual's changing needs and hopes are met (see Project Delivery Flow Diagramme on following page).

A key part in the implementation of the Individual Action Plan is supporting the individual in accessing community services, supports and facilities. Examples of these include:

- Community Organisations, e.g. Rural Transport Initiative, MABS, Community Resource Centre, West Cork Community Partnership, NALA
- Support Groups, e.g. GROW, Irish Advocacy Network, Aware, Schizophrenia Ireland
- Health Services, e.g. GP, Mental Health Day Activity Services
- Community leisure facilities, e.g. Swimming Pools, Sports Centres, Libraries
- Employment Supports - FAS, Work Start
- Training and Education Supports: V.E.C., NALA, National Learning Network, Post-Leaving Cert courses, and evening courses.

PROJECT DELIVERY (FLOW DIAGRAMME)



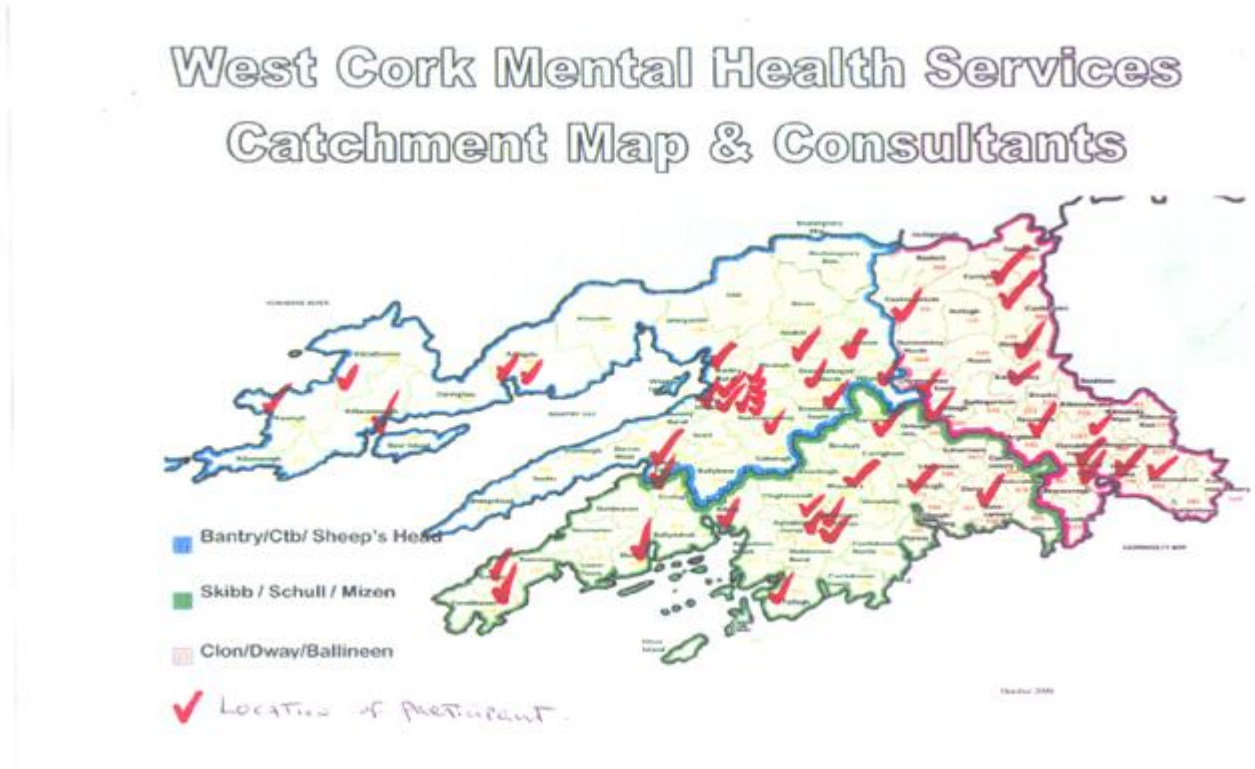
Elements of Home Focus

Based on individual participants' needs, relevant elements from the following categories are delivered:

Individual Elements	**Home Elements**	**Community Elements**
Personal Hygiene and Appearance	Independent Living Skills	*Access to:*
Mental Health and Wellbeing	Health and Safety	Mental Health Services – e.g. Clinic, Day-Centre
Mental Health Management	Home Management	Medical Services – e.g. GP
Physical Wellbeing	Money Management	Support Groups – e.g. GROW, IAN, Aware, Schizophrenia Ireland, AA
Lifestyle – Diet, Nutrition, Exercise etc.	Healthy Lifestyles	Alternative Therapies
Personal Development	Familial Relationships	Employment Supports – FAS, Work Start
Confidence Building	Home Improvements	Voluntary Work – e.g. Tidy Towns, Charity Shops
Coping Skills	Access to County Council Support re. Housing	Work Experience
Stress Management	Support for Change in Accommodation (if appropriate)	Training – e.g. FAS, VEC, National Learning Network
Motivation	Home-Based Leisure Activities and Hobbies	Education – e.g. VEC, NALA, IT, Night and Day Classes
Communication Skills	Home-Based IT	Leisure Activities – e.g. Gym, Swimming
Assertiveness	Home-Study Courses	Community Facilities – e.g. Banks, Library
Knowledge of Rights and Entitlements		Community Services – e.g. CWO, MABS
Self-Advocacy		Community Activities – e.g. ICA, IFA, Church Activities
Peer Support		Transport (Public and/or Personal)
Spirituality		Creative and Cultural Activities – e.g. Drama, Art, Music
Individual Routine		
Time Management		
Relationships and Sexuality		
Job Seeking Skills – Application Forms, Interview Skills, etc.		
Clarification of Vocational Goals and Preferences		

Target area

The coverage area for this project is the Health Service Executive West Cork Community catchment area. It stretches from the towns of Clonakilty to Castletownbere. In 2006 the population of this catchment area was 53,445. There were 4,982 (9.32%) people with disabilities living in the area. Figures for the prevalence of mental health problems as outlined in the Southern Health Board's "*Focussing Minds*" Report (2002) indicate that there are 7,268 adults with mental health problems in West Cork. The difference between the two figures above can be explained by the fact that many people with mental health difficulties would not be willing to divulge this in the Census of Population form.



This rural area is one of the most isolated parts of Ireland, extending over 100 miles from Clonakilty to Allihies. In general terms, economic disadvantage in West Cork closely correlates with topography and access. In this context, large swathes of land to the west and north of Dunmanway, as well as on the extremities of the region's peninsulas, represent significant challenges in achieving balanced regional development. With a fragmented settlement pattern, low population densities, poor

public transport and a high dependence on car usage, the road network represents the principal means of access and transport in the region. An extensive network of roads of variable quality links for the most part the West Cork region. Outlined here is a demographic analysis of the area.

Statistics	West Cork	National	WC as a % of national stats
Population Statistics			
Total Population 2002	53,445	4,239,848	1.26%
Population Density per sq. mile (urban & rural)	42.11	60.56	69.53%
Population Density per sq. mile (rural)	27	60.56	44.58%
Household Statistics			
Total Households	18,918	1,469,521	1.28%
Household Statistics living alone			
All people 45+	3,534	344,272	
% Of Households with people 45+ living alone	18.68%	23%	
(Gender balance not available for 2006 but 2002 statistics show an even balance between males and females)			
Household Statistics retired			
Retired population	6,713	467,926	1.43%
% Of population retired	12.56%	11.03%	
Affluence and Deprivation			
Overall affluence & deprivation score 2002	16.1	17.4	
Relative affluence & deprivation score 2002	0.9	2.2	
Disability Statistics			
Persons with a Disability	4,982	393,785	1.26%
% Of total population Persons with disability	9.83%	9.28%	

The broad conclusion for the area is one of significant peripheral and rural make-up. Overall the area is more deprived than the national average, with significant deprivation existing on the peninsulas and isolated rural areas. The sparse population density and lack of services result in both rural and social isolation, which are contributing factors to mental health difficulties. The implications of the rural nature of the target area on the work of the Home Focus team are further discussed in chapter 2. 4.

1.4 The Evaluation Process

The Home Focus project was evaluated from the outset. The evaluation is concerned, in the first instance, with establishing the extent to which the original objectives of Home Focus have been achieved, how, and with what implications for future development. "*Evaluation research, as its name implies, is concerned with the evaluation of such occurrences as social and organisational programmes and interventions. The essential question that is typically asked by such studies is: Has the intervention (e.g. a new policy initiative or an organisational change) achieved its anticipated goals?*" (Bryman, 2001:40).

The design of the study was informed by the philosophy underpinning (a) current developments in mental health, and (b) the development and delivery of the Home Focus project. Echoing the recommendations of Vision for Change (2006), Home Focus provides a community-based, user-centred, recovery-oriented outreach service. In this process, service-users play key roles in defining and taking charge of the changes they want to bring in their lives. The author proposes an approach to evaluation which reflects this ethos of such a project. In a period where evidence-based practice is central to service development and delivery, this evaluation study highlights the significance of evidence constructed by the narratives of people who have direct experience of mental health services.

1.4.1 Objectives of the evaluation

The basis of this evaluation and the data collection were determined by the original objectives of the Home Focus project, outlined in section 1.3. The study was designed

with the intention of focusing on both the *process* and the *outcomes* of the project, in order to provide a comprehensive evaluation of:

(1) the impact of the project on (i) service users, (ii) service providers, (iii) community resources, and (iv) policy-making
and
(2) the broader context in which the project was set up

It is hoped that the evaluation process will also help to:

e. achieve clarity regarding progress, assess the strengths and weaknesses of the approach taken
f. plan the future development of the project
g. foster a capacity for ongoing self-evaluation
h. address some broader policy issues permeating the administration of recovery approaches through 'home-focused interventions'
i. contribute to a discussion on the relationship of a recovery approach and evidence-based practice.

1.4.2 Methodology: Capturing evidence of recovery

The main methodological tool employed was *qualitative* in nature. Participant observation (with *ethnographic* elements) and semi-structured interviews were employed to examine all individual components of the project. *Quantitative* approaches have also been utilised to consider demographics; participant profiles; hospital admission trends; and health and social gains measures and outcomes.

Qualitative evaluation research

Applying a qualitative approach in the evaluation of the Home Focus project was considered appropriate and compatible with the ethos of the project for a number of reasons. Firstly, qualitative research provides an "*immersion in situations of everyday life*" (Shaw & Gould, 2001: 6). In this case it allowed an examination of the participants' experiences in the context of their everyday life, in their own

environment. Secondly, a qualitative study is concerned with how people understand a given topic - in this case, 'recovery', 'assertive outreach' and 'partnership'/ 'community development' approaches to responding to mental distress. Thirdly, a qualitative enquiry aims to understand beliefs and events within their social context. The term 'holistic' is often used to describe a commitment to examining social entities as wholes (see Bryman, 1988:44). This is consistent with the holistic nature of the service delivered by the Home Focus team.

Strengths of Qualitative Research:

- Researching people in natural settings
- Achieving a greater understanding of the respondent's world
- Emphasising interpretations and meanings
- Humanising research processes by raising the role of the researched, allowing higher flexibility
- Presenting a more realistic view of the world.

(Sarantakos 1998:53)

As data was collected from the standpoint of the participants, an *interpretive* framework was employed to consider the service users' subjective experiences. This subjective dimension was particularly useful in exploring how project participants defined (i) their own recovery and (ii) a positive service intervention. Furthermore, as the evaluator has been actively involved with various aspects of the Home Focus project, the evaluation is also informed by elements of *ethnographic research* and *participant observation.* This is "*a distinctive qualitative research strategy which enquires into social life and behaviour through first-hand intensive observation in naturally occurring settings; such research is also participant insofar as the researcher …constitutes the primary research tool, participating in social activity in order to gain a close and unforced understanding of people's lived experience"* (Hall in Shaw &

Gould, 2001:51). In the case of the Home Focus evaluation these settings included the participants' own homes, community- based facilities and services used by the project participants, and Home Focus management and planning meetings.

Evidence

Considering the need for an evaluation framework consistent with the collaborative, strength-based philosophy of the project, the study was also informed by the principles of *participatory* research. "*Participatory research, like empowerment practice, is a strongly value-based attempt to built on strengths and to work with people who are taking control of their lives by understanding and tackling oppression and injustice*" (Dullea & Mullender, in Shaw & Lishman, 1999:82). A significant contribution of participatory research is that it can inform evaluation practice by "*placing in a wider range of hands the right to say what counts as effective, successful and desirable outcomes"* (ibid:93).

Too often, evaluation is regarded as an exercise by outside experts to measure practice interventions against 'value for money' and efficiency criteria instead of as a debate about interventions which might be valued by users and practitioners (*ibid*). This evaluation is primarily concerned with the impact of the Home Focus project on individual lives. Measurements developed outside this experience fail to fully capture this impact as such indicators are not connected with the lived experience of the participants.

Furthermore, the Home Focus project is underpinned by a recovery philosophy. A discussion on recovery as a individual journey of re-gaining control and meaning over one's life, regardless of the presence of symptoms, is provided in chapter 2. However, at this point, it is important to emphasise that the meaning of recovery is closely related to "*the struggle of survivors to have the right to tell their own stories in their own way*" (Bracken & Thomas, 2005:227). This has significant implications for an evaluation process which aims to capture 'evidence of recovery'.

Evidence-based practice is central to service provision. Evidence-based practice relies on empirical evidence of the effectiveness of treatments, interventions or services, as such evidence is used to endorse interventions, and to provide grounds to sanction or refute new developments. This has obvious implications for service evaluation, where the questions of 'what constitutes valid evidence of recovery' and 'how can it be measured' are central. It is argued that a difficulty arises in fitting recovery-oriented services into an evidence-based culture. What constitutes acceptable evidence depends on the framework within which practice and outcomes are evaluated. When practice is primarily based on a medical model of mental health difficulties, outcomes are almost exclusively defined in medical terms e.g. symptom or hospital admissions reduction, resource utilisation and so on (see Anthony, 2001). As a result, the outcomes described do not necessarily reflect the key concepts and new meaning of recovery identified mainly in service user literature, including recovering lost potential, or regaining some degree of control, however great or small, over personal and social life (see Ramon, 2007).

As individual stories have been the main body of evidence in the re-discovery of the concept of recovery, the evaluation needs to capture the stories and claim them as valid evidence. This form of evidence, however, can often be marginalised or even discredited in a wider research community where positivist approaches assume superior status (see Ramon 2007, Mancini *et al.* 2005). However, the fact remains that personal accounts of recovery journeys over the last two decades have had a significant impact not only on service users, their families and carers but also on the formation of mental health policies. This impact is evident in the Discussion Document on Recovery produced by the Mental Health Commission (MHC, 2005) and in the consultation process informing the mental health strategy 'A Vision for Change' (2006).

In order to overcome the difficulties of accepting such qualitative approaches in an era where credible evidence is primarily based on positivist enquiries, Anthony *et al.* (2003) suggest that the notion of evidence needs to be broadened:

Recovery and evidence-based practice

"The notion of evidence-based practices and recovery-oriented services can work well together. However, if evidence-based practice research is to inform the development of recovery-based services, then the concept of evidence-based practice must be broadened. … Recovery-oriented system designers, programme planners and clinicians must be aware that their current efforts remain guided by the best available evidence, while we accumulate the best evidence possible" (Anthony, 2003: 112).

Broadening the concept of evidence-based practice was a key aim in the design of this evaluation study. The evaluation also aimed to create space for continuing input by service users, project staff and management in the evaluation process. Claiming that the research was user-led or carried by service users would certainly be inaccurate. However, the methodology employed aimed to ensure that participants were not merely the 'respondents' to questions posed from outside but those who, by articulating and constructing the meaning of 'positive outcomes', also formed the relevant questions to capture their own experiences. This was done by building trust between the evaluator and the interviewees, by using a combination of semi-structured interviews and open-ended questions[18], and by using the service-users' narratives as the basis for identifying the key outcomes of the evaluation. In that sense, service users' input was central in deciding (a) what should be evaluated, (b) how it should be done, and (c) what the evaluation findings mean.

The evaluation data

The data for this evaluation consist of:

(1) Documentation and literature pertaining to the project's aims and objectives. This includes:

   a. a broad review of relevant policy relating to the 'operational environment' (e.g. 'A Vision for Change', 'A Vision for a Recovery Model

[18] The construction of the questions was also informed by an independent user evaluation of a model of assertive outreach in Norwich. U.K. (Graley-Wetherell & Morgan 2001).

in Mental Health Services'), in order to locate the project in the broader context of service provision trends.

b. a literature review on recovery, community-based, assertive outreach and evidence-based practice.

(2) Individual interviews with participant service-users. The questions and the schedule for the interviews are included in Appendices 1-3.

(3) Individual and/or group interviews with the staff team. The interview questions are included in Appendices 4 &5.

(4) Individual and/ or group interviews with the project's management board and the partners involved. The interview questions are included in Appendices 6 & 7.

(5) Individual interviews with two consultant psychiatrists /members of the project's management board whose clients have participated in the project (see appendix 9).

(6) Questionnaire to the mental health team co-ordinator and management board members who were not available for interviews (questions as in Appendices 6 & 7).

(7) Participation at management and strategic meetings where the progress of the project was discussed.

(8) Third-party information on participants who did not agree to be interviewed by the evaluator (including interviews with staff team and management, the 'Pen Picture' reports by the staff team, and informal discussions with the staff team).

A chronology of the data collection process

The initial phase of the evaluation provided the baseline data against which the progress of the Home Focus project could be measured. The purpose of the baseline was to develop a profile of the Home Focus initiative with reference to the overall objectives (as outlined in section 1.3) and considered:

- The operational context of the project (mental health policy, community profile, demographics, identified needs)

- The profile/needs/ expectations /of individual service users

- The expectations of the staff team

- The expectations of the management committee

The first part of the baseline data was collected in June 2006 and involved:

- documentary analysis
- individual and/or group semi-structured interviews with the project's management committee and the partners involved
- individual interviews with the staff team

Baseline on participants could not be collected until the beginning of their engagement with the Home Focus staff team. This work started in September 2006. The question of 'the appropriate timing' to interview participants and the ethical issues regarding consent were crucial in the process. The issue was discussed in two management meetings and the evaluator had ongoing discussions with the staff team in relation to the readiness and willingness of participants to be interviewed.
Due to the nature of the relationship of the service user group with the mental health services, the priority was for the staff team to establish a trusting relationship with participants and *then* introduce the evaluator. As a result, most interviews with participants took place three to four weeks after their engagement with the project at the earliest. Therefore, all first interviews with participants collected both baseline and interim evaluation data. These interviews were largely focused on the way participants described (a) their own needs and expectations at the initial point of engagement with the project and (b) their experience of their participation in the project (see Appendices 1 & 2).

As new referrals were received throughout the course of the project, the collection baseline was an ongoing process. Overall, the evaluator interviewed 14 active participants. Some of these participants were initially unwilling to be interviewed but

agreed to do so at a later stage of their involvement with the project. The remaining active participants were unwilling to be interviewed and data on their progress was collected through third-party information outlined in the previous section. Baseline interviews started in October 2006. Review interviews took place between April 2007 and February 2008. In the case of two participants who agreed to be interviewed at an early stage of the project, an interim review also took place.

Interim and final interviews were held with the staff team and members of the management board. As the first progress report on the project was produced in December 2006, interim interviews took place between October and November 2006. The final interviews with staff and management took place between November 2007 and March 2008. Both individual and group interviews were utilised, depending on availability of interviewees and interview content. In the case of the staff team, interim and final interviews took place in a group format as this stimulated a better discussion on their experience of the project.

Ethical Considerations; Informed Consent

The engagement of the evaluator with the service users-interviewees in order to establish a trusting relationship has been of crucial importance. To ensure that the evaluation would be an integral part of the project, the Home Focus management committee decided that the evaluator would be introduced to the client group as part of the project's team. At the beginning of their engagement with the project, all participants signed a form in which they consented to partake in the Home Focus evaluation.

