

# **Equal and Inclusive User Involvement**

**in the**

## **Mental Health Services in Ireland:**

### **Results from Participatory Action Research**

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**in collaboration with**

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Committees' research group**

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## **Table of Contents**

|   |    |
|---|----|
| Executive Summary .....   | 4  |
| 1. Introduction .....   | 9  |
| 2. The Irish Context for User Involvement.....                                    | 11 |
| 3. Equal and Inclusive User Involvement: An Equality of Condition Framework ..... | 14 |
| 4. Methodology .....  | 19 |
| 5. Barriers to Equal and Inclusive Involvement .....                              | 21 |
| 6. The Experience of Empowering Involvement.....                                  | 41 |
| 7. Defining an Ethical Framework for User Involvement: Service Users'             |    |
| Recommendations for Supports and Structures to Assist Equal Involvement .....     | 51 |
| 8. Conclusion .....   | 58 |
| References.....   | 59 |

## **Executive Summary**

User involvement is not always a means of empowerment. It is also a process which can disempower mental health service users (Croft & Beresford 1995). If, as is recommended in Ireland's new policy document *A Vision for Change* (Department of Health and Children 2006), user involvement is to be extended to all levels of the mental health services, and if it is to go beyond the exceptional few, it is necessary to put in place a framework for equal and inclusive involvement.

Service users want to participate in decision-making on how the mental health services are run and they feel capable of participating:

*"I think that they should wake up and see that there are service users all over this country who are quite capable of sitting on committees, quite capable of effecting change, and this fear that health care professionals have I think needs to be really seriously challenged."*

(male leader aged 40)<sup>1</sup>

However, they face a range of disadvantages relative to the professionals on planning committees, including unequal access to economic, social, cultural, and physical and mental resources, lack of authority over decision-making, deficits of knowledge and skills, lack of respect and recognition both in Irish society and within the mental health services, and the need for emotional support.

### **The Irish Context for User Involvement**

Mental health service user involvement is a relatively new phenomenon in the Republic of Ireland compared to its close neighbours, Northern Ireland, England, Scotland and Wales. *A Vision for Change* recommends user (and carer) involvement at every level of the mental health services (Department of Health and Children 2006, p.24) and initiatives to develop user-run services, education programmes to enable service users to represent themselves and others, and establishment of a National Service User Executive (Ibid., p.26-27). Implementation of user involvement needs to take account of the history of psychiatric power in Irish society. A recent discussion paper by the Mental Health Commission confirms that a hierarchical organisation of the mental health services continues today (MHC 2005). *A Vision for Change* continues to assign both clinical responsibility and 'vision' to psychiatrists. Within this context, there is a danger of tokenism for user involvement in Ireland.

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<sup>1</sup> Throughout the document, "leader" refers to a service user leader in Ireland, "participant" refers to a participant in the participatory action research group, "pilot interviewee" means a service user who took part in a pilot interview but did not participate in the research group. Respondent text appears in italics; researcher text appears in normal font.

### **Equal and