The consent was a continuous process. An explanation of the evaluation was given to each interviewee, outlining the reasons for the evaluation and consulting them on the process. Recording methods and confidentiality in relation to data presentation were explained. All interviewees except for one agreed for the interview to be recorded with the use of a Dictaphone. Participants' consent was also sought for the evaluator to attend meetings where individual cases were discussed. To protect confidentiality, data generated from the interviews with participants is presented

using anonymous direct quotes to illustrate themes such as ‘training’, ‘leisure’, ‘involvement in the community’ etc.



Community Wall (Dick Page 2007)

Developing Community, Recovery-Oriented Practice

The philosophy and practice of the Home Focus project involve a community-based, recovery-oriented outreach service in line with the recommendations of the National Mental Health Strategy Vision for Change (2006). This policy considers assertive outreach as one of the four community-based intervention programmes employed in the effective delivery of community-based care.

This chapter outlines the conceptual, policy and practice frameworks within which the Home Focus Project evolved and developed. For this purpose an examination of (a) 'community care' and 'community development' approaches; (b) recovery-oriented practice, and (c) assertive outreach as key elements of mental health care is provided. The discussion will then progress to describe how the Home Focus project developed its unique identity on the basis of these elements.

2.1 Mental Health and the 'Community'

There are different ways in which the concept of 'community' has manifested itself in the area of mental health care. The development of community-based alternatives to service provision originates in the process of de-institutionalisation and the recognition of the importance of treating people with mental health problems in their own environment. Over the past four decades, community care has become the official term to describe changing policies and practices in mental health care and to indicate a commitment to social inclusion.

In Ireland, the framework for community mental health is outlined in *Planning for the Future,* a policy document published in 1984 following a major review of psychiatric services which was carried out between 1981 and 1984. In summary, the report set out guidelines for future development as far as possible in a community setting, with the emphasis on resources being transferred from large psychiatric hospitals to a large range of alternative community-based services and to acute units in general hospitals. However, while the service was intended to engage patients

with the context of their own lives, families and communities, "the operational system of mental health services has continued to be predominantly hospital based" (DoH&C Policy, 2006: 93).

Community care is considered to be a core principle of the new mental health policy *Vision for Change* (2006). "*People with mental health problems should be cared for where they live and if inpatient care is necessary it is to be provided in the least restrictive setting*" (DoH&C Policy, 2006:15). The strategy envisages that care in the community will be delivered through Community Mental Health Teams offering "multidisciplinary home-based treatment and assertive outreach, and a comprehensive range of medical, psychological and social therapies relevant to the need of service users and their families" (DoH&C Policy, 2006: 79).

While community-care is a popular and broadly adopted term, it is not an unproblematic one. Ife (2002:13) argues that a fundamental weakness of this approach is that "*it assumes that there is an entity called 'community' in which human services can be based…This assumption is problematic as community in the traditional sense is not a significant element of contemporary industrial society…given the lack of strong community structures in contemporary western society…The central issue can be expressed as follows: How can there be community-based services if there is no community in which to base them?"* However it is not just a concern about the existence or lack of communities. Assuming that community is a caring place is also problematic as the community can in itself be a mechanism of social exclusion of people who are considered to be 'different' (see Symonds & Kelly, 1998).

In recognising the importance of these social factors for people experiencing poor mental health, a community development approach has been advocated as a 'missing ingredient' to complement community-care (see Ife 2002, Henderson & Thomas 2002, Gilchrist 2004).

2.1.1 Taking a step further: A community development approach to mental health

"*Community development models of mental health are particularly useful in the provision of mental health services…Services need to reach out actively to communities to find alternative paths to channel supports to individuals and families*" (DoH&C Policy, 2006:40).

The formation and delivery of the Home Focus Project is informed by a community development model. This involves an integrated approach to mental health care based on a partnership between statutory agencies, voluntary agencies and service user groups. Such a process allows for a holistic approach to care, recognising the broader context within which mental health problems arise and within which a recovery process can be facilitated.

As mentioned earlier, 'community care' is a popular though ambiguous term in mental health care. However, a community development approach is a somewhat unfamiliar area to mental health professionals. In order to fully appreciate its contribution, it may be useful to highlight some key differences between the two frameworks.

In general terms, community care aims to provide support at a community level from service providers or informal support networks. The focus of the intervention is on the individual receiving treatment. The shift of services from institutional to community settings does not necessarily lead to addressing the broader factors which contribute to mental distress. In other words, community mental health can be interpreted as 'medical care in the community', an approach that was broadly adopted in Irish mental health care. In this case change occurs in the location of care but not in the prevailing paradigm, which interprets and treats mental distress through predominantly medical/pharmacological interventions.

On the other hand, the process of change in community development is brought about by people working together to design and implement their own solutions to

shared problems. "*Community development is distinguished from social work and allied welfare professions through its commitment to collective ways of addressing problems. Community development helps community members to identify unmet needs, to undertake research on the problems and present possible solutions*" (Gilchrist, 2004 in Seeboth *et al*. 2005:24).

A community development approach to health is "…*the process of organising and/or supporting community groups in identifying their health issues, planning and acting upon their strategies for social action/change, and gaining increased self-reliance and decision-making power as a result of their activities*" (Labonte, 1993).

A community development approach to mental health is informed by the social determinants of health models. This recognises the wide range of economic, social, physical and psychological factors that impact on the mental health of individuals and communities. It recognises that experiences of poverty, discrimination, unemployment, racism, family difficulties, sexual abuse, domestic violence and spiritual conflict have a profound impact on mental health (see Bracken and Thomas, 2005).

The Combat Poverty Agency (2007) identifies the following key principles of community development:

- **Empowerment:** Working with people to enable them to take control of decisions that affect them and their communities.

- **Working Collectively:** Supporting people to come together to identify the things they want to change in their community and to work together with others to achieve that change.

- **Participation:** People have the right to participate in decisions and structures that affect their lives.

- **Social Justice and Equality:** Community development is concerned with achieving social change that enables individuals, groups and communities to realise their full potential, uninhibited by unfair or discriminatory social structures and systems.

Benefits of applying community development approaches to mental health (adopted by Lynan, 2007):

- **Ensuring a genuine involvement of currently marginalised groups such as service users and carers:** Community development facilitates the inclusion of people experiencing "*inequality and exclusion in the decision-making process, not as target groups, but as strategic partners with their own specific concerns, insights and objectives*" (Lynan, 2007:14). The practice of the Home Focus project provides evidence of commitment to service-user involvement in planning their care and other areas that affect their quality of life.

- **Adopting a social model of mental health**: Recognising the contextual factors contributing to mental distress and facilitating recovery. A community development approach challenges the dominance of the medical model by engaging with the multiple dimensions of people's lives rather than focusing on symptom management. This was evident in the work of the Home Focus team by:
  - Working in people's own environments
- **Building relationships and social networks**
  - Breaking down geographical and social isolation
  - Developing life skills
  - Facilitating engagement with services
  - Enabling participants to become part of the community
  - Addressing practical problems of everyday living which can hold back recovery
- **Promoting integrated approaches:** Recognising the complex interactions between environmental factors and health leads to the promotion of

integrated approaches to address the well-being of individuals and communities. The Home Focus project is a prime example of this approach, as a diverse range of expertise at both management and front-line levels allow for a holistic mental health practice.

Adopting this broader perspective of mental distress allows a deeper understanding of the process of recovery and the conditions that facilitate this process.

2.2 Recovery-Oriented Practice

"A recovery approach to mental health should be adopted as a cornerstone of this policy"` (DoH&C Policy, 2006:15).

2.2.1 Recovery as a philosophy

Historically, mental health systems were based on a tradition of diagnosing and treating people with life-long psychiatric conditions with no hope of recovery and meaningful social life. The underpinning principle of this practice was that people with severe mental illness did not recover, and that the course of their illness was a deteriorative, or at best a maintenance course (Anthony, 2000).

While the concept of recovery in mental health is not a new one, during the past two decades there has been a redefinition of recovery which is of particular relevance to the Home Focus Project. This involves a shift from the literal understanding of recovery as 'absence of symptoms' or 'recovery to normality' to a process of 'recovering what was lost': citizenship, rights, meaningful roles, responsibilities, decisions, potential and support (see Curtis 1997, Crowe and Taylor 2006, Bracken and Thomas 2005). As Roberts and Wolfson argue, the current *"redefinition of recovery as process of personal discovery, of how to live (and to live well) with*

enduring symptoms and vulnerabilities opens the possibility of recovery to all" (2004:37).

This conceptualisation of recovery is primarily associated with Anthony's 1993 paper in the U.S. in which he argued that *"a person with mental illness can recover even though the illness is not 'cured'. Recovery is a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness"* (Anthony, 1993:15). On a similar note, Deegan (1988) suggested that recovery is a process of taking control of one's life. This focus on the journey rather than on reaching its end is a metaphor which many users prefer (see Ramon *et al*., 2007). This view has been adopted as a Recovery Competency by New Zealand's Mental Health Commission (2001). "*Recovery is a journey as much as a destination. It is different for everyone. For some people with mental illness recovery is a road they travel on once or twice, to a destination that is easy to find. For others recovery is more like a maze with an elusive destination, a maze that takes a lifetime to navigate"*.

While acknowledging the uniqueness of this journey it is important to be aware of the common themes in recovery stories. Such themes include a sense of hope, a vision of the life people want to live, seeing and changing patterns, finding new ways and reasons, and being in charge of wellness (see Crowe and Taylor, 2006). A further dimension of the recovery approach is its organic link with the service user/survivor movement. For the survivor movement, recovery is about having a voice. As Bracken and Thomas argue, "*through social action, the survivor movement has created safe spaces in which individuals can start the process of telling their own stories…the meaning of recovery is very closely tied to the struggle of survivors to have the right to tell their own stories in their own way*" (Bracken & Thomas, 2005:227). A recovery approach does not involve the implementation of technical measures. It is a philosophy requiring a fundamental shift in understanding, responding to, and being with mental distress. In this shift, the voice of the service users in defining their own recovery is central.

The Home Focus Project has provided a safe space for the participants to tell their stories and more importantly to realise that they do have desires and hopes for their lives. As discussed in the methodology section, the voice of the project participants in constructing the meaning of their recovery has been central to the evaluation of the project. Chapter three presents these stories and voices as the main evidence of the project's positive contribution to the lives of the participants.

2.2.2 Policy developments

Strong interest in incorporating the recovery philosophy into mental health care and service provision is evident in the United States, New Zealand, and more recently in the U.K. In the U.S., public policy has embraced the concept of recovery, and the President's New Freedom Commission on Mental Health (2003) places the concept of recovery at the centre of a transformed mental health system (cited in MHC, 2005). In New Zealand the Mental Health Commission defined the principles of recovery in their *Blueprint for Mental Health Services in New Zealand in* 1998, and further elaborated this approach with the publication of the *Mental Health Commission Recovery Competencies* (2001). The U.K. developments in recovery have been linked to disability and anti-discrimination legislation, the social inclusion agenda, the emergence of the service user movement, and broad initiatives in support of the Department of Health's Expert Patients programme. In 2001 the Department of Health issued the National Service Framework for Adult Mental Health entitled *The Journey to Recovery - The Government's Vision for Mental Healthcare.*

In Ireland, the consultation process leading to the new Mental Health Strategy *Vision for Change* (2006) identified the need to adopt a recovery perspective at all levels of service delivery. As already discussed, *Vision for Change* promotes a community-based service whereby Community Mental Health Teams (CMHT) would adopt a recovery model and involve users and carers at every level of care planning and delivery. Momentum for change is also evidenced in the Mental Health Commission's discussion paper *A Vision for a Recovery Model in Irish Mental Health Services* (2005).

This paper provides a comprehensive review of recovery literature and provides a foundation to consider how mental health services in Ireland could incorporate the recovery approach.

However, as already discussed, the process of change in the Irish mental health system is slow. Partners to the Home Focus Project expressed their concerns about the resistance to change, the lack of co-ordination between various services dealing with mental health, and the stigma attached to mental illness. "*Evidence that mental health services on the ground are actually willing to take up the radical agenda is very patchy. There is actually evidence of substantial resistance to change. It is very positive that…the Mental Health Commission adopted a recovery model and that senior people in the Department of Health and the HSE endorse radical changes. It will be a challenge to make that happen*" (member of management board). Two years after the publication of *Vision for Change*, interest groups of service users, professionals, and mental health campaigners have expressed their concern about the lack of progress in implementing the policy recommendations (see IPA 2008, IMHC 2008). These concerns are outlined in chapter one.

The most significant contribution to recovery initiatives in Ireland emerges from service user groups and organisations such as the Irish Advocacy Network and voluntary organisations such as Schizophrenia Ireland. Evidence of change towards recovery-oriented practice can be found in participatory research projects such as the *Pathways Project*, the first user-led research on people's experience of the mental health system in Galway (see Brosnan *et al*. 2002); *The Views of Service Users* Report (Making Minds Matter, 2004); *What we Heard* (Crowe, 2004) and *Talking about Choice* (Schizophrenia Ireland, 2006). A review of further projects incorporating a recovery ethos is provided by the Mental Health Commission's discussion paper on recovery (MHC, 2005).

The Home Focus project is clearly based on a recovery philosophy, engaging with people in the context of their lives, facilitating them to decide how they want to move on with their lives. As the staff team has 'reached out' to meet people 'where they

were at' in their own communities, an assertive outreach approach has also informed the formation and delivery of the project.

2.3 Assertive Outreach

"…Assertive outreach teams providing community based interventions should be the principal modality through which these teams work" (DoH&C Policy, 2006: 195).

2.3.1 Background and International Developments

Assertive (Active) Outreach (AO) originated from the U.S.A. de-institutionalisation project in the 1970s and was initially designed to help mental health patients develop the skills necessary for independent living in the community. The routes of the approach can be traced in Stein and Test's model of home-based treatment in the U.S., an alternative approach to psychiatric hospitalisation (see Stein & Test 1980, in Killaspy *et al*. 2006). Treatment was tailored to individuals' needs, focused on helping them to develop independent living skills, and took place in the community rather that the hospital (see Test & Stein 1978, Sainsbury Centre for Mental Health 2001). This gradually evolved into two specific models - assertive community treatment and crisis resolution. Assertive community treatment has gained popularity amongst those working with service users who have problems engaging with services but for whom mental health care is essential. Systematic reviews concluded that when targeted at high users of inpatient services, assertive community treatment reduces the costs of care by decreasing frequency and length of admissions. Other positive outcomes include increased engagement with services, more stability in accommodation and improved satisfaction for service users and their carers (Killaspy *et al*. 2006).

Assertive outreach was further researched in Australia in the 1980s and was then introduced in the U.K. in the early 1990s. In 2002 the U.K. Department of Health, Social Services and Public Safety (DHSSPS) identified the introduction of assertive outreach as one of its priorities for action.

In Ireland, the new mental health policy 'Vision for Change' considers assertive outreach as one of the four community-based intervention programmes employed in the effective delivery of community-based care, and a key principle underpinning the rehabilitation and recovery mental health team. Vision for Change defines the central principle of assertive outreach as "*the provision of individualised, focused and proactive care to service users to minimise the risk of disengagement and to maximise the recovery process*" (DoH&C Policy, 2006: 108).

Definition

Assertive (Active) Outreach is a "*way of working with an identified client group of severely mentally ill adults who do not effectively engage with mental health services. The approach is characterised by work with clients in their own environment, wherever that may be"* (Sainsbury Centre for Mental Health, 2001:2). It is a flexible and creative team-based approach to working with the complex needs and wishes of service users in their own environment (see Graley-Wetherell & Morgan 2001).

The flexibility of the approach allows for services to be provided to people who may not otherwise receive them, in a place where they feel most comfortable. Staff may also visit or accompany service users when they use other services in the country. This encourages a two-way engagement that helps to develop trust and rapport and to establish links with other agencies (Sainsbury Centre for Mental Health, *ibid*).

The relationship between staff and users is central in this process, and assertive outreach staff expect to have regular contact with the client group, however difficult that may be. Assertive outreach workers aim to build a trusting relationship with clients in a flexible, creative and needs-focused way that enables the delivery of a care package which fits each client's individual needs (*ibid*).

Aims

Assertive outreach services aim to help clients to:

- reduce the frequency and duration of hospital admissions (especially for social rather than psychiatric reasons)

- find and keep sustainable accommodation
- sustain family relationships
- increase social network and relationships
- improve their money management
- increase co-operation with treatment
- improve their daily living skills
- undertake satisfying daily activities (including employment)
- improve their general health
- improve their general quality of life
- stabilise symptoms
- prevent relapse
- receive help an early stage.

(adopted from The Sainsbury Centre for Mental Health, 2001).

Core Characteristics

- It is multidisciplinary, comprising a range of professional disciplines (nurses, psychiatrists, social workers at a minimum; also, depending on user-needs, support workers, workers who have also been service users, psychologists, occupational therapists, housing workers, substance misuse specialists and vocational specialists)
- Improved client functioning (in employment, social relations, and activities of daily living) is a primary goal
- There is a low ratio of service users to workers (usually ten clients per case load)
- There is more frequent and more intensive client contact compared to that of standard community mental health teams
- An emphasis on engaging with clients and developing a therapeutic relationship
- Treatment is individualised
- Offers or links to evidence-based interventions

- Work with people in their own environment, often their own home; engagement with the users support system of family friends and others
- A team approach that provides flexible and creative support to the individual case co-ordinators

(adopted from The Sainsbury Centre for Mental Health 2001 and Burns & Finn 2002)

2.3.2 The Effectiveness of Assertive Outreach - the International Experience

Assertive outreach is one of the most widely researched models of mental health provision, with a strong evidence base for its effectiveness.

Systematic reviews in the U.S.A., Australia and the U.K. concluded that when targeted at high users of inpatient services, assertive outreach reduces the costs of care by decreasing the frequency and length of admissions (see Marshal *et al*, 2000, Mueser *et al*. 1998). Other positive outcomes include increased engagement with services in the community, more stability in accommodation, and improved satisfaction for service users and their carers (see Marshall *et al*. 2000, Killapsy *et al*. 2006).

The following table is adopted by Stein & Santos (1998) and Davidson (2007) and summarises the key findings on the effectiveness of assertive outreach programs from various international studies.

Table 1: International Research on Assertive Outreach (AO)

(adopted by Davidson, 2007)

Year	Site	Investigators	Psychosocial and Clinical Outcomes
1973	Madison, Wisconsin	Marx, Test and Stein	AO more effective (5 month trial) in reducing use of hospitals and ER's, in improving residential status, and in preserving occupational status
1980	Madison, Wisconsin	Stein, Test and Weisbrod	AO more effective (12 month trial) in reducing use of hospitals, nursing homes, and law enforcement services; in improving residential status, socialization, instrumental functioning, and symptom profiles
1983	Sydney, Australia	Hoult and Reynolds	AO more effective (12 month trial) in reducing use of hospitals and ER's; in improving instrumental functioning, symptom profile, residential status, and occupational activity
1992	London, England	Marks, Muijen, Connolly, et al.	AO more effective (20 month trial) for symptoms, social functioning, patient and family satisfaction, and reduced use of hospitals
1994	London, England	Audini, Marks, Laurence, et al.	AO treated subjects in study above randomized into AO or standard services with only significant difference at 45 months being increased family and patient satisfaction
1992	London, England	Merson, Tyrer and Onyett	AO more effective than usual hospital aftercare (3 month trial) regarding symptoms, satisfaction with services, and reducing use of hospitals
1992	St Louis, Missouri	Morse et al.	For homeless sample, AO more effective for satisfaction with program, number of days homeless, and use of community resources
1992	New York, New York	McFarlane et al.	AO plus family psychoeducation more effective in reducing use of hospitals and facilitating and maintaining client employment

1996	Australia	Sanderson et al	More users maintained in treatment longer than in routine case management; Fewer admissions involving the police; Fewer involuntary admissions; Significant improvement in functioning over 12 months in Living Skills Profile cases
1998	Australia	Hambridge & Rosen	35% decrease in hospital admissions 62% reduction in number of bed days Increase in number of users in stable accommodation
1999	Bradford Home Treatment Service, UK	Cohen, B.	81% surveyed preferred home treatment to in-patient care; 79% felt they were better able to cope with their problems; in the first 12 months –25% reduction in hospital; admissions
2006	REACT London	Killaspy et. Al.	Satisfaction with services, symptoms, social functioning, needs, quality of life, engagement, medication and alcohol/drug misuse
2007	Belfast, Northern Ireland	Davidson, G.	51% reduction in hospital use; improved engagement with services; reducing perceived coercion; minimising risk for coercive services; engaging high-risk clients

2.4 An Emerging Identity for the Home Focus Project

Home Focus has been set up on a model of an assertive outreach team providing individualised treatment to service users who have disengaged from services in their own environment. While Home Focus has moulded ideas of assertive outreach (as implemented in the U.S. and the U.K.) into its philosophy and practice, it has also developed its own unique identity. This identity is a constellation of variables including the philosophy informing mental health provision in West Cork, the diversity of the staff and management teams, and the geographical and social characteristics of the target area. This distinct identity is evidenced in:

- The application of creative, strength-based engagement strategies
- The provision of a holistic, non-medically driven service
- The provision of a service in a rural context where issues of isolation and limited access to services is pertinent to the experience of service users.

2.4.1 Creative, strength-based engagement

The term 'assertive' can be interpreted in different ways, which may also imply various degrees of involuntary treatment and coercion in the community. While this discussion goes beyond the purpose of this report, it is important to be aware of some critiques of AO, particularly in relation to coercion in the community, which can be more subtle that in institutional settings. Assertive Outreach has been criticised as being a quite coercive form of intervention (see Diamond, 1996; Gomory, 1999; Spindel &Nugent, 2000) which could be potentially damaging in terms of human rights and self-determination (see Spindel & Nugent 2000, Davidson & Campbell 2007). These concerns are particularly relevant to practice contexts where Community Treatment Orders (CTOs) are in operation. On a more positive note, a recent study in Northern Ireland showed that AO appeared to be more successful than community mental health teams in reducing perceived coercion among service users (Davidson & Campbell, 2007).

Burns and Firn (2002) argue that assertive outreach can be divided into constructive, informative and restrictive approaches. Constructive approaches include befriending and strengths-focused interventions; informative approaches involve persistent efforts to acquire information about the clients, and restrictive approaches include the use of statutory powers such as involuntary admissions and community treatment orders.

In the case of the Home Focus project, 'assertive' manifested itself as a constructive approach, employing persistent and creative engagement without violating the rights of users 'to say no'. This was evident in the practice of the team who showed

remarkable perseverance in their engagement, particularly in cases of participants who would not answer the door or wouldn't would not feel like talking to them. Rather than interpreting this as rudeness or rejection "*the staff team would go back to try to find something that the person identifies as, something that can help them - can be housing, leisure, advice on benefits or help them to get their house done up - whatever it is and establish a trusting relationship*" (management board member, December 2007). Examples of such practice are provided in chapter three. The participants also said very clearly that the engagement was positive and respectful of their wishes, choices and pace.

2.4.2 Non medically-based, holistic interventions

Participants, staff and management of the Home Focus project articulated the holistic nature of the approach taken. During the baseline interviews, a clear distinction was made between Home Focus and the U.S. model of AO which is mainly used "*as pharmacotherapy giving depo* [injections] *at home*" (management board member). As another management member put is "*a lot of assertive outreach is over-medical…just moving the medical* [care] *out in the community rather than having a fresh look at things*".

On a similar note, it was stressed that considering a reduction in admissions as a primary goal of the project represents a narrow medical view of AO. "*Our primary goal is to improve participants' quality of life… reduction of bed occupancy may be a result of this improvement. Already … admissions have been significantly reduced in the Bantry hospital"* (management board member).

Another important point is the distinction made between Assertive Outreach and Home Based Treatment. "… [AO is] *a multifaceted approach to working with individuals in their homes and in their communities, but … there is a clear distinction particularly for assertive outreach work that's based in the home and home-based treatment which is what mental health services mainly provide….home-based treatment…is literally moving the location in which treatment is being delivered from a hospital setting to a home setting, where that the nature of the work involved in*

assertive outreach is a much broader… and multifaceted approach to the individual, and working with the individual on a broad range of areas" (management board member).

This multifaceted approach was evident in the testimonies of participants and staff who engaged in activities ranging from counselling and home study courses to social activities in the community and home restoration projects. Taking such an approach was facilitated by the diversity of the staff team and their willingness to work creatively beyond the confines of their job descriptions.

2.4.3 The rural nature of the project

"Rural disadvantage may take the form of poor households in rural areas but there are several problems that can disadvantage a rural community, including a lack of services or a threat to services, because of declining population or dispersed population, a lack of employment opportunities, relatively poor transport, and high incidence of isolation and loneliness" (DoH&C Policy, 2006:38).

The Home Focus project covers large rural areas with low population densities, in one of the most isolated parts of Ireland. As discussed in chapter one, economic disadvantage in West Cork closely correlates with topography and access. Key characteristics contributing to social disadvantage in the area include:

- Fragmented settlement pattern
- Weak urban structure
- Low population densities
- Poor public transport
- High dependence on car usage
- Poor road network
- Lack of community services and facilities
- Poor access to services

The rural nature of the target area has significant implications for the work of the Home Focus team, as access to people living in isolated areas is poor. Furthermore, linking participants to community resources may be difficult due to the lack or the inaccessibility of such resources. In addition, the Home Focus project is delivered by a small team covering a large geographical area. This means that there is significant travel time involved, with an average of 637 kilometres weekly. This has implications for the team's workload and the availability of space to accommodate new referrals.

Rural mental health

The broader theme of mental health in a rural setting has been of particular interest to academic researchers. Philo *et al*. (2003) identify three thematic concerns in the literature of rural mental health. The first tackles *rural incidence,* enquiring about the prevailing types of mentally ill health in rural populations, tracing causes, considering the risks associated with rural areas and the variety of stress factors such as isolation. Such studies also broaden the focus on incidence to consider the "*possible influences on the manifestations on mentally ill health within given rural areas*" (Philo *et al.,* 2003).

The second thematic concern tackles *rural services.* Such studies focus on how rural populations are under-serviced with an unequal distribution of resources. The enquiry targets issues of (in)accessibility, distances of travel, transport costs and related matters. Of particular interest are the resultant stresses on mental health staff and users, which rarely affect those involved in urban mental health systems (Philo, 2003, Bachrach, 1983, 1985 in Philo 2003).

The third thematic concern tackles *rural lifewords.* Such studies enquire more closely into the everyday life of people with developing and diagnosed mental health problems as they struggle to cope with everyday living in rural areas (Philo, 2003). One remarkable contribution in Ireland is Nancy Scheper-Hughes' (1979) ethnographic study in a village in the West of Ireland. She identifies impaired family communication, child-rearing practices (particularly the mother-son relationship), religious scrupulosity and fear of sexuality as keys to understanding the experience

of ‘madness’ in rural Ireland. Furthermore, Scheper-Hughes (1979) proposes the social construction of ‘madness’ suggesting that “*there were appropriate and inappropriate ways of ‘going’ and ‘being’ mad in rural Ireland*’” (Scheper-Hughes, 2000:122). As a result she argued that “[e]*xtreme eccentricity was allowable, even coddled, if it could pass as harmless ‘foolery’ or if it came wrapped in the mantle of Irish spirituality*’” (*ibid*), yet there were certain boundaries of “*speech and action whose transgression would lead to the attribution of madness and the possible interventions of local social control agencies, including removal to the nearest mental hospital”* (Scheper-Hughes 2000, in Philo 2003). In the context of a disintegrating ‘subsistence-based peasant economy’ in rural Ireland, Scheper-Hughes' account is usefully complemented by Saris’ (1996, 2000) insights into how elements of a pre-modern culture in rural Ireland could merge with distinctly modern and rational calculations based on utility, money and the bureaucracy of psychiatric institutions (see Philo *et al*. 2003).

The incidence of mental health problems, accessibility and availability of services, and lifewords in West Cork Communities are key contextual factors in the life of Home Focus participants. The next chapter examines the impact of the Home Focus project at individual, local and service levels.



Road to a brighter future (Dick Page 2008)

Introduction

This chapter constitutes the main body of the Home Focus evaluation and is based on the fieldwork undertaken as part of the study. This part of the evaluation is designed to examine the impact of the Home Focus project at three different levels: (a) service users (micro-level); (b) services providers (mezzo-level); and (c) the community (macro-level).

This chapter discusses experiences of the project (at the three levels) from the point of view of service users, Home Focus staff and management. Furthermore, feedback on operational and administrative issues is considered.

3.1 Micro-level; Impact on service users

This part of the report discusses service-users' experiences of their participation in the Home Focus project. The first section outlines the participants' expectations from the project as articulated in (i) the interviews with them and (ii) the feedback of the staff team. This is followed by a summary of the gains achieved by participants since their engagement with the project. Then the views of service users, staff and management are considered.

3.1.1 Service users' expectations of the project

A significant factor that needs to be taken into account, when considering participants' expectations of the project, is that many of them have had a history of enduring mental health problems. It is well documented that through such history people's lives are primarily defined in terms of their 'illness', which leads to a lack of hope of living a life where they can make plans and have choices.

The Home Focus project provided a space where most participants could articulate desires and make some plans for the future. Through the interviews all participants expressed a sense of hope for the future. Studying the 'Pen Picture' report also showed that most participants indicated their aspirations for the future. On some

occasions, while participants did not articulate aspirations, they expressed an openness to learn about the potential benefits from their involvement with the project. A number of participants were clearer about their expectations a few months after their engagement with the staff team.

A vision for recovery

All interviewees indicated a hopeful vision for the future. This was expressed through plans to become more independent, improve the social aspect of their lives, get/feel better, link with services, or simply do something they are interested in.

It is important to note that through the interviews, they communicated that they experience a *sense of possibility*; in other words, things they consider important are possible to happen. Participants identified a diverse range of interests and a desire 'to have a go' at things such as art, going to the gym, joining an interest group, further education and training, and getting a computer.

Developing skills for independence and self- care

Specific expectations of participants included skills development and training as an avenue to becoming more independent and planning for the future. Such plans could involve a career, employment, or just better self-care and a better sense of self. People expressed a desire to be able to look after themselves; for example, one participant joined a home management course, hoping to address some of the difficulties he has with tasks such as using the washing machine or the frying pan. Another participant was hoping to get their own place, while other plans included doing specific courses in areas such as computers, maths and horticulture.

A better lifestyle

Also, while not explicitly articulated by all participants, a plan for improvement in lifestyle was underpinning all interviews. Some participants had concrete plans about such improvements; for example, one participant was hoping to lease his land as cattle caused him difficulties and he was not able to work outside the farm or get a job: "*I suppose to have a better lifestyle, …. and lease the whole lot of the land, and*

get some class of a handy jobeen, I'd have a better lifestyle then, I'd have my wage every week then". Another participant talked about plans for home improvements, which would also improve his quality of life by having bathroom facilities in his house. Others described aims such as starting to go for a walk, going out on their own, moving out of the house more and linking with the community through activities such as going to the gym or to a local football match.

But also questions about 'quality of life' indicators

It is interesting to note, however, that some clients challenged the concept of 'quality of life' in their initial interaction with staff, as they did not see any problems in this area. This issue highlights how professional perceptions and definitions may misrepresent the way that service users perceive their lives. It also highlights the importance of user-defined rather than professional-defined plans and outcomes.

Employment

A number of people expressed a wish to find employment, mostly part-time. Some participants also indicated the need for support in seeking employment. Not all participants considered working or starting to go out of the house as an immediate possibility; however, some of the interviewees reviewed this position during the course of their engagement with the project and as their confidence grew they were in a position to consider either full-time of part-time employment. Overall, most participants seemed to appreciate the social aspect of the project and the possibilities this opened to them, including the possibility of employment.

Social and community contact

A significant number of participants articulated a desire for more social contact, such as 'going out more', socialise more, find new interests, going to the library, going to a local football match, going to the cinema, accessing public transport, or simply by going out for a walk. Participants also expressed hopes to find and pursue new interests. A number of people also look forward to the contact with the staff-team, as it is for them a significant, and in some cases the only, personal and social relationship.

When evaluating 'community engagement' it is important to make a distinction between 'engaging with the community' and 'being part of the community'. While many people do not engage with community groups and services, they can still be part of the community. In that sense, plans for more socialising, getting a driving licence or accessing public transport are valid indicators of a willingness to be 'part of a community'.

Engaging in the process of identifying tasks and personal development

Articulating a concrete plan for the future, however, is not the only way to evidence a sense of hope and possibility. While some participants articulated expectations of achieving concrete tasks, others focused more on issues of personal development and learning how to cope with 'mental illness', symptoms and medication. One person made reference to anxiety management, while another participant said they would like to 'get their mind working again'.

One of the participant interviewees provided an interesting insight by saying that at the moment he is primarily interested in himself and while he is aware that *'maybe that's bad thing'*, he also indicated that he is now learning about himself in a way that can help him improve his life. Further on, the same person articulated that part of an inability or unwillingness to express hopes is that "*this [*expression of hopes] *can accelerate my stress… by expecting too much too soon. Well maybe that's part of the problem too, looking for everything at the same time... you know… maybe that's part of my make-up, I kind of look for too much at the one time, maybe most people are like that, but well* [staff member] *was saying to take it in small bits you know, and work towards a goal or whatever like you know. Try to achieve something small first".*

Awareness that change is a slow process

It is also important to stress that people showed an awareness that their plans and expectations may be slow to materialise. Awareness that change takes time was well articulated by one participant who described himself as *'lethargic',* and while he

wants to move out of that state, he is clear that it is a slow process and that he needs time.

"Well I suppose in time maybe, maybe things like getting out of the house more, and trying to get out of my comfort zone… So maybe to try to get out of that you know and, in time kind of what you're looking at is in the end is to get a bit of part-time work or something, maybe that, down the line, kind of after a while like, work towards that you know".

Two of the interviewees were very vocal about the need to pace changes in their life and recognised that it will take time to change patterns in their everyday lifestyle.

3.1.2 Gains achieved by participants

The following table provides a summary of the gains achieved by the project's participants since their engagement with the Home Focus team. The figures are presented as a percentage of the total numbers on the programme

Gains Achieved by Participants
(as % of total numbers who participated in the programme [35])

Health & Social Gain: (e.g. improved decision-making, better daily routine, improved sleep patterns, increased social interaction with family, friends and professionals, improved social skills)	**89%**
Improved Social Engagement: (e.g. established means of transport – car, taxi, bicycle, public transport - allowing increased community access to shops, services and businesses;	**72%**

developed routine in the community – hairdresser appointments etc.; playing indoor soccer)	
Links with Community Groups and Support Organisations: (e.g. GROW, Aware, Rental Accommodation Scheme, Drop-in centres, involvement in fundraising for local hospital)	**40%**
Improved Mental Health: (e.g. Marked reduction in paranoia and suicidal ideation, better understanding of medication and own mental health, improved ability to communicate re. mental health, enhanced awareness of mental health issues such as stressors, highs and lows, etc., improved ability to seek help and support, reduced incidence of crises)	**69%**
Improved Independent Living Skills: (e.g. Buying and driving a car, taking the driving test, using taxi & public transport, using a bicycle, moving to independent accommodation, shopping, dealing with government bodies, increased awareness of rights and benefits, increased telephone use, improved functional literacy in social settings e.g. restaurants)	**71%**
Employment: (e.g. starting full-time or part-time employment)	**11%**

Further Training: (e.g. attending a full-time or part-time training course)	**14%**
Certification: (e.g. working towards an accredited award, such as FETAC, ECDL)	**6%**

3.1.3 Stakeholders' views on the project

All participant interviewees stressed that they felt more comfortable working in their own environment. They also felt respected and supported by the staff team. The time afforded to them was a new but welcome experience.

A flexible individualised service beyond psychiatric labels

Participants and project staff described Home Focus as a flexible individualised service, which met people 'where they were at' with no pre-conceived ideas about diagnostic categories "*…that's one of the strengths of the project – that we do approach the individuals as individuals first and foremost, and everything comes from that then afterwards. It's not… this person has been diagnosed as schizophrenic so we'll do this, this and this, it's always about the individual first and then from there on*" (staff).

"*When people with the same diagnosis on paper will have totally different recovery journeys, and want totally different recovery journeys, and for some people it may be appropriate for them to address past issues whereas for other people that could be the absolute worst thing for them to do, and I think it's again the nature and flexibility of the project is that we can address some of that*" (staff). Participants also spoke

extensively about how they felt the staff team met them as human beings first and foremost.

"From a service user point I think that they [participants] *did receive a more intensive input which was sustained, it was over and above what the ordinary service could provide, it was tailor-made to them, it was highly individualised and considerate of their own particular needs in the ways that the ordinary service couldn't quite extend to in a sustained way"* (consultant psychiatrist & member of management team).

Inspiring Hope

"[The project] *helped me to be positive about certain aspects of my life, and certain directions… to reappraise things*" (project participant)

As said in the previous section, while not directly mentioning the word 'hope', participants made reference to future plans and articulated a hopeful vision for the future. All service user interviewees expressed a desire 'to do things' that are meaningful to them.

Being treated with respect

Service users felt that they were treated with respect, particularly when comparing their experience of the Home Focus project to previous experiences of mental health services. They particularly appreciated that their relationship with staff allowed them the space to start working things out for themselves. Participants reported a sense of control over their choices and plans for the future, and they appreciated that plans were not made *for them* by staff.

"..with other people in the [mental health] *service, … they might be a bit pushy or they might tell you do this, or do that or, where I think it's better to work it out for yourself - kind of, because it's kind of you that knows your own mind you know".*

Participants also felt that while staff encouraged them to move on, they also respected 'the way they were at the moment'. As one person put it *"… they* [staff]

always ask me why don't I go out more and I don't [feel I have to] *give them any legitimate excuse"*.

Participants also recognised that respectful engagement is about genuine relationships and about being real. "*I could be told what I don't really want to hear, but I would still come away from that feeling positive to some degree, not humiliated, not belittled, not patronised*".

Being listened to; being valued; having choices

On a similar note, being listened to and being valued was a new experience for many participants. Most participants stressed that they set the agenda during their meetings with the staff team.

"They kind of let you do the talking you know, they listen to you instead of you listening to the mental health services people, which most people are fed up of listening to...(laugh) being told what to do you know".

"… it's people listening, you know that is the biggest thing because I felt up until seeing [staff names] *that nobody really listened. You'd talk to them* [other professionals] *and you'd say my arm is hurting and right ok – well fine see you next week."*

Participants overall felt that staff met them 'where they were at' and started working with participants' own interests and expectations. The staff and management teams also confirmed that project participants are being empowered through a new experience with staff where their opinion is valued; staff said that initially some service users were fearful that staff would *'"go and tell them what to do"* but "*we* [staff] *would have said, well that's not really how it works, we're interested in your opinion and what you would like to do different, and how it might be achieved together, and that was a new perspective for them, and …one or two of them kind of said they felt the whole thing was to empower* [them]*. That was different for them, the first time that their opinion might have been asked about their situation".*

Time and availability of staff

"I never met anyone with so much patience in all my life" (participant about staff member).

Service users, staff and management said that the amount of time staff spent with participants was a big asset. It was possible for staff to get to know participants in the context of their lives, as opposed to traditional services where '*you get 5-10 minutes* [with your psychiatrist] *in the most'* or 'a maximum of *20 minutes with the CPN once or twice a month'*. Participants stressed the significance of time in building a relationship.

…*"definitely you have to give people more time anyway, you're not going to get to know somebody in five minutes, you're not going to know how they are feeling …you know".*

" [staff member] *was here for about two hours and it's good in a way because you get to know the person. It's more friendly kind of thing".*

"And I always know that I have [staff member] *to call on, you know, and it's different from the mainstream psychiatry services, you know* [staff member] is *more of a friend you know".*

"I think what they're doing at the moment is spot on, you know they are there for you when you need them, like I can text them, I can phone them if I want to, and … they come back every week, a lot of the other people don't and they've certainly proved to me that they don't".

"I just can't stress how important that is, to know that I have that connection there you know, and to know that they are good to their word and they will be up and they will talk to you, and they'll spend two or three hours if necessary and things get sorted

out… So the issues I had on Monday when I wanted to speak to the psychiatrist, I don't feel it's so urgent today…"

The importance of time available to participants was also recognised by the staff team*: "I suppose the strength we have is that we have time – we can give somebody time, and when somebody is given time they feel valued, and that in itself then, if somebody feels valued they feel better about themselves, they feel more motivated, and continue on their journey towards recovery, but if somebody is watching the clock and gives somebody 5 or 10 minutes, it's very demoralising for the person, so we have that strength in that we have the time available".*

A number of participants described the availability of staff as surprising. As one person put it "*it's very surprising – 2 hours like and they didn't seem to mind like – I hope they're getting well paid for it*". Staff also talked about participants' responses to their availability. "*At the start there would have been several occasions where we would have been in a house and somebody would say to us, your hour is up, assuming that we had only an hour to spend with them – but we'd say look we're here as long as you need us to be here".*

Intense support was not the rule for all participants. Home Focus participants had various degrees and forms of contact with the team depending on their needs. Some kept in touch by texting and by meetings on a needs-led basis, rather than a regular basis, which is also very important. In many cases participants talked about appreciating the responsiveness of the team when they expressed the need for a meeting.

Another angle of this is the persistent engagement of the staff team with participants, while also respecting people's choice not to engage. As one participant put it "…[staff name] *religiously phones me several times a week... sometimes she doesn't catch me, but keeps in contact until she makes contact, and then makes an appointment to come and see me – she is always there, and says she will be. And you know sometimes she stays an hour, and I can just tell her any of my problems, and I*

do get on with her, so you know you never feel totally alone". People also appreciated that they were in charge in terms of meeting the team. As one participant said *"saying 'I don't feel I need you now' is a perfectly acceptable thing to say"*.

Consistency of staff and continuity of care

Participants talked about the importance of their consistent contact with same staff in comparison with the mainstream mental health system where there is a regular change of psychiatrists in the outpatient clinics and hospitals. As one participant said, "*inside in hospital you're kind of caged in…and they change their doctors, you get to know one doctor, and just about when you're getting to know the guy, you know because I have to go and see a psychiatrist every month, you get to know him and what do they do - they go and change him*".

Continuity of care was also identified as a strength by participants *"I think it's a brilliant service really because a lot of people leave hospital and* [while] *they might have some contact with the psychiatrist sources for a short period of time but then that fizzles out and then, [staff] just keeps on coming you know, and there's just no limitation, so if I feel suicidal I can phone* [*staff*], *if I felt anything I can phone…".*

Time to work at individuals' own pace

Participants appreciated the way their pace of 'working things out' was respected.

"Well I think people with mental illness…need time to work out things for themselves and I suppose you don't want to be treated like a school kid you know…"

"They didn't - they never put any pressure on me to do anything, they left it up to myself you know. A gentle push like you know (laugh)".

An interesting point was made by one individual who said that while he appreciates that no pressure is put on him at present, *"maybe they might apply some pressure after a while maybe, and maybe I might be able to deal with it better now that I'm stable you know".* This confirms the fact that people experience a sense of the

possibility of changing their own attitudes and patterns of behaviour and that they feel stronger to take such risks in the future.

Social contact and relationship building

"I suppose people with mental illness or people that have gone through mental illness tend to isolate themselves to a certain degree anyway, and they tend to kind of keep to themselves a bit you know, and it's a great help for someone to call to the house and see how things are going…"

All service user interviewees appreciated the openings for more social contact offered through the project. One person who, as a result of his work with Home Focus, started attending an NLN course, said *"The one thing is that you're in an environment with people and they're much the same as yourself, kind of that way. And you've company all day and you have your hours and…. you are into something you are interested in".*

Participants also welcomed the personal relationship with Home Focus staff. This contact was seen as an opportunity to get more support and, as one individual said, to deal with possible concerns and feel safer. *'…If there were people that were living kind of isolated within the community…. And things might happen over the week, so it was good to have somebody to call around to make sure I was OK in that sense… I suppose the expression would be – a couple of paid friends".*

The opportunity to do things outside the home, in the community, was also appreciated by participants. "*And we've been down in the café twice just for a break from the house, and we have a cup of coffee and a chat then and that feels good*."

On a similar note, another participant who suffers from agoraphobia appreciates the opportunity to go out with the staff to her local coffee shop, an activity she enjoys but has no confidence to do on her own. The same participant said that she is looking forward to the staff's visits and wished they would visit her more regularly. "*It's nice to see them coming*" she said "*they look after me good…they minds me*".

A participant who lives on a farm and does not meet people regularly said that he likes the social contact provided through the project because *"you get to meet people… that's the main thing anyway..."*.

Another person talked about becoming more confident in social situations "…*I was in a soccer tournament… over Christmas, just up the street here, so that was a start, it was only on for one day like, I got out and I met old friends and people that I used to know, they were all there, we played a bit of soccer and it was a good day…"*

As another participant put it "*I mean it's a lifeline really. It's – ya, I mean I'm lucky, I've got a lot of friends but when I'm depressed I shut myself away from them, so if it wasn't for organisations like this I would be pretty much alone you know"*.

People also appreciated being given the space to talk. One person who finds it *'difficult to talk to people'* views the contact with the staff as an opportunity to '*practise*' talking to people. She said that she has gradually become more comfortable talking with the staff team and also more comfortable '*being with people'.*

This was also recognised by the staff team "…*but when you just talk to people they would say that they find they have built trusting relationship with us, that they've learned to open up a little bit more, it's easier for them to have a conversation then with a neighbour or family or a friend or whoever, and that's what makes a difference to their every day life really*".

A further participant stressed that *"…it's crucial that people like these guys* [home focus team] *are available for people like me, because you know without that kind of attention or without that kind of help, you know I got to the point …I'd given up… but if the guys hadn't been here… I'd still be in the position wondering what am I going to do, what am I going to do with my life. I'm 53 and I feel like I'm 103, I haven't had social contact, you know mixing with people".*

"*Firstly Home Focus gave me the belief in myself and the confidence in myself to actually get up and get out, and I remember saying to* [staff names] *after the first week* [of joining a training programme]*,…I realised I wasn't as bad as I thought I was. You know that I actually could get out, I could communicate with people and I could, you know I was scared, you know, I didn't know how I'd cope, honestly…if* [staff] *hadn't brought me down here* [training centre] *first of all, and if they hadn't in their own unique way given me the push I needed to try at least… I wouldn't be here, it's as simple as that. So ya, again they gave me a bit of self-belief, a bit of confidence, and everything took off from there you know".*

Another participant who has led an isolated life for the past 15 years talked about how, through the contact with the project and the possibility to discuss things, he was encouraged to pursue his interests. For example, he is now hoping to join to Green Party. The same person talked about how new skills, such as computer skills, will help him to "*discuss things*" with other people so "*it will affect my relationship with other people*". A further participant, who also had minimal contact with the community, bought a car and talked about the possibility of getting employment and making contact with the outside world.

Again, the issues of choice and control (in this case over the regularity of contact with the staff team) came up in the interviews with service users. For example, a person with minimal social contact other than the staff team acknowledged that '[meeting with staff] *it's slightly intensive, but it's something to do kind of thing*'. He said that '*maybe once a week* [contact with staff], *maybe twice a week would be enough really*' and he is happy with the way he can decide how often the meetings are held.

Staff also talked about how, in some cases, achieving basic contact with participants was an important step. "…*Realising that we were achieving something by just actually visiting the person and it was never going to get past just the physical social contact of the visit, …that was as high as it was going to go, but that was an achievement in*

itself (staff member)". Overall, the staff team described the experience of engaging with participants as *"very fulfilling''.*

Progress and change can also be frightening

Two participants made an interesting point about the unsettling impact of progress in their lives. One participant said that while his *"movement forward, education and social contact*" were positive, the changes achieved, like getting a computer at home, undergoing training and getting a car, have been "*quite drastic, dramatic and scary in a way*". Another participant who suffers from panic attacks appreciates the visits of the staff team at home but found that moving out of the house with the team "*made it* [her attacks] *worse*". Despite that, both participants appreciated that their fears were respected by the staff team.

Creative and flexible engagement with service users

The staff team demonstrated remarkable creativity and flexibility in their engagement with service users. This was particularly evident in their work with 'difficult clients'. For example, on one occasion staff brought copies of National Geographic magazines to a person, consistently unwilling to engage, who had however mentioned that he had enjoyed reading the magazine in the past. The participant was 'pleasantly surprised' by this gesture. Similarly, in situations where clients presented as unwilling to engage, staff would ask '*Are you OK when we are here?'* or say '*See you next week'*, rather than asking '*Do you want to engage with us?'*. It is evident that the staff team showed an ability to gently persist in establishing a relationship and 'leave a door open' while respecting people's choices not to engage, a balance which is indeed hard to strike.

Creativity was also evident in other methods of engagement, particularly in identifying participants' meaningful interests. One participant talked about his interest in writing poetry and how through the project he was able to plan to get a new computer to type his poems. Another participant talked enthusiastically about being invited by a staff member to go to a photographic exhibition *"… I had to decline because I had a headache anyway, but for somebody to turn around, who doesn't*

even know me to say, do you fancy coming and seeing this photographic exhibition and they've invited me out for lunch… to suddenly have that contact with people it's kind of like overwhelming…to do normal things…I don't do that, I can't remember the last time I went out to dinner, or culture - I can't remember the last time I had any contact with any type of culture at all, because let's face it - I'm isolated aren't I. I can't just jump in a car and drive to a museum, or and those things excite me, museums and art galleries, and photographic exhibitions and all that kind of stuff".

A number of participants mentioned the value of talking with the staff about various things outside their mental health. Things like sharing a joke, talking about football and current affairs were valued as they were viewed as a way of being in touch with the world around them. And, it is the simple small things that appear to make a big difference in one's life. For example, one participant said *"they* [staff] *are helping me in ways that you wouldn't dream about".* When asked to expand, he said that staff brought him two newspapers and *"I read it because interesting stuff because it helps, but I mean reading is an outlet, you get rid of everything".*

Staff and management stressed that employing these diverse approaches was supported by the wealth of expertise and resources from partner organisations (training, employment, mental health, advocacy, community development).

Diversity of interventions and the value of practical help

The diversity of the expertise brought to the project by the staff team was greatly appreciated by the participants. As mentioned in the previous section, this diversity was evident in the creativity of engagement methods.

Participants appreciated the variety of staff interventions, such as going for walks or to the local café or clinic. "[staff] *offered to take me down the shop… I didn't go down the shop, my home-help is very good, and she brings me in things that I need… But they did take me to the clinic - that was good because my home-help couldn't take me that day…"* Another participant talked about how during her depression she did not get out of the house and "[staff*] bought me some food one day when I wasn't*

able to get out to buy some food, and it's just knowing that someone is going to come around when you feel like that".

Participants also appreciated the practical help which contributed to the improvement of their quality of life. For example, one participant who had fallen twice down the stairs in his house talked about how he now feels safer and happier in his house as the team put a bar at the end of his staircase. *"…So that was good and unless they'd been in the house they* [staff] *couldn't do it, which I couldn't get otherwise"*. The same participant said how much he appreciated the positive attitude of staff and the help he received in planning home improvements and in getting planning permission for an extension to his house. "…*If it hadn't been for the team and talking I wouldn't have probably bothered to get this extension and this and that and the other, because I don't like change but this is a good change, and they are going to help me with it*." He also spoke about how this will improve his quality of life. "*I think it might be a lot better when I've got a bed downstairs, and I've got a toilet and a bathroom, it will be more convenient to live in, I'll be able to live like an ordinary person then, because people take those things for granted but if you haven't got them they are very important and you miss them – and hot water, I've only cold water now unless I boil it*".

What is of particular importance is that the staff team were open to transcend traditional professional roles and to consider 'valid' all kinds of interventions aiming to improve service users' quality of life and community integration. "*Lets say from putting on our clothes and getting into a person's house and helping them actually making it liveable – to showing them how a shower operates – to working with them on the very basics of mental health, personal hygiene, literacy, communications, up to the higher functioning end of things, where you are introducing a person to the options that they have in the bigger communities such as college, or work, work experience, so the range is as wide as the number of people that we have"* (staff member).

Identifying possibilities and being facilitated to access information and resources

"If somebody takes the trouble to tell you what's out there, and be supportive and come back every week that's important".

Receiving concrete information about available resources in the community and being facilitated to access these resources was also a benefit for participants. One person articulated very clearly how he struggled with accessing information about possibilities particularly because of his depression as *"my confidence has taken such a hammering over the 18 months, you know it's hard to get out of bed some days and let alone suddenly decide… I'll ring up and I'll try and sort out a course out for myself"*. He found the staff team ***reliable*** *as "they put their money where their mouth is, rather than telling you oh ya you can do this, this and this, and just leaving it at that, they've actually physically got me into a position when I now have funding, you know to go on a course and I now know where I can go to go on a course".*

The same participant appreciated that the team facilitated his transport to the location of the training centre rather than expecting him to leave his house, a place he likes and *"has worked to make home*".

Another participant said that the main strength of the project is that the staff team "*keep you aware of opportunities*" referring to job and training opportunities. The same person said that the team would provide support if he gets a job.

A further participant talked about the advantage of getting access to a computer at home and "*I can use it whenever I want to, and you wouldn't have that facility with other mental health services".* The same person also said that through the Home Focus team, it was possible to access information about and apply for a County Council grant for home improvements, which will have significant impact on his quality of life.

The staff team also acknowledged the significance of accessing information and resources. "*Even from a purely practical point of view, at one stage we had, and we still have, a participant who identified transportation as a main problem so we needed to get a driving licence, and we couldn't afford that on our budget, the participant couldn't afford that, so the Disability Guidance Team came up with the funding for 15 driving licences, and that person now has bought a car*".

A staff member also said "*getting people to do training at home that they never would have done otherwise. Watching them progressing through that, it's important that they are progressing through that, then getting involved in social activities within their own local community and supporting them to do something that they might not have done otherwise, they certainly weren't doing it prior – even with all these achievements, it's about ultimately aiming for the person to be doing, accessing this stuff on their own and working towards that*".

Furthermore, participants talked about the value of getting information about issues that concern them, including mental health and medication. For example, one participant who is concerned about the potential addictive nature of his medication said "*Well do you know sometimes when I'm down, I can ask them any medical questions about certain tablets, that I wouldn't have time for when I go into a doctor to ask him about them".*

Working in one's own environment - A striking difference from previous experiences of the mental health system

"I think the major thing is seeing people in my own environment…whereas going to see the Psychiatrist in a clinic… whereas Home Focus will come to you in your environment and see what you're about and that type of thing – that's very good".

A strong point was made by participants when comparing *Home Focus* with previous experiences of care.

People described being more settled now as they are in an environment where they feel comfortable: *"I'm not used to being locked inside at all for four weeks, I'm used to my freedom, get up in the morning, go out, have a cup of tea and a slice of bread, go out and get the parlour ready…"*

"Oh Jesus Christ hospital is the last word – it's like jail to me. Like being in prison….you're upset and scattered inside".

"…any of experience I've had with going to hospital, going to a mental hospital, I found it kind of a cold experience you know, mental hospitals aren't nice places you know, some people say they're OK, they've had a good time there like, but I don't know, that was my experience of them anyway, I just found it cold. I suppose it's not an easy job either for the people that are working in these places, it's not an easy job like you know".

"I prefer being at home. It's better than plastic forks and knives and spoons and doing work therapy or whatever, almost a factory environment, and that's regarded as therapy but I prefer to work at home, it's easier".

Working in their own environment made people more relaxed with professionals.
"It's easier all right. I used to be nervous [in hospital], *if you make a mistake or something like that … when you're in the home house you relax more…..If I wasn't here this morning I wouldn't be that relaxed at all".*

"Well it's better really because you're probably more relaxed and you can be more focussed then on what you want to talk about…"

Participants also said through this service they can be more open about identifying their own needs as "*the onus is on you to bring up whatever you want"*. As another participant suggested, this work allows more room for service users to ask questions to professionals. "*Well the difference between this type of work and others that I've seen…what I've been doing before I went to Home Focus is going for my three monthly*

appointment to see the public psychiatrist and he would just ask you the same questions all the time, so at least they don't do that, they don't ask you the same questions all the time, you know…. it's up to you to ask questions…"

Participants also identified that working from home makes it possible to access help which would have been difficult to access otherwise. "*The fact that they are coming to you instead of you going to some place that maybe you're not comfortable with, or you mightn't be feeling that well, and you don't want to go out that day, have an appointment or something, and they can come to you, and that's a big help, because a lot of time when people are sick mentally, or going through depression or…whatever they are going through, they are not in a frame of mind to go out of the house…*"

Working in an environment where people are comfortable also creates more possibilities for the participants. One person who began a computer course at home said "…*well I couldn't get out now to anything, I couldn't get out to do any courses or anything, so them coming to the house means a lot"*. On a similar note, another participant who withdrew from an NLN course because he wasn't '*comfortable being around people'* said that he feels more comfortable at home where he has started an ECDL course.

Furthermore, working within a relationship where people felt comfortable and respected facilitated them to set goals for themselves and "*to find out what was out there, what was available, where could I go, what could I do…"*.

The staff team also confirmed that as their engagement with the project progressed, participants became gradually more relaxed in their presence.

A safe informal space

A significant contributor to relationship-building between staff and participants was the informal nature of their contact. This was much appreciated by participants. As one person put it, this facilitated him to '*talk about things and how I feel*'. A number

of participants expressed a sense of safety with the team and said that they look forward to their visits.

One participant who said she gets frustrated in the presence of others because "*I find it very difficult to converse with people, and I feel I have nothing in my head…".* said that *"… it's nice to have them* [staff team] *in the house, it's nice to have them coming… I like chatting to them. It's company and the hour seems to go quickly which is good".*

Participants also talked about the benefit of having a space to express their fears and concerns *"...I suppose it* [the contact with the staff team] *gets … my fears out. I'm very fearful of what will happen to me, and I can't walk or I can't think or anything, and I don't know what's going to happen to me".*

Furthermore, receiving support at times of possible crisis is crucial for all participants. A participant whose father died last year found Christmas difficult but acknowledged the support received from the team. "*Christmas - I was having tension around Christmas all right, tension all right, but I suppose I got through it".*

In terms of physical safety, a number of participants talked about feeling safer by knowing that the staff team is in regular contact with them.

Feeling better, getting better

Without using the word *'recovery'*, service users made reference to the process of feeling better since they engaged with the project. This was also confirmed by the 'Pen Picture' document where staff reported '*reduction of symptoms along with increased relaxation*' amongst some participants. On one particular occasion, they also observed '*less reference to paranoid ideas'* and on occasions '*where ideas are still present they are not being so dominant in their* [service users'] *life. '* This is a good example of conceptualising recovery as a process that moves beyond the absence of symptoms.

These are some of the ways in which participants defined a movement towards well-being. "*Ya it works for me, and you know I just carry on from day to day, I don't think much about medication, I just kind of carry on and do the best I can, I don't think too much about it. I used to think a bit more about it before you know - but I'm happy enough".* As another person put it, "*I am definitely feeling a bit better since I've been talking to* [staff name].. *Actually I had a lot of pressure in my head there over the summer…..but I find in the past few days that that's after clearing up a bit you know… I don't know there seems to be some bit of release of pressure or something".* The same person said at a later interview "*I'm more relaxed, my thoughts don't race as much about myself and about other people and all that, and I'm more relaxed".* A further participant talked about how through his contact with the team he has developed a better understanding of his own mental health.

People also recognised how their contact with the project motivated them to work towards some changes in their lives. "…[staff names]*… they were advising me that I should do something, probably only for them I mightn't have done anything you know, I might have just carried on the way I was*".

"*I'll be starting a job now on Monday, I'll be trying to focus on other things, focus on the job, trying to do my best at it, and hopefully stick it out for as long as I can anyway… I had a kind of tendency in the past to just kind of give up for no reason really… but hopefully that won't happen this time. If I do feel that coming on me again I can – you know Home Focus are always there, I can give them a ring and tell them".*

Another interesting comment comes from a participant who, during a follow-up interview, talked about taking a more realistic assessment of his situation. *"I've actually taken a bit of time to reassess my situation, and get more realistic about things, and it was nice to be able to talk to [staff] and he was encouraging and supportive and it was fantastic, and also continued with information, because I'm discussing doing advocacy work, because that's really, I feel really what I want to be doing".* The same person who was previously adamant about not moving out of his

current accommodation is now considering moving in to a less isolated part of the country where he will have more access to employment opportunities, activities and so on.

Other participants welcomed the opportunity to do *'things you are interested in'* or things they found helpful. For example, two participants did things they found helpful; one person mentioned health management which helped him get over a cold more quickly, while another person mentioned how home management can help him feel more confident about looking after himself.

Being empowered to take responsibility for one's life is central to the recovery process. This was clearly articulated by one participant who said that "…*what I like, they've made their position clear… that what they can help you do, it's not like we'll do this for you – it's what we can help YOU to do, which is also important because it's like, it's that balance isn't it of not making you reliant on other people to do things for you, but to get yourself motivated enough to say right I need to do this for myself, so I think that is very important… it's good to have that because you know that you've got to put a bit of effort in as well".* Participants also talked about how they realise that, no matter how much support they receive from the project, achieving change is 'up to them', and while this can be scary it has also been experienced as an empowering prospect.

Through these new opportunities, many project participants have developed a broader view of their lives. As a consultant psychiatrist (also member of the management team) put it, " [what changed] *fundamentally is how they* [participants] *view the illness as just one context of their lives and that they are not locked into… their illness*".

It is important to note that participants felt supported in their vision of recovery. As one participant said "[staff] *always emphasised to me, you know you're going to have it, you know you're going to come out the other side, and try and focus on, you know it's hard to do but when you are in that place, to try and say to yourself, you'll come*

out the other side". This vision was also articulated by the staff team. As one staff member suggested "*I think we probably focus more on recovery rather than… goals, and about having people, somebody to come to a place where they feel a bit better about their lives, not necessarily about getting into college or working, but that they have a definition themselves about what recovery means to them, and if it means that it's easier for them to have a conversation now than it was a year ago, then they are further down in their road of recovery".*

Other mental health professionals, outside the Home Focus team, also articulated this sense of participants' movement towards recovery. Psychiatrists, occupational therapists, social workers and nurses expressed the view that people referred to the project had benefited greatly from it.

Developing insight and self-awareness

This is an important part of the recovery process. One particular interviewee was very articulate in relation to the opportunities for insight offered through his work with a staff member. Despite his long-term involvement with services (over 20 years), it is the first time he has had an experience of counselling. He spoke with sadness about how much time of his life had been wasted because this type of work (outreach and counselling) was not available to him before this project.

"Do you know I always seem to be kind of on the run or something like, (laugh) or kind of running from something, and it's only in the past three or four years that I've sat down and kind of thought about it – like what I was doing you know. I don't know, …. I wish it had happened sooner you know, because I - a lot of years went to waste you know. But that's not saying the next ten or twenty years are going to be perfect or anything like you know (laugh) but maybe they might be some degree better".

The same person said at a later interview "*You know I was too focussed on myself, there's a lot more out there than myself…just dealing with every day life is hard especially when you're in a kind of a cocoon for twenty years… Well I don't think anymore really, I've kind of got over the idea that there's something wrong with me,*

and I think that comes from kind of talking to people and kind of getting over yourself a bit… Before I used to say I'm depressed and I'm this and I'm that, and now I just say I'm normal".

Another person talked about becoming more aware about how her depression patterns changed *"…this* [slower move out of depression] *is a total change in the pattern… and I think I can see it from a more positive point of view because to go slower in the change might be more beneficial in the long run".*

Another participant said that he felt that, through his contact with the Home Focus, it was the first time his depression had been recognised. This was experienced with a sense of relief and also provided him with an opportunity to consider appropriate treatment.

Participants also talked about how this work helped them to become more aware of their position in the social world and in other relationships. For example, a participant who described himself as an "*inward person*" said "*I've noticed that the isolation is stopping relationships, because when I was in the company of others in* [name of hospital] *I actually had a girlfriend for a couple of weeks, so in that sense the isolation is a problem for personal, and personal development. … I think the more isolated you are the more difficult it is to be in the situation of mixing with people. The opportunities aren't there*." While he didn't express a desire to change his lifestyle, the acknowledgement of contextual and situational factors is of great significance.

Developing a more positive perspective of mental health services

An interesting finding of this study was that some participants who had previously negative experience of services appear to be more open to using available supports, including hospital-based treatment. For example, one participant said that at a crisis point the Home Focus team persuaded her to go to hospital, which saved her life. *"I might easily have killed myself – so I mean that's pretty crucial – and it was thanks to the two of them that I came* [to hospital]…*but if I hadn't been able to get in touch with them, there wouldn't have been anybody who could have persuaded me to come*

into hospital, so I think that's the greatest thing I can say really. I must say that they saved my life. What bigger thing can you say than that?"

The staff team also talked about the changing nature of the contact between participants and mental health services. "*For another person it might be a hospital admission on a voluntary basis rather than having to be sectioned as they would have been in the past… that is a huge improvement for some people… the fact that the hospital is there as a place of respite for them, if they feel that life is just getting too much for them, that they know they can go in, stay for a couple of days, or a week or two weeks, and avail of what's there for them, this service has been set up for them, and they can avail of that, and go home when they feel ready to go, rather than feeling that a hospital is some place that they are kept prisoner*" (staff).

While the project is home-focused it is also flexible in its sites of interventions. Where necessary, staff provided participants with support and an advocacy role while in hospital. On a few occasions the staff team physically brought service users to hospital and supported them through their admission. This happened at the request of participants who themselves identified this need for support from the team. One participant expressed concerns in relation to perceived coercion by a team member during his admission to an inpatient unit. According to the participant, this was mainly related to the staff's insistence on compliance with medication. However, this did not affect his overall assessment of the project, but led him suggest that "*two staff members should come together in order to have a more balanced view*".

Home Focus staff and management also stressed that the expression of a need to avail of a service can be evaluated in positive terms. For example, as one consultant psychiatrist (also member of the management team) said, the involvement of the Home Focus team in service delivery could increase the activity of the community mental health team, which would be a positive step. The impact of the project on service delivery in the West Cork area is discussed in the next section.

3.2 Mezzo-level: Impact on service provision

This section presents both quantitative and qualitative data on the impact of the Home Focus project on service provision. Quantitative information presents the considerable reduction in hospital days for participants who engaged with the project and highlights the subsequent savings in hospital-based care. The qualitative section considers the views of Home Focus staff and management on the contribution of the project to service provision. Service users were not directly asked to consider this question; however, indirect references were made to the nature of mental health service they wish to receive.

While primarily focusing on the impact of the project at the local level of West Cork, it is important to recognise that Home Focus articulated the possibility of providing an alternative model of community support within a recovery framework. This has significant implications for service provision at a national level as well. The first part of this section discusses how the Home Focus approach impacted on service provision. The second part considers administrative and operational issues related to the project.

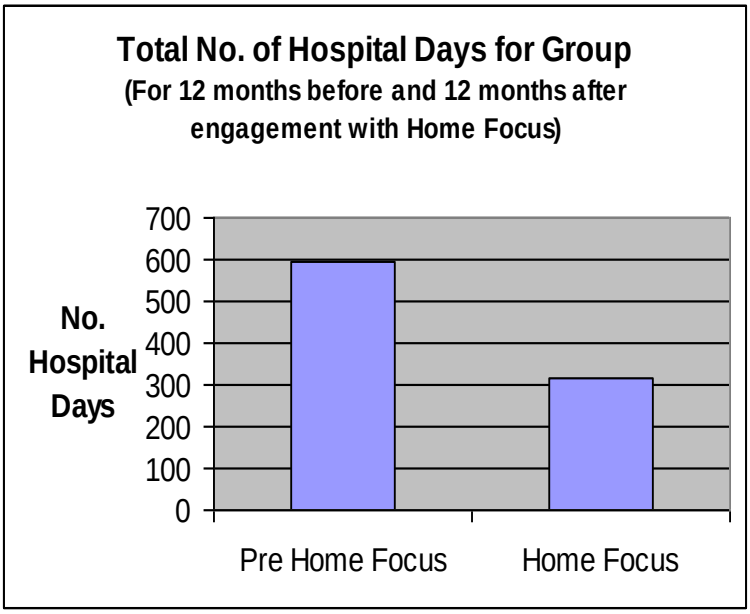
3.2.1 New approaches to service provision

A significant reduction in hospital days

The Home Focus project provided intensive, consistent and person-centred support to its participants, which was a unique experience for them. This intervention has also affected their need for long-term hospital care. As a staff member put it "*…before our intervention the cycle would have been pretty well defined, hospitalisation, a brief period of relative wellness, then the deterioration through drink and maybe non-compliance with medication, and eventually back into the hospital again and the cycle would have been maybe as short as six or eight weeks, whereas that cycle has been broken and there have been no more hospitalisations,*

and the person is relatively stable, which was as good as we could have ever hoped for, for that particular person".

The following table provides a picture of the reduction of hospital days for Home Focus participants, over a period of 12 months.



This represents a 47% decrease in the number of hospital days for the group. This also represents significant savings in hospital admissions

Savings in Hospital Admissions

Total number of hospital days for the group over the 12 months preceding Home Focus engagement: 595

Total number of hospital days for the group over 1st 12 months of Home Focus engagement: 318

This represents a saving of 277 days at €1,268.25* per day over a 12-month period equalling a total of: €351,305.25

***Information received from Management Accounts Office, HSE.**

Articulating a vision for recovery and community support

"Home Focus is a wake-up call in relation to collective pessimism and a collusion of chronicity within the service itself…" (management member).

Home Focus management and staff stressed that the project played an important role in service provision at a local level as it provided an additional resource for intensive support closer to people's life situations. It has also contributed to a broader view of service design as it demonstrated the possibility for a flexible, user-centred service which is community-based and recovery-oriented. On a similar note, the project provided an opportunity to consider what could be achieved if (a) additional input was provided to service users, and (b) thinking informing service provision shifted beyond the current medical paradigm.

As a member of the management team said, the project showed "*it's demonstrably possible to do mental health working in this kind of way; it's safe, it's productive, it's a good way of working and… by showing that it can be done I would be hopeful that we can influence future directions of services*".

Inter-service relationships

Overall, staff and management described their dealings with partner agencies as positive and from an early stage had an expectation that the Home Focus project 'will go well'. Reference was also made to the good relationship between mental health services and the staff team, facilitated by the new post of the mental health team co-ordinator. Staff and management consider this post as a positive development towards a co-ordinated approach in the delivery of the project. The Home Focus team regularly attended sector meetings where new referrals and participants' progress were discussed.

The links between the Home Focus team and mental health services were described by a member of the management team. "*I think that it's worth emphasising what I*

thought was excellent liaison and respectful liaison as well. I think the focus was on rehabilitation and to be able to offer home visiting and involve the family so it was an extension of what is being done already, but a more thorough extension of that. And then it did have an emphasis on recovery and rehabilitation so that was a positive thing – so these were the strengths as I thought".

Professionals working within the mental health service have given very positive feedback on the Home Focus team's openness to new referrals, and their enthusiasm and commitment. "*They've worked very hard to put in place a very flexible responsive service…. we've not had any difficulties with referring people to them, they've never really come back with any bureaucratic kind of stuff about … 'we can't take this person because they've got this diagnosis, or that diagnosis', they've basically been open to taking whoever was – as far as I can see and that's really what you want in a mental health service, and what we often don't get. I'm very pleased with the philosophy that they have developed which I think is very progressive, user-focussed philosophy, they haven't got tied up with all the technology of diagnostic systems… It's about human contact, human time and imagination really about trying to find a path forward for people*" (consultant psychiatrist & management member).

The partnership approach

The strengths of the partnership approach underpinning the formation and running of Home Focus were identified from the early stages of the project. The partnership was seen as an important element of the success of the project. The inter-agency partnership was identified as the way forward to service provision as it brings the responsibility for mental health out of mental health services to a broader range of services and interest groups.

Early comments on the strengths of the partnership approach were that through the "*different perspectives of the different partners, there is the potential to learn from each other and further development to be gained from the partnership*" (management member). In addition, it was felt that the participants will benefit from this approach as more resources will be available to them. Indeed, the staff team

talked extensively about the benefit of drawing from a wide and diverse range of sources. As a staff member said "*We have a lot of expertise sitting around the table… psychiatrists… psychologists… nurses… management, people from the Advocacy Network… Disability Guidance and they are all coming from different angles, they all have very worthwhile things to say".*

As the project progressed, differences in approaches between partner organisations became more apparent, particularly in relation to the Home Focus target group. This is discussed later in this chapter. However, all stakeholders stressed that the partnership was able to focus on the project's success, to work through some of these differences and to maintain good relationships. Furthermore, it was acknowledged that while some partners were located more in the background rather than the frontline of the project, they were very important in shaping the holistic orientation of the project, by providing advice and resources. As a management member put it, these partners "*made us think outside the box in some cases*".

A number of management members proposed more regular meetings between all partners, in order to have more opportunities for collaboration, shared learning and development strategies.

Community, outreach approaches as 'the way to go' - Mainstreaming

"It's the best service I ever had anyway I'll tell you that"
(participant on the Home Focus project).

In discussing the impact of the project on service provision, all stakeholders (i.e. service users, staff team and project management) recognised that community-based outreach work is one of the ways forward for mental health care. This recognition, however, has led to considerable levels of anxiety, as Home Focus is a pilot project operating within a tight time frame of eighteen months.

At the time of writing this report, a decision regarding mainstreaming has not yet been made. The pilot project was to come to an end in December 2007 and, through

internal funding, has been extended to June 2008. As a result, the project has operated within a climate of uncertainty which has been stressful for participants, staff and management. Staff have expressed serious concerns about the impact of this short time-frame (and the imminent termination of the project) on service users who, possibly for the first time, have had a positive engagement with a service. *"How do you withdraw it if you have done all this which is ethical and good, how do you withdraw that then, and what does that mean for the individual, and creating false expectations"* (consultant psychiatrist & management member).

As a staff member said "*it's unfortunate that the mainstream decision has to be made so close to the end of the project given the nature of the individuals and what we're doing, because that definitely has an impact on people. The prospect of stopping coming up to a Christmas* [2007] *was very stressful for participants*". The uncertainty about the sustainability of the project also affected the availability of the staff team to take new referrals.

The majority of the service user interviewees also indicated the necessity for the outreach approach to become mainstreamed. A participant who described himself as *'security conscious'* said he wished the project was *"24–7… it would be even better, if something did happen over the weekend"*. Another person recognised how much time of his youth was wasted because he did not get appropriate support and, making reference to the project, said *"I wish it had happened earlier",* while *a* third person said "*…it would be a crying shame if the funding was pulled on that* [Home Focus]*,* [if] *that wouldn't be available any more".*

Another participant talked very emotionally about the need for this work. "*We need it – I'd go crazy without it, I think this would be a void in my life if* [staff names] *were taken away….I mightn't do anything desperate or I might, but I doubt if I would because I have got myself to a calmness now, I think my faith keeps me going, but I need them at the same time, because I feel very weak at times and they are a great help to me*".

3.2.2 Administration and Operational Issues

The Referral process

The referral system is administered through the mental health team co-ordinator who is located in the Bantry Hospital and is the link between the HSE and the Home Focus Project. The team co-ordinator receives the referral forms and passes them on to the staff team. The staff team attends the meetings of the two mental health sectors. In these meetings, staff receive and discuss new referrals and bring feedback on their work to the mental health team. As previously stated, the post of the team co-ordinator was considered a positive development, contributing to the standardisation and consistency of the referral process. Staff members are introduced to participants by their Community Mental Health Nurse (CMHN). This process has worked well because of the predominantly good relationship between participants and CMHNs.

The staff team said that the criteria for referrals to the project need further definition and that a review is needed to agree on the target group. They recognised that it is hard to get a definition covering the diverse group of people that the team engages with, and they also recognised that such criteria should not lead to a practice of exclusion or 'cherry-picking'. However, the team acknowledges that they cannot accommodate everybody, and in particular people who are already engaged with other services.

Staff said that such criteria should be included in the referral form. This would help people making the referral to be clear about whether and how Home Focus can meet the needs of the individuals referred to the project. The staff team is also aware that the flexible nature of the project should be reflected in referrals and said that such criteria should be constantly considered rather than 'set in stone'. The staff team also stressed that, at the end of the pilot programme, it is important to have the referral parameters clearly defined so that the project can be communicated more easily to other sources of referrals such as GPs.

This evaluation study identified different views among partner organisations regarding referral criteria, length of interventions and referral process. Firstly, in relation to referral criteria and length of interventions, the National Learning Network proposes focusing on individuals with lower level of need, providing short-term and outcome-oriented interventions such as re-engagement with studies or training. On the other hand, mental health services view as the primary target group individuals with enduring mental health problems, who are disengaged from services, their communities and their sense of themselves as citizens. Mental health services recognise that this group requires a flexible approach to meet their diverse needs and propose a model of long-term interventions. Secondly, regarding the referral process, some concerns were expressed about the need to move this process beyond the mental health system. Some management members are of the view that the referral system has to open up to primary care teams and GPs as well as to self-referrals so that people who are not currently engaged with mental health services could access support. Others expressed some reservations about this opening as it may lead to excessive workloads from a group that is relatively 'well', while not affording time for those with long-enduring problems who need this time to build trusting relationships. Despite these different views on the referral process and the target group, all partner organisations recognised the benefits of the Home Focus intervention on all participants regardless of their level of need.

Resource issues

Direct work of service-user staff with participants. The staff team and two members of the management group identified the lack of a service user in the staff team working directly with participants. Having service users working at that level was considered valuable as they can better connect with participants' experiences.

"I think that that is something that we are missing and we have felt the need for it right through the programme, because if somebody, if one of our participants is describing their experiences to us, and why they haven't been able to get out of the situation they are in, none of us can look him straight in the eye and say 'I know how

you are feeling or I know what you are going through' – because we don't. We can look at it from the outside but we haven't gone through it ourselves, so I think having somebody there as an advocate who has been a service user or is a service user is hugely important for any future programme anyway" (staff).

Covering a big geographical area. This needs to be factored into the workload. As it is a small team covering a big rural area, the possibility of not being able to accommodate further referrals in the future was identified. This was a concern as it meant that people who could benefit from the service could not be included.

The issue was discussed in the management group and the need to keep some spaces available was identified. Another proposal was to rationalise resources through a better planned combination of high and low maintenance caseloads.

9-5 Monday-Friday service. Despite the flexibility of the staff team within the 9-5 time frame, this structure is a concern for the team as weekends and holidays are the times when people experience more isolation and their need for support is more intense. The Christmas holidays (2006 & 2007) were also a concern for staff as there was no contact between the team and participants for 1-2 weeks.

The staff team discussed extensively the need (a) *"to be careful of* [professional] *boundaries";* (b) "*for participants to understand that staff will not always be there, particularly that you are not setting up a permanent 'buddy' type system for people",* and (c) *"focusing on exit strategies".*

Resources and support to staff team. The staff team were satisfied with the training opportunities provided by both NLN and other sources. The team said that training was both accessible and available. The team itself has also been a good source of support. During the duration of the project, the staff team has been in regular contact with both NLN and the mental health services.

Working in isolation. The nature of the work (i.e. visiting people's houses and spending a lot on time 'on the road') can mean that staff work in isolation as that team support is not always readily available.

Staff Supervision. The staff team recognised that *"this kind of work even when running smoothly can be emotionally draining or charged".* Independent supervision (i.e. from outside project management) was mentioned by some staff as a space to deal with personal and professional issues arising rather than containing them within oneself or *'dumping on co-workers'*.

3.3 Macro-level: Impact on the community

Home Focus has operated on a pilot basis for a period of approximately eighteen months, and the community is only gradually 'becoming aware' of the project. This has made it difficult to consider comprehensively its impact at a community level, at least during its first year of delivery. However, from an early stage, there has been general agreement that the programme has provided an opportunity for intensive, user-centred support at a community level which was not previously available.

As the project progressed, staff and management talked extensively about a positive impact on the community and recognised that Home Focus itself has a high profile. "*I think the mental health, the profile of mental health in West Cork as a result of the programme in the community definitely is higher than …before*" (management member).

A community development approach

The project is committed to a community development approach and a collective way of addressing mental health difficulties. As discussed earlier, this is evident in the partnership between statutory, voluntary organisations and service user groups allowing for a holistic and contextual approach to responding to mental distress. The community development philosophy is also confirmed by the creation of the

recovery resource worker post as part of the Home Focus staff team. This post is located in the West Cork Community Resource Centre.

The recovery resource worker, who is also a mental health service user, is involved in a number of innovative community initiatives including the West Cork Mental Health Forum (WCMHF) and the C.R.O.W. Centre in Bantry. The West Cork Mental Health Forum is a broad coalition of individuals and organisations who have come together to develop a positive agenda around mental health in the West Cork area. At the heart of this development is a concern to overcome the social exclusion of those who use mental health services.

The C.R.O.W. (Community, Recovery Ownership Wellbeing) Centre is a user-run centre aiming to provide a drop-in service, information and support for mental health service users. The C.R.O.W. Centre seeks to work actively with other groups and organisations related to and associated with mental health, disabilities and care in the community, as well as the mental health service providers themselves, whilst at the same time maintaining its independence and its unique sense of identity. Through his involvement with the C.R.O.W. centre, the recovery support worker supports the development of an advocacy, user-centred approach. "*If some person is feeling depressed or …low… they get a bit of a burst of enthusiasm for life when they show up at the C.R.O.W. centre, and they come across other services that they wouldn't have come across otherwise because they hear from of them [members of the centre]– it's definitely very good – the service users would be totally at sea only for showing up at C.R.O.W…. one fellow says that it gives him a reason to get out of bed in the morning*" (recovery resource worker).

The role of the recovery support worker has been key in researching and developing community resources and in promoting awareness around mental health issues. A particularly positive outcome of this post was the production of the information booklet 'Signposting; Community Supports and Services in West Cork' (October 2007). The purpose of this booklet was, as the name suggests, to indicate to the general public how to access various services and bodies in West Cork. The booklet

is included in Appendix 10. Service users found the booklet particularly useful. As the recovery resource worker put it "*they were amazed that there were so many* [services], *a lot of service users didn't realise there were so many people out there willing to help them and paid to help people*".

The recovery resource worker has also contributed to the organisation of the two World Mental Health days in 2006 and 2007 in West Cork organised by WCMHF and the C.R.O.W centre. These events took place in Bantry, Clonakilty and Dunmanway and included information sessions, dialogue on mental health, art exhibitions and cinema. The events were well advertised and well attended by members of the community who had an interest in mental health. Above all, these events provided space for dialogue on mental health issues and for the voices of service-users to be heard and validated. As the recovery resource worker suggested, "*a lot of service users* [participated] *and some of them gave a testimonial, and that really impressed people, especially it impressed the service providers, they were just amazed at what a person could go through and still come out smiling at the end of* it". These events also provided an opportunity for the promotion of the Home Focus project in the broader community.

Normalisation - Locating care for mental distress within mainstream services

Locating the community support element of the project within a mainstream service (such as the community resource centre) was considered important for bringing mental health into the 'centre of community'. It was a step towards shifting mental health away from the monopoly of mental health services and working towards a partnership approach involving various community groups and services in responding to mental distress. Shifting the responsibility for mental health supports into the community *"de-stigmatises mental health issues and makes the use of a service normal, easy, and accessible"* (management member).

Stigma and community education

While 'community involvement' is considered as an indicator of 'progress' for a participant, the staff team acknowledged that this could be a daunting task as stigma

is still prevalent. Staff mentioned one example of a negative reaction by a community social organisation which, when asked about a possible linking of a project participant with them*, "… made every excuse possible not to allow that person into their particular social group, and it's just something, it caught me* [staff] *by surprise"*. Staff acknowledged that a lot of work needs to be done at a community level to *'avoid setting service users up for exposure to stigma and all the stress'.*

A community development/education perspective provides a platform for such negative attitudes to be addressed and challenged (see chapter two). It was also suggested that the community development aspect should be developed further and "*hopefully this will help create a strong service user group"* (management member). The expansion of the open mental health days (discussed previously) was seen as an avenue to achieving a better engagement of the community with mental health issues. Home Focus staff and management suggested that such events need to have a more continuous and consistent presence in the community in order to provide a forum where people with an interest in mental health can interact and plan further actions.

"I think there could be more open days I think, because people were just starting to get to know each other and make other links during the meeting, but then the day ended and they haven't seen each other again then, since then, and they've lost contact and some people were feeling very enthusiastic about everything after the open day but then it all faded away then again as they were separated from each other again" (staff).

The staff team also acknowledged the need for community education initiatives to engage with the general public rather than people who are in the service or are affected by mental health. To achieve that, the Home Focus project cannot work in isolation but needs to be part of a larger long-term initiative focusing on education forums (such as schools) and media (such as television and entertainment).

Home Focus as component of a changing system

As already stated, Home Focus provided an excellent resource in the community and articulated a model of working creatively with people in the context of their lives. However, sustaining the positive contribution of Home Focus to the community requires the project to be part of an integrated comprehensive network of community resources rather than working in isolation as an 'additional' resource filling existing gaps. The need for a broader network of community services offering more options to service users and linking people with their communities was identified by staff and management. Particular gaps identified in community resources included services for alcohol and substance misuse (including prescription drugs) and gambling, as well as broader amenities including recreation, leisure and transport facilities – all of which are important to the promotion of mental wellbeing.

At a broader level, the Home Focus project is an example of how the recommendations of the Mental Health Strategy "*A Vision for Change*" (2006) can be implemented. While the project itself has been very successful it cannot be sustained in isolation. It has to be part of a broader changing system where (a) the community is a source of support for mental distress; (b) recovery is an underpinning philosophy, and (c) the service user is at the centre of all interventions.

Chapter Four: Conclusions and recommendations



Now I can face the mountain (Dick Page 2008)

The wider implications of the evaluation study

This evaluation study examined the Home Focus project within (a) the local context of service provision in West Cork and (b) the broader context of adopting a recovery perspective to service provision for people with mental health problems in the community. The impact of the project was considered in relation to three different levels: service users (micro-level); service providers (mezzo-level) and the community (macro-level). In this study, the review of the Home Focus experience and the literature on mental health, community and recovery approaches enables us to learn in a way that is potentially transferable to other areas where mental health innovation is required.

Furthermore, this study proposed an evaluation framework where the experience of service users is central in constructing evidence of recovery. This is of particular importance in a period where evidence-based practice is central to service development and delivery. A broader conclusion to be drawn is that mental health research, and more specifically the evaluation of mental health services, needs to both reflect and influence innovative approaches through the development of participative methodologies and the generation of outcome indicators based on service-user experiences.

Strengths of the project

In line with national mental health and primary care policy, the Home Focus project provides flexible, intensive and person-centred support to its participants. Service users are met in the context of their own lives, in their homes and communities, which is a unique experience for them. The quality of the service provided, the commitment and enthusiasm of the staff team was remarkable. This is a summary of the strengths of the project as identified by the evaluation study:

- ***Gains achieved by project participants*** included reduction in hospital days; health and social gain; improved social engagement; linking with community groups and support organisations; improved mental health; improved independent living skills; employment; further training and certification.

- ***Positive service-user experiences.*** The project is underpinned by a user-focused philosophy and the team deliver an individualised service to people in their own environment where they feel comfortable and respected. Participants felt listened to by the staff team, they also felt they had choices in their interactions with the team. They appreciated opportunities to build social relationships and liaise with resources in their communities. Participants also identified a hopeful vision for their future and an improved sense of themselves in the world.

- ***The project's resources.*** The diverse and rich experience of the staff team (including occupational analysis, counselling and focusing on mental health problems, and community development) is a great asset to the project. The enthusiasm and commitment of the team, their flexibility and ability to engage with people beyond psychiatric labels is also important. The partnership approach between statutory and voluntary organisations provides access to diverse resources and expertise, which are very beneficial to project participants.

- ***The nature of the service.*** Home Focus delivers a user-centred, outreach service based on a recovery approach to mental health. The relatively small caseload allows the staff team to build relationships with individual participants. The flexibility of the approach taken and the creative methods of engagement made the contribution of the project a unique experience for its participants. Taking a community development collaborative approach to service delivery allowed providers to think 'outside the box'. The partnership approach also facilitated an improved co-ordination between services and the best utilisation of existing resources in the community.

- ***Demonstrating possibilities for future development of community mental health projects based on partnership.*** The Home Focus project articulated

the possibility of providing a recovery project within a community-based setting. It also demonstrated that:

- It is possible to move supports for people with mental health problems beyond the territory of mental health services to the broader community
- The community needs to take an active role in supporting individuals who suffer from mental distress
- A partnership approach is the way forward in the provision of services for people with mental health difficulties
- Advocacy and user-led services contribute greatly to mental health recovery
- A community development approach is central in broadening the understanding of, and responses to, mental distress.

Challenges

As Home Focus is a new pilot project, a considerable amount of time and resources were utilised in setting it up. Given the limited time frame available for the project delivery (18 months), this has 'eaten up' time from direct work with participants. The main challenges faced by the project are related to the fact that in many ways Home Focus operates in isolation, as it is not supported by a network of parallel developments at a community and national level. Furthermore, the uncertainty about the continuity of the project through mainstream funding has created and sustained high levels of anxiety among participants, staff and management.

The partnership approach also posed some challenges to the project, as different philosophies, procedures and views emerged in relation to operational and administrative matters. Despite this, all stakeholders acknowledged the strength of the partnership approach as a way forward to service provision. Moving supports for mental health beyond the territory of mental health services is viewed as a positive challenge, as it provides opportunities for a holistic approach to materialise and for the community to play a more active role in the promotion of good mental health.

A further challenge was posed by the size of the geographical area and the scarcity of resources in the local communities. Travelling long distances (approximately 637

km weekly) limited the time staff could spend with participants and the team's capacity to accept new referrals. This is a concern as it means that people who could benefit from the service could not be accommodated. The lack of resources at local level (including health and social care, transport, recreation facilities, etc.) has also been a concern as it restricts the possibilities for participants to be liaised with aspects of their communities.

Recommendations

- **Mainstreaming as part of a commitment to recovery, community-based supports at local and national levels.** The Home Focus project contributed positively at three different levels:
    - (a) Service users – by providing a new, unique, individually-designed service to people who have, overall, limited or negative experiences of services.
    - (b) Service providers – by articulating the possibility of a recovery-oriented, community-based, outreach service and by enhancing collaboration between statutory and voluntary organisations.
    - (c) The community - by providing an additional resource and by bringing the community to the centre of service provision.

  Based on the findings of this study, it is recommended that the project should be mainstreamed in order to (i) continue and expand its contribution to service users in the community; and (ii) provide a model of good practice which can be transferred to other parts of the country. However, this study also suggests that the project's contribution depends on it being part of a broader commitment to service provision, where community supports and service-user involvement are central in the recovery process.

- **Breaking social isolation – continuity of care.** Through participants' positive experiences of the project, a number of unmet needs at a community level were identified. The majority of people referred to the project were isolated in both social

and geographical terms. Many of their difficulties were a product of this sense of isolation rather than their mental health problems. This study found that the principal needs of many people suffering from poor mental health are about basic human contact, relationships, meaningful activities, and practical and ongoing support. This does not suggest that Home Focus is the only or the best service to respond to these needs. However, the project laid the foundations to explore other ways of providing continuity of care in the community. For example, one possibility to provide ongoing but low intensity home-base support is through the expansion of the HSE Home Help system to the area of mental health, after the relevant staff receive appropriate training (at a FETEC level 4 or 5). Furthermore, as the project's approach is based on a user-centred philosophy it would be appropriate to involve service users in providing both formal and informal support to other service-users in the community. The Peer Advocacy Training Course provided by the Irish Advocacy Network could provide training for this purpose.

- **Community development.** A community development approach to mental health is essential in shifting the responsibility for mental health to the community, recognising the contextual factors that contribute to well being, and combating the stigma associated with mental health problems. The partnership approach adopted by the Home Focus project is a good model of collaboration between various actors, which allows for a more holistic response to mental health difficulties and a better utilisation of community resources.

- **Geographical considerations.** To be effective (cost/impact), there is a limit to the territory a single team can cover. For the West Cork project, it is recommended that the West Cork catchment area be divided into two geographical regions, with one team delivering the programme in each region.

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Appendix 1

Interview Questions for Home Focus Participants (Baseline)

1. What kind of things you do with (name of staff)?

2. How is it (this work) going so far?

   Probes: - Likes
   - Dislikes
   - Anything you would like to change?

3. Is working at home different from other contacts you had with mental health services?

   Please explain

4. How does this work compare with previous dealings with/experiences of mental health services?

   Please expand

5. When you started working with (name of staff) what were you hoping to achieve?

   Probes: - What changes did you want to see happening in your life?
   - Anything else you hope to achieve?

6. Any other comments?

Thank you!

Appendix 2

Interview Questions for Home Focus Participants (Review)

1. What kind of things you do with (name of staff)?

2. How is it (this work) going so far?

   Probes:
   - Likes
   - Dislikes
   - Anything you would like to change

3. When you meet who decides what you will talk about?

4. Can you ask for a meeting if you want one? What happens if you do?

5. Is working at home different from other contacts you had with mental health services?

   Please explain

6. How does this (work) compare with previous dealings with/experience of mental health services?

   Please Expand

7. When you started working with (name of staff) were you hoping that some things would improve? How do you see the progress so far?

8. Anything else you hope to achieve?

9. Has the support that you have received from the team had an affect on your life?
   - Living situation
   - Occupation/training
   - Relationships with other people
   - Use of leisure time
   - Physical and mental health
   - Personal safety (how safe do you feel?)

10. Any other comments?

Thank you!

Appendix 3

Interview Questions for Home Focus Staff Team (Baseline)

2. What is your role in the Home Focus project?

3. What is your previous experience (if any?)
   a. in the area of mental health?
   b. in assertive outreach/community based interventions?

4. What is your understanding of 'assertive outreach'?

5. What are your expectations of the project?

6. In your opinion what are the strengths of the project (assertive outreach in particular)?

7. In your opinion what may be the areas that need to be further developed?

8. At this point do you think that you have:
   a. adequate in-service and other training?
   b. appropriate support in your position?
   c. adequate resources to do your job as you think it should be done?

9. Current mental health policy advocates quite radical changes in service delivery. How do you think are these changes manifesting in the practice context?

10. How do you think Home Focus will impact on mental health service delivery in West Cork?

11. Home Focus is a product of a partnership approach between various stakeholders. What are the benefits of the partnership? What are the possible limitations?

12. At the end of the pilot program:
   a. what would constitute a successful outcome?
   b. what would constitute failure?

13. Are there any other points concerning Home Focus that you would like to make?

Thank you!

Appendix 4

Interview Questions for Home Focus Staff Team (Interim & Final)

1. How are your expectations of the project being met so far? [in your answer make reference to expectations in relation to (a) service users, (b) service providers and (c) the community (as discussed in the baseline interview)]

2. In your opinion what are the strengths of the project /approach (assertive outreach in particular)?

3. In your opinion what may be the areas that need to be further developed/areas of concern?

4. How do you think the referral process works?

5. At this point do you think that you have:
    a. adequate in-service and other training?
    b. appropriate support in your position?
    c. adequate resources to do your job as you think it should be done?

6. Based on your experience so far what are your views on the partnership between various stakeholders?

7. Based on the work you have carried so far what are the indicators of a positive piece of work? How can you capture positive changes?

8. Are there any other points concerning Home Focus that you would like to make?

Thank you!

Appendix 5

Interview Questions for Home Focus Management Board Members (Baseline)

1. What is your role in the Home Focus project?

2. What is your previous experience (if any?)
    a. in the area of mental health?
    b. in assertive outreach/community based interventions?

3. What is your understanding of 'assertive outreach'?

4. What are your expectations of the project for:
    a. service users?
    b. service providers?
    c. the community?

5. In your opinion what are the strengths of the project (assertive outreach in particular)?

6. In your opinion what may be the areas that need to be improved/further developed?

7. Current mental health policy advocates quite radical changes in service delivery. How do you think are these changes manifesting in the practice context?

8. How do you think Home Focus will impact on mental health service delivery in West Cork?

9. Home Focus is a product of a partnership approach between various stakeholders. What are the benefits of the partnership? What are the possible limitations?

10. At the end of the pilot program:
    a. what would constitute a successful outcome?
    b. what would constitute failure?

11. Are there any other points concerning Home Focus that you would like to make?

Appendix 6

Interview Questions for Home Focus Management Board Members (Review)

1. How are your expectations of the project being met so far? [in your answer make reference to expectations in relation to (a) service users, (b) service providers and (c) the community (as discussed in the baseline interview)]

2. In your opinion what are the strengths of the project/ approach (as it developed its own identity?)

3. In your opinion what may be the areas that need to be further developed/areas of concern?

4. What are your views on the referral process?

5. Based on your experience so far, what are your views on the partnership between various stakeholders?

6. Based on your understanding of the work carried so far, what are the indicators of a positive piece of work? How can positive changes be captured?

7. Are there any other points concerning Home Focus that you would like to make? Thank you!

Tracing evidence of institutionalisation in the process of de-institutionalisation - the Irish case

Citation: Sapouna, L. (2006) 'Tracing evidence of institutionalisation in the process of de-institutionalisation-the Irish case', in L. Sapouna & P. Herrmann (eds) Knowledge in Mental Health; Reclaiming the Social, New York: Nova Science: 85-99. (Reprinted with permission from Nova Science Publishers, Inc.)

ABSTRACT

In discussing the nature of evaluation in mental health care and examining the construction of 'valid evidence', this chapter will focus on a type of evidence which is consistently ignored in Irish mental health policy. This concerns the continuation of institutional patterns of thinking and practising and the severe violation of human rights experienced by people suffering from mental distress. The discrepancies between the scandalous conditions of care and the unreserved heralding of progressive changes will be examined. Furthermore, I will trace components/indicators of institutionalisation in mental health policy and practice. While the discussion is based on the Irish system, its aim is not to construct Irish mental health as a pathological model of care but rather to highlight how institutionalisation can be reproduced through 'reform' policies that fail to take a broader view of mental distress. This question is of universal rather than local relevance. To conclude, the concept of institutionalisation will be re-defined in terms of policy, practice and broader political considerations.

SETTING THE SCENE

I did my social work training in Greece in a period when the 'scandal' of Leros Psychiatric hospital was at its peak. The exposure of the inhuman and shocking conditions of custodial psychiatry brought about a big controversy amongst professional groups and the broader public and provided the driving force for a

reform in the mental health sector. A five-year mental health plan was devised within the context of European Community funding towards the development of psychiatric rehabilitation services (EC, Regulation 815, 1984). Since 1984 there has been a significant reform movement which was also quite politicised[19]. The 80s was a time of change in Greek mental health, and while the institutional tradition and the centrality of the medical model were by no means displaced, a number of innovative ideas and projects were developed.

After gaining experience in mental health social work in Greece, I went to Ireland in the early 1990s to do research in the area of de-institutionalisation and community care for adults with mental health problems. My initial expectations were that I would learn from good practice, believing that I would certainly have the opportunity to study different, if not more 'advanced' developments. Such expectations were probably the product of a typical southern European inferiority syndrome, where 'western' forms of social organisation and practice are regularly assumed to be far superior and more advanced. However, I was faced with a rather different reality. The process of de-institutionalisation was being implemented but to a large extent community care evolved, both physically and ideologically, in the grounds of big Victorian institutions. Mental health in Ireland is perhaps one of the most marginal and under-resourced areas in social service provision and in the practice of social professions. Hospital admissions are still regulated by the 1945 Mental Treatment Act, a legislation that does not fulfil Ireland's commitments under a number of international agreements. Community care services, such as day care services and community residences, are both underdeveloped and under-utilised, with their primary emphasis being on ensuring safety through compliance with treatment rather than interaction with the community. This situation is both maintained and exacerbated by the absence of a public debate on issues concerning mental health problems and their treatment in Irish society.

[19] For a comprehensive account of the mental health reform program in Greece see Madianos and Yfantopoylos (1984), Stefanis, Madianos & Giltelman (1986), Strutti and Rauber (1994), Yfantopoulos (1994).

Encountering these conditions made me question the point of my exercise. What can be learned from the absence of good practice? It took me time to realise that studying the Irish attachment to institutional forms of practice could provide valuable insights. One particularly challenging task was finding the tools to evaluate de-institutionalisation projects such as resocialisation and day care units. As my hypothesis was that institutional practice is reproduced in the process of de-institutionalisation, I had to consider the nature of evidence that would support such a claim. A significant part of the study was an inquiry into the 'making' and application of knowledge in the areas of de-institutionalisation and community mental health. Through this inquiry it was possible to consider the micro-level of practising de-institutionalisation by focusing on themes such as the quality of interaction between service users and professionals, an indicator largely ignored in the dominant technicist evaluation frameworks. It was also possible to consider the macro-level of policy-making and critically explore the nature of the measures that have been heralded as 'improvements' in mental health care (see Sapouna, 1993; Leane and Sapouna, 1998). This latter consideration will be the primary focus of this chapter.

A central theme in this book is the nature of evidence in mental health service evaluation. In Irish mental health, the evidence of human rights abuse is overwhelming. "Nowhere in Irish society are human rights more systematically abused than in mental institutions and nowhere are these abuses more ignored" (Brown, 2001: 20). While there has been no systematic evaluation of community care, every year the Report of the Inspector of Mental Hospitals is published. Every year it reveals shocking conditions in mental hospitals throughOUt the country and abuses of the rights of patients in these hospitals. Every year this report is systematically ignored at both political and policy levels.

The state of mental health services is now explicitly identified as a cause of concern by an internationally recognised body for human rights- In February 2003 the Irish Branch of Amnesty International launched a campaign on mental illness with the publication of the report Mental Illness.- the Neglected Quarter. The report argues that the Irish Government has failed to act on a series of national and international reports critical of its inaction in respecting the human rights of people

with mental illness. Amnesty's report reveals that services in Ireland are slow, inadequate, inconsistent in their application throughout the country, and severely under-resourced in terms of staff, money and available therapies. Mental health services for children and adolescents, the homeless, prisoners, and other vulnerable groups are particularly deficient. To date there has been no indication that the content of this report has been taken into consideration. A prime example of the state's indifference towards the conditions of mental health care is the government's reaction to the Annual Report of the Inspector of Mental Hospitals for the year 1998 (Department of Health and Children, 1999). This report suggested that the state has been involved in the wilful and possibly criminal neglect of vulnerable people in its care and that, because of such neglect, citizens have died. It further revealed that citizens continue to be deprived of their liberty, often without elementary inquiry into the justification of such deprivation. The 'response' of the Department of Health to this shocking report was: "The health services aim to achieve the best quality of life for each individual through the provision of high-quality, patient-centred services, and the work of the Inspectorate helps to ensure that high standards are maintained in our mental health services " (Cowen, 1999).

This chapter examines the discrepancy between the indisputable violation of human rights in Irish mental health care and the heralding of progressive changes such as new legislation, primary care and advocacy. The discussion highlights the marginal place mental health occupies within the health and social care system and the continuation of institutional forms of thinking and practising in both hospital and community settings. However, while the focus is on the Irish system, this situation is not just an Irish problem. The question of 'institutionalisation' is one of universal relevance and the Irish example is perhaps an excellent opportunity to consider it and re-define it by acknowledging its complex and subtle manifestations.

THE POLICY AND POLITICAL CONTEXT

Mental Health Policy

In Ireland, as elsewhere, the concepts of de-institutionalisation and community care underpin the policy and practice of mental health care. Significant

progress has occurred since the publication of the *Report of the Commission of Enquiry in Mental Illness* in 1966, which criticised the predominant institutional response to mental illness and recommended the development of community care structures. Indeed, during the past three decades the number of the inpatient population has declined and a range of community-based facilities have developed [20]. 2 However, it will be shown that mental health services are still dominated by institutional patterns of thinking and practising.

The Expert Group on Mental Health Policy was established in 2003, to prepare a new national policy framework for the mental health services, updating the 1984 policy document Planning for the Future. The group consists of eighteen people with a wide and diverse range of experience in the area of mental health. The process of developing the new framework indicates a willingness to recognise the expertise of previously unheard and traditionally discredited voices of service users, relatives and carers. This is evident in the representation of the Irish Advocacy Network in the Group and the broad consultation process with all concerned with the development of mental health policy. The findings from the conSU1tation process provide a very clear indication of service users' views in relation to the present state of the mental health services and how they should be developed in the future (see www.mentalhealth policy.ie).

At the time of writing this chapter the report of the Expert Group has not been yet published. It is expected to be launched in early 2006 proposing a mental health service which is service user centred, recovery oriented, holistic and community based. While these proposals indicate a promising and much needed shift in service provision, we need to remember that a community-based approach is by no means a 'new' policy in Ireland.

The framework for community mental health is outlined in Planning for the Future, a policy document published in 1984 following a major review of psychiatric services carried out between 1981 and 1984. In summary, the report set out

[20] A full picture of these developments is provided by the Annual Health Statistics Reports, published by the Department of Health and Children and the Annual Reports of the Inspector of Mental Hospitals.

guidelines for future development as far as possible in a community setting, with the emphasis on resources being transferred from large psychiatric hospitals to a large range of alternative community-based services and to acute units in general hospitals. Among the key elements in the planning framework were:

- the location of services close to where people work, and a strong emphasis on outpatient care.

- the provision of inpatient treatment in psychiatric units in general hospitals, with the role of the traditional psychiatric hospital diminishing as alternative community based services are developed.

- the provision of high-support hostels for a small number who will require long-term inpatient care, and the provision of appropriate housing in the community.

- services to be provided on a sectoral basis for a given population by a multidisciplinary team to be based in each sector.

Ironically, while many aspects of this policy are considered outdated, a number of its targets remain under-implemented. A critical review of Planning for the Future and its implementation is provided later in this chapter. The 1994 health strategy Shaping a Healthier Future recommended that "mental health services should be comprehensive, integrated with other health services, based as far as possible in the community and organised in sectors close to the people being served". In 1998, the Department of Health and Children published the Guidelines for Good Practice and Quality Assurance in Mental Health Services. Their emphasis on the patient as consumer and the duty to provide "the highest level of mental health care possible" also remain under-observed (Amnesty International, 2003). The 2001 national health strategy Quality and Fairness/A Health system for You took a primary care approach, advocating the development of integrated

health care and making a commitment to increasing community care facilities. This approach aims to facilitate the development of primary care responses to mental illness and the treatment of mental illness in general health care. More specifically, the 2001 Health strategy proposed the introduction of an interdisciplinary team-based approach to primary care provision. Members of the primary care team will include GPs, nurses/midwives, health care assistants, home helps, physiotherapists, occupational therapists, social workers and administrative personnel. A wider network of other care professionals such as speech and language therapists, community pharmacists, dieticians, community welfare officers, dentists, chiropodists and psychologists will also provide services for the enrolled population of each primary care team. At the time of writing this chapter, the implementation of the new health strategy recommendations for primary care and the reform of health services remain under-observed.

The lack of a concrete resource commitment has been the main explanation for the inaction upon the above policies between professional and policy circles. Amnesty International's report Mental Illness: the Neglected Quarter (2003) highlighted that the mental health sector has been preferentially hit by cutbacks in the 1980s. In a re-appraisal of the closing of mental hospital beds in 1993, Dr. Marcus Webb stated that "the share of gross expenditure provided in Ireland for the psychiatric services has been reduced by 20% since 1976. This slide must be halted and reversed if this country is to preserve a semblance of mature and civilised care for its mentally ill" (Webb 1993, in Amnesty International, 2003:54). However, since then the situation has not been reversed and revenue expenditure In mental health has remained disproportionately low. "While overall growth in Irish non-capital health expenditure between 1990 and 2001 was over 300 per cent, that of the psychiatric programme was 131 per cent, by far the lowest. In 1994, mental health spending accounted for 9.4 per cent of total health non-capital expenditure; by 2001, it was just 7.2 per cent" (Amnesty International, 2003:54).

Poor resource allocation is a broader issue, however. It is an indication of poor political will to deal with people with mental distress in a way other than

exclusion. This is evident in the failure of the 'reform policies' to take a broader view of mental distress and to change the power imbalances between service users and professionals through a more participatory form of service development and delivery. A brief examination of health politics can provide some useful insights.

Health Politics: 'Value for Money', Consumerism and Mental Health Reform

The aim of this discussion is not to highlight the need to act upon an overall inclusive and fair mental health policy but rather to raise some concerns regarding the nature of the proposed changes and the broader political context of health care. One such concern was noted by the UN Committee on Economic Social and Cultural Rights (CESCR) who noted "with regret that a human rights framework encompassing, inter alia, the principles of non-discrimination and equal access to health facilities and services was not embodied in the…National Health Strategy" (CESCR, 2002 in Amnesty International, 2003:53).

This is a manifestation of a political climate within which the provision of health services is guided by a 'value for money' principle and a managerial approach to service structure[21] rather than a commitment to an equitable health system. As one health board official put it "as a ChiefExecutive Officer of a Health Board I am a manager of a business. It is as simple as that. If health is a business, then value for money is what is going to drive that business from now on" (Sean Hurley, in the "Irish Examiner" 28 April 2003). Part of this trend involves what Offe (1984) referred to as the 'commodification' of welfare services, a process incorporating market principles into the health service. In a context where economic effectiveness and efficiency become state priorities "there has been a widespread acceptance of privatising the impacts of poverty, lack of education, isolation and neglect of those who are unable to contribute economically" (Rioux, 2002: 218). Rioux further argues that this trend had a significant impact on people with disabilities, leading to disability being privatised. A similar argument can be made for mental health. In Ireland, a shrinking public health service fails to provide much beyond hospital-based acute psychiatric care where human and citizenship rights are consistently violated. While the new

[21] Such trends can be clearly identified in the Value for Money Audit carried by Deloitte & Touche on behalf of the Department of Health and Children (2001), and the 2001 Health Strategy.

health strategy (2001) emphasises the need to move beyond medical perspectives of mental health, Ireland remains the only country in Europe without a position of a consultant psychotherapist working in the psychiatric system. 'Alternative' therapies, including psychotherapy and counselling, can be accessed only privately and are not refundable by either public or private health insurance schemes, a situation rendering mental health a private rather than a public good.

In this political context 'value for money' and deficit reduction is argued to be a greater social good than social justice and basic rights (see Kuttner, 1984). While the development of the Irish health system has not been influenced by a commitment to universal provision and social justice (see Barrington, 1987; Curry, 2003; Powell, 1992; Fanning, 1999), a health reform has the potential to address such limitations. However, this does not seem to be the case as the narrow perspectives of efficiency and profitability replace these potential goals. As Arora (2001) argues, "health is not simply turned into a business with growing access on market orientation; implicit in this process is its loss of status as a right. It is this denial of meaning of citizenship through a denial of even basic rights that is the most disturbing implication of project liberalisation" (Arora, 2001 :3 1-32).

A discussion on the inequalities of the Irish health system[22] and the implications of the marketisation of health services goes beyond the purpose of this chapter. However, it is important to understand the impact of these trends in shaping the context where mental health policy and practice take place. Through this understanding it will be possible to consider whether institutional patterns of exclusion have changed through the proposed policy reforms by: (a) taking a broader view of mental distress and (b) increasing service user participation in mental health policy and practice.

A BROADER VIEW OF MENTAL HEALTH?

Community Care Policy and Practice

This chapter has already provided evidence of the continuous under-funding of mental health services in Ireland. I also argue that as long as 'value for money'

[22] A comprehensive discussion on the questions of accessibility and equity in Irish health care is provided by Maev-Ann Wren in her book 'Unhealthy State' (2003).

priorities dominate health care, there is limited scope for changes that move beyond improvements in buildings and management structures. If 'value for money' is the guiding principle in the provision of health care, how are community-based/holistic forms of mental health practice 'priced'? community care is not necessarily the 'cheap alternative' to institutions. Implementing deinstitutionalisation requires a concrete resource commitment which has not been evident in the Irish case. However, the type of commitment required for community care to work goes beyond the question of monetary value. It also relates to appreciating the value of community care as an ideology and practice. Unfortunately, as the Report of the Inspector of Mental Hospitals for 2002 reveals, the value of community care is still not recognised by many professionals. "There still continues to be on the part of many psychiatrists and others difficulty in comprehending and effecting the benefits of community care in all its ramifications. This understanding or the lack of it leads to an over-reliance on in-patient care and a reluctance to move out into the community" (Department of Health and Children, 2003:7).

In reviewing the transition towards community-based mental health, I have already argued that many of the targets set by Planning for the Future (1984) remain under- implemented and that many of its recommendations are considered outdated. A further point I wish to make concerns the way in which 'mental illness' is viewed in this document. While Planning for the Future advocates for community mental health, it fails to challenge the dominant medical model and the way mental illness is constructed and treated within this model. As a result, it fails to consider the broader factors that affect the incidence and diagnosis of 'mental illness'. As Butler (1987) argued "Planning for the Future is above all a medical report; that is, it is based on the implicit assumption that the planning of the psychiatric services is merely a matter of assessing the prevalence of mental illness and establishing the structures which best facilitate the delivery of modern scientific treatment methods" (1987:48). This policy is primarily a debate of relocation and modernisation of the existing services through administrative restructuring rather than a debate that considers broader policy issues. An examination of the trends in psychiatric provision during the past 20 years may provide some further insights into the practice of community mental health. The following table maps the developments in this area.

Trends in Psychiatric Provision, 1984-2001

	All Psychiatric Hospitals and Units		Day Facilities	Hostels
	Admissions	Patients	No. Places	No. Places
1984	28,330	1 1,613	32 800	121 900
1993	27,005	6,657	145 2,556	361 2,556
1998	25,158	4,340	175 3,361	380 2,850
2001	24,446	4,321	179 3,653	404 3,077

Source: Health Research Board.

As this table shows, the number of patients admitted to psychiatric hospitals declined significantly between the years 1984 and 2001. A considerable development in community facilities such as day centres and residential care has also taken place. However, while the number of patients was reduced by more than fifty per cent for the period 1984-2001, the same argument can not be made for the number of admissions. A consistent high rate of admissions indicates a high re-admission rate, amounting for 70% of all admissions in 2001 (Daly & Walsh, 2002). This is a reflection of two closely linked factors: the over-reliance on inpatient care and the lack of adequate community care facilities.

Community mental health is still not the norm in Ireland. For example, in 1998 only one third of first admissions took place in psychiatric wards located in general hospitals, and in 2001 less than half of the first admissions took place in such a setting. Furthermore, it has to be stressed that the physical integration of psychiatry with general medicine does not necessarily guarantee an open, or indeed a less institutional, care environment. A prime example of how such relocation may perpetuate or even intensify segregation is a newly established psychiatric ward in Cork city which has been heralded as 'a model of de_ institutionalisation' following the closure of an isolated psychiatric unit in a suburb of the city. While this unit is part of a centrally located general hospital, it is in the meantime a separate highly secured section of the overall building. The Inspector

of Mental Hospitals highlighted, after the 2000 Inspection, that "the entrance to the unit was locked and security was provided on a twenty-four hour basis. Also, its location on the first floor without any outdoor space for the patients constituted a major difficulty" (2001 : 163). Four years after, the Inspectorate's recommendations for less intimidating security presence and access to open space and fresh air for the patients of this unit have not yet been implemented.

There is also a considerable variation between regions in the availability of community mental health services, with some catchment areas having no multidisciplinary teams. The over-reliance on acute hospital units was also highlighted by a Health Research Board (HRB) study We have no Beds on the availability and use of acute psychiatric beds in the Eastern Health Board (Keogh, Roche & Walsh, 1999). The findings of the study showed that there is an adequate number of acute psychiatric beds, but an inadequate number of these beds were available for acute psychiatric use, with 45% of these acute beds occupied by non-acute patients. The same study also found that there was a shortage of day hospital places and that many day hospitals were not operating as alternatives or complements to acute inpatient care. The lack of fully and equally distributed community-based facilities has been a concern of the Mental Health Inspectorate for a number of years. The absence of such facilities reduces the sources of support for people in mental distress to inpatient care. An interesting observation, made by both the Inspector of Mental Hospitals' report for 1998 and the 1999 HRB study, concerned the excessive use of inpatient units for assessment of patients. "Community-based mental health centres were inadequate and unequally distributed throughout the catchment area and even where they were in place, assessment of patients, particularly in relation to possible inpatient care or its alternatives, was rarely carried out there. As a result many patients presented to the inpatient unit for assessment, thus making inappropriate admissions more likely" (HRB, 1999: 109). A more recent HRB research highlighted that day care options are not utilised to their full potential. The findings of this study, published in 2003 in a publication entitled "Psychiatric Day Care-An Underused Option? "showed that many psychiatric day hospitals and day centres were occupying premises unsuitable for day care purposes and did not provide a comprehensive range of treatments.

Additionally, returning to a point made earlier, "many mental health professionals...had limited perceptions of the role of a day hospital and what type of illness could be treated at such a facility" (Hickey, Moran and Walsh, 2003:7).

This is some further evidence of the continuous commitment to institutional forms of thinking and practising as mental health policy and professional practice have failed to take a broader view of mental distress. This is also evident in the new mental health legislation.

The Legal Status of Community Care

Planning for the Future is a policy document, not a legal framework. That means that it states the desirable way to deal with mental health problems but it does not allow the explicit right to be treated in the community. In other words, there is not a statutory obligation to provide mental health services in line with current policies.

Admissions to psychiatric hospitals are still regulated by the 1945 Mental Treatment Act. The Mental Health Act was passed in 2001 and has not yet been fully implemented. The 1945 Mental Treatment Act was considered a major innovative piece of legislation in its time, as it signalled a shift away from the previous 'legal' attitude to mental health care towards a medically based model (see Guckian, 1998). For example, the Act allowed for the first time the admission of 'voluntary' patients to psychiatric hospitals. A legal reform was necessary as the current criteria for detention in Ireland do not conform to those required by the country's international commitments, particularly the European Convention for the Protection of Human Rights and Fundamental Freedoms (1950), the UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (1991) and the Recommendations of the Council of Europe.

The 2001 Mental Health Act attempts to restore some of the long neglected rights of people with mental health problems in Ireland. However, it fails to provide for the inclusion of people with mental health problems in Irish society. The primary concern of the Act is detention; and in particular involuntary admissions, and the rights of involuntary patients. The debate is clearly located within inpatient care of a compulsory nature and fails to provide a broader representation of the mental

health sufferer, making no reference to the rights of voluntary clients and the rights of people receiving treatment in the community. It is ironic that while the Act re-constructs the position of the 'Inspector of Mental Hospitals', to 'Inspector of Mental Health Services', these services are very narrowly defined as those under the clinical direction of a consultant psychiatrist. This represents a narrow, medical view of mental health services, which as Keys (2002) argues "may prevent the Inspector from having the authority to visit independent services not under the control of a consultant psychiatrist. This issue has been raised by some interested organisations...to try to ensure that there was some supervisory control in the provision of accommodation or work-related services by independent providers" (Keys, 2002:70).

The forthcoming legislation has been heralded as a discourse of 'change' in mental health care. However, it does not reflect a commitment to ensuring 'patient' rights in the community and it does not deal with the picture of mental illness with any broad vision. It is more like a necessary administrative/regulatory provision which may bring this state in line with the kind of protective provisions that have long been available in other European countries. Therefore, this discourse does not seem to be a meaningful step for the relocation of people with mental health problems in the community. on the contrary, sufferers' rights are secured outside the community, as the status of the involuntary patient seems to be a precondition to qualify for such rights. Within such an approach, service users remain in the place of the 'other' and can only be passive recipients of care and control rather than active citizens with the right to be involved in service development and provision.

The Mental Health Service User: Consumer or Participant?

The importation of market principles into health care has created a space for a consideration of the mental health service user as a person with entitlements within this market place. Pilgrim and Rogers (1999) describe this as an alternative way of conceptualising psychiatric patients as 'consumers' of services rather than objects of clinical intervention. "The term 'consumerism' implies the existence of choice between products, and an active insistence on value for money" (Pilgrim and Rogers,

1999:165). This consumer definition does not question the biomedical basis of psychiatry, nor does it encompass a more democratic ethos in service provision. It does, however, provide the space to consider the patient as a person with entitlements, and this transformation contains the potential for resistance (see Speed, 2002a). The question is whether the shift to community care in Ireland has led to the development of sites where institutional forms of thinking and practising can be resisted. In order to address this question, I will briefly consider (i) the role of service user research in constructing a platform for their experiences to be heard and validated and (ii) the nature of service user involvement in their care plan.

Service User-led Research

In a discussion on Irish mental health social movements, Speed (2002b) argues that contrary to the UK, Irish mental health organisations have been much more closely tied into the mental health service system. The dominant type of organisations have been for users of services such as AWARE and Schizophrenia Ireland. However, during the last three years there has been a significant move for some representation *of* users *by* users[23]. 'One vehicle through which the views of service users can be heard is their involvement in mental health research projects. The contribution of service user research in the construction of evidence in mental health care evaluation is discussed by Shulamit Ramon in her chapter on pages 101 ff. While I do not intend to cover this topic comprehensively, I wish to highlight some issues related to the nature of service user participation in Irish mental health research. In the limited literature available, I can identify in particular the concerns raised by Speed (2002b) through his involvement in two user-led mental health research projects in Ireland as a research coordinator. Speed, drawing on Beresford's and Wallcraft's model of emancipatory research (1997), argues that in his experience, Irish user-led mental health research "is composed of mental health service users acting as paid and unpaid consultants and researchers for non-statutory and statutory mental health

[23] For example the Irish Advocacy Network is a user run user led organisation providing information and support to fellow mental health service users, to empower them to speak up and take control of their own lives. Cork Advocacy Network is an also organisation working for better mental health care in the Cork region. It was initially set up by a group of families with a son or daughter caught up in the revolving door of the psychiatric system.

organisations" (Speed, 2002b:2). This form of involvement is obviously a significant step, as it may signify a shift Of power from mental health professionals and organisations to service users themselves. For example, for the purpose of reviewing its mental health services one health board commissioned the Irish Advocacy Network to undertake work, offering users of mental health services an opportunity to input into the review. In total 163 semi-structured in-depth interviews were held with users of mental health services in two counties. The outcome of the review was a report published in 2002. This exercise is certainly an innovative step in the Irish mental health context; nevertheless it should not be confused with research controlled by service users. In this model we have an organisation for service users, doing research of service users, conducted by service users (see Speed, 2002b). I found reading the report a somewhat disappointing experience, as the views of service users are hardly prominent in the discussion of the findings. In other words, there was very limited information on what was actually heard during the consultation process. Speed raises some concerns in relation to this type of participation in service user research, as empowerment can be reduced to simply "letting the service users construct a questionnaire, administer and analyse data" (2002a: 3), rather than effecting social change within the lives/situations of service users. As these projects have been recently completed their impact remains to be seen. However, despite the concerns raised in the previous discussion the contribution of such research is not to be undermined, as it can be a tool to empower service users[24] and challenge the monopoly of the medical profession in the management of their condition. The importance of service user involvement and peer-advocacy is now recognised by governmental policy. The 2001 health strategy recommends that "independent patient advocacy services will be encouraged and resourced" (Department of Health and Children, 2001a:72). Indeed, since September 2002 the Department of Health has been funding the posts of regional advocates in five health board areas, which is certainly a positive step.

Nevertheless, while this is a significant shift towards a more 'inclusive' form of mental health care, there is enough evidence to suggest that service users still

[24] For a full discussion on empowerment strategies in mental health see Barnes & Bowl (2001).

experience exclusion at different levels of service provision. The following discussion will consider how this exclusion manifests itself in the areas of information and consultation and the involvement of service users in their care plan. This by no means suggests that user rights are or can be reduced to 'access to information'. Ensuring such rights presupposes a complete transformation of power relations between the different stakeholders and can not be achieved through fragmented and often tokenistic, measures. In this discussion, 'access to information' is understood as an indispensable component of this transformation.

Involvement in Care Plan

I argued earlier that in a health system dominated by market principles, service users are primarily constructed as consumers. While being a consumer rather than a patient implies the right to choose, this right is rendered meaningless by the lack of information provided to mental health service users. Choice presupposes information on and control over the available options and this is certainly not the case in the Irish system.

The Annual Report of the Inspector of Mental Hospitals outlines a number of concerns regarding the Irish mental health system. The issue of information and consultation has been highlighted as particularly deficient for a number of consequent years; however its reoccurrence indicates that there has been no significant progress in this regard. For example, the report for the year 1998 expressed a concern about the adequacy and quality of medical note-taking in a number of mental health services. This related particularly to consultant inputs, and the Inspectorate felt that "in some services the practice of consultants in this regard falls short of what might reasonably be considered good professional practice" (Department of Health and Children, 1999:4). Such practice poses major challenges to basic human rights, in particular related to the deprivation of liberty, as the inspection found that often involuntary patients were re-certified without careful evaluation and that such re_ certification was not always recorded in the case notes. The report also stressed that in some cases notes had not been reviewed for over 10 years. Similarly, during the 1999 inspection some the patients were found to have "had no medical note entries for over four years and -the case notes of three recently

admitted patients had no consultant entry and one of these patients had been in hospital for over two months" (Department of Health and Children, 2000:139). This situation is in breach of the Guidelines for Good Practice and Quality Assurance in Mental Health Services recommending that "treatment plans should be discussed with patients... including any medication, clearly recorded in case notes" (Department of Health and Children, 1998:5) and the recommendations of the Inspector of Mental Hospitals that "nursing records should reflect the involvement of patients in planning and making decisions about their own care and treatment, and subsequent evaluation of care plans should include patients' views about progress" (Department of Health and Children, 2001b: 209).

The lack of communication about both diagnosis and treatment plan between service providers and service users has also been a significant finding of two studies on service users' experiences published in 2002. One of these studies is Pathways, a service user-led survey of people's experiences of west Galway mental health services in 2000. The Pathways report stressed that "71% [of the interviewees] believed their illness was not discussed adequately with them, and 51% said their family was not given an opportunity to discuss the users' illness. Also 67% reported that their treatment programme was not adequately discussed with them, and 67% said this was not discussed with their family. ...82% said they had no involvement or input into their treatment plan" (Brosnan et al., 2002:43). The second study, Focusing Minds, is a review of the Southern Health Board mental health services. This report revealed that one of the main frustrations of service users was not knowing what their illness was. 53% of those interviewed did not know what their diagnosis was and 67% said they got no adequate information about their medication (Southern Health Board, 2002).

These are just some illustrations of the continuous exclusion of people with mental health problems from any meaningful involvement in the management of their condition. The dominant market-led consumerist perspective does not necessarily entail a more democratic approach to service user participation (Croft & Beresford, 1991). On the contrary, it has been argued that "the construction of people with mental illness as consumers encourages the distinction between patients and providers and professionals" (Bolzan et al., 2001: 320). I believe that

such patterns of exclusion are as valid indicators of institutional thinking and practice as physical incarceration behind high walls.

CONCLUSION

People with mental health problems are a group whose rights are consistently violated in the Irish mental health system. Despite the rhetoric of community care, patterns of institutional thinking and practice still dominate mental health care. Throughout the above discussion, institutionalisation has been re-considered as a form of exclusion that moves beyond the physical incarceration of psychiatric patients behind high walls. Evidence of such exclusion was provided through an examination of the political factors shaping mental health services, the limited nature of service user involvement in mental health care and the narrow view of mental health problems taken by current policy and legislation. It was argued that it is particularly difficult to promote the rights of people with mental health problems in a political context where health increasingly loses its status as a right and becomes a commodity. The institutionalisation of the 'mad' has been a political act of the past. The current reproduction of institutional ideologies within community care is also a political act. Mental health reform in Ireland did not originate in a social demand for a more democratic psychiatry. The hospitals monopolised the debate on mental illness for many years and the medical model still monopolises both hospital and community-based care. Despite the significant development of the Irish service user movement, the dominance of this model has made it difficult for other groups to develop a politically powerful alternative to bio-medical ideology and practice. Within this context, community care developed in an instrumental manner as a collection of services rather than a form of practice providing a broader view of mental distress.

While this discussion has utilised material and evidence from the Irish system, it is important to stress that the questions raised are of universal relevance. The failure to provide inclusive forms of care for people with mental distress is not just an 'Irish problem'. The Irish case, however, can perfectly highlight how institutional thinking and practice can be reproduced through 'reform' policies. To conclude, I wish to evoke the very appropriate description by the Italian psychiatrist Franco

Basaglia (1986) of psychiatric institutions as places that simplify and regulate human pain. For a meaningful mental health reform to happen, it is imperative that such forms of institutional thinking and practising will not be reproduced through measures aiming simply to regulate mental distress in the community.

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Appendix One: Co-authors' declarations and letters of support

In the following statements, my co-authors identify the extent of my individual contribution to the material submitted for consideration, and the conditions and circumstances under which the collaborative work was undertaken.

22 July 2022

Re: Sapouna, L. & Pamer, E. (2014) The transformative potential of the arts in mental health recovery – an Irish research project, *Arts & Health: An International Journal for Research, Policy and Practice*, 8(1): 1-12.

Sapouna, L. & Pamer, R. (2012) Beyond Diagnosis; The transformative potential of the arts in mental health recovery. Arts + Minds/University College Cork, Cork. http://www.artsandhealth.ie/wp-content/uploads/2012/11/Beyond-Diagnosis_lowres.pdf

To whom it may concern:

The aforementioned peer-reviewed journal research paper and research report above were co-authored by Ms. Lydia Sapouna and myself, Elisabeth (Rudie) Pamer. Lydia and I have written and published an academic report on a mental health community project together (Arts and Minds, 2012). This report was my first academic publication I was part of. In this report Lydia was the principal investigator and contributed 80% of the research design, methodology, data analysis and report writing. Lydia invited me to work with her again, and we produced the above paper for publication. Lydia's input consisted of 80 % and I contributed 20 %. Lydia took full responsibility for the content, structure, and research method analysis. She also took on the role of main editor and was the main author for publication, making sure that all the required details were correct. Lydia's commitment to academic writing was crucial in getting this paper published. In addition, Lydia's extensive knowledge has given me immeasurable skills for hopefully my own future publication as main author.

Yours Sincerely,



Elisabeth Pamer

14, Skiddy's Almshouse
Bob and Joan Walk
Shandon
Cork City

115 Atkins Hall

Lee Road

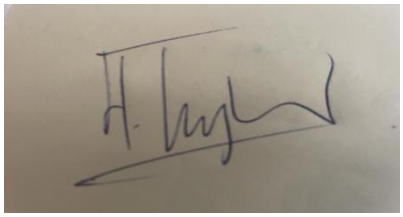
Cork

8 May 2022

To Whom it May Concern

Re: Sapouna, L. & Gijbels, H. (2016) Social movements in mental health: the case of the Critical Voices Network Ireland, Critical and Radical Social Work, 4 (3): 397-402.

This paper was the outcome of a longstanding collaboration in the area of mental health activism between Lydia Sapouna and me. We each contributed to the original idea for the paper and agreed a timescale for the paper and the respective contributions. We met on several occasion to discuss progress. We worked independently on our various sections, and Lydia monitored the overall content and structure of the paper. Lydia took the lead in constructing the final draft, creatively amalgamating our distinctive but complementary contributions. Lydia also took the lead in the final edits of the paper and also communicating with the journal editor. Her contribution to the paper was about 70% and mine about 30%. Lydia's original scholarship considerably added to the overall strength and depth of the paper.



Harry Gijbels

57 Coillte Mhuirlinne,

Ballybane

Galway

7/07/2022

To Whom It May Concern:

Re: Brosnan, L. & Sapouna, L. (2015) 'Opportunities for social workers' critical engagement in mental health care' in A. Christie, B. Featherstone, S. Quin, and T. Walsh (eds) *Social Work in Ireland. Changes and Continuities*, Basingstoke, Palgrave Macmillan:159-177.

I wish to affirm that Lydia Sapouna was invited to contribute a chapter to this textbook and she asked me to collaborate with her on the writing of it.

As lead author Lydia took the lead on formulating and drafting the chapter structure, compiling social theory analysis. She also took the lead on liaising with the book editors, responding to the peer review suggestions and saw it to publication.

Due to other time commitments that limited my availabity she took on most of the work shortly after we commenced but also kept me fully informed and briefed about the process.

I can confirm she contributed 70% of the work on the chapter.

Yours truly,



Dr Liz Brosnan

25/59 Admiralty Street
Edinburgh
EH6 6JR
Scotland

6 July 2022

To whom it may concern

Re: O' Donnell, A., Sapouna, L. and Brosnan, L. (2019) Storytelling: An act of resistance or a commodity? *Journal of Ethics in Mental Health,* Special Theme Issue VI: Disordering Social Inclusion: Ethics, Critiques, Collaborations, Futurities.

Lydia Sapouna is joint lead author of the above paper, contributing 40% of the work with Anne O'Donnell. Liz Brosnan contributed 20%.

Lydia and Anne had worked together on a previous paper (Sapouna and O'Donnell, 2017) and had to omit some material on story telling. We responded to the call for papers for the Journal of Ethics in Mental Health. Lydia already had some conversations with Liz on the same topic so we invited her to contribute. Together, Lydia and Anne reviewed the material we already had and shared it with Liz. We drafted the paper through dialogue and shared and developed subsequent drafts. Because of Liz's other commitments, Lydia and Anne took on most of the final writing and editing of the paper. Lydia and Anne worked with the editors and responded to the reviewers' comments.



Liz Brosnan



Anne O'Donnell

25/59 Admiralty Street
Edinburgh
EH6 6JR
Scotland

6 July 2022

To whom it may concern

Re: Sapouna, L. & O'Donnell, A. (2017) Reflections dialogue: 'Madness' and Activism in Ireland and Scotland, *Community Development Journal,* 52(3): 524-34.

I am writing to confirm Lydia Sapouna's contribution to the above article as 60% of the overall work. We were both invited by the editors of the Community Development Journal to write a reflection on our experiences as a lecturer in Ireland (Lydia) and as an activist in Scotland (myself) for a special issue on mental health.

Lydia and I met to talk in person about our different experiences. I typed up the transcript. Lydia and I together discussed by skype and email what would be the key focus of the article with Lydia taking a lead on the structure and analysis. She also was the main person who linked our reflection with the literature. I proofed the article at various stages. At the time I had very little publishing experience so Lydia took on dealing with the journal, responding to reviewers, so that it was ready for publication. She is also the corresponding author.



Anne O'Donnell

Appendix two: Publishers' permissions

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Sent: Thursday 1 September 2022 10:27
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From: Sapouna, Lydia <L.Sapouna@ucc.ie>
Date: Thursday, 14 July 2022 at 13:13
To: Catherine Jackson <catherine@pccs-books.co.uk>
Subject: Permission to re-publish book chapter

Dear Catherine and PCCS team

I hope this finds you well.

I am writing looking for your assistance with getting permission to include the book chapter below in my PhD by prior publication which is going to be available in the University College Cork library and online at https://cora.ucc.ie/handle/10468/1
The version included will be the final pre-publication submission.

Sapouna L. (2019) 'Social work education as a critical space' in H. Gijbels, L. Sapouna, & G. Sidley (eds.), *Inside out, outside in: Transforming mental health practices*, Ross-on-Wye: PCCS Books: 17-39.

Please let me know if you need any further information

Warm wishes

Lydia

From: Sam Taylor <sam@pccs-books.co.uk>
Sent: Thursday 14 July 2022 16:32
To: Sapouna, Lydia <L.Sapouna@ucc.ie>
Cc: Catherine Jackson <catherine@pccs-books.co.uk>
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Sam

Sam Taylor

Business Director – PCCS Books

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From: Dr. John Maher <jmaher@cmhastarttalking.ca>
Sent: Sunday 31 July 2022 18:51
To: Sapouna, Lydia <L.Sapouna@ucc.ie>
Cc: Liz Brosnan <miseliz@gmail.com>; Anne O'Donnell <odonnell.ae@gmail.com>
Subject: RE: permission to include article in PhD by prior publication

Dear Ms Sapouna,

You have the permission of the Journal of Ethics in Mental Health.

Best wishes.

John Maher MD FRCPC

Editor-in-Chief, JEMH

From: Sapouna, Lydia <L.Sapouna@ucc.ie>
Sent: July 14, 2022 12:01 PM
To: Dr. John Maher <jmaher@cmhastarttalking.ca>
Cc: Liz Brosnan <miseliz@gmail.com>; Anne O'Donnell <odonnell.ae@gmail.com>
Subject: permission to include article in PhD by prior publication
Importance: High

Dear Editor-in-Chief

Re: O' Donnell, A., Sapouna, L. and Brosnan, L. (2019) Storytelling: An act of resistance or a commodity? *Journal of Ethics in Mental Health,* Special Theme Issue VI: Disordering Social Inclusion: Ethics, Critiques, Collaborations, Futurities.
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I am writing to seek permission to include the final pre-publication version of the above article as part of my PhD thesis by prior publication. My thesis is entitled "Problematising inclusion mental health", the final version of which will be submitted to University College Cork (UCC). My thesis will be made available as an electronic version deposited in UCC's online repository, CORA Open Access Archive https://cora.ucc.ie/handle/10468/1. Please see the UCC thesis libguide: https://libguides.ucc.ie/theses/etheses for more information I include Anne O'Donnell and Liz Brosnan, my co-authors in this paper, who have kindly agreed to support my application to this PhD.

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Lecturer and BSW Course Director

School of Applied Social Studies

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Sapouna, L. (2016) Education for critical practice in mental health: opportunities and challenges, *Critical and Radical Social Work,* 4 (1): 59–76.

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Lydia Sapouna

Lecturer and BSW Course Director

School of Applied Social Studies

University College Cork

Ireland

Re: Brosnan, L. & Sapouna, L. (2015) 'Opportunities for social workers' critical engagement in mental health care' in A. Christie, B. Featherstone, S. Quin, and T. Walsh (eds) *Social Work in Ireland. Changes and Continuities*, Basingstoke, Palgrave Macmillan:159-177.

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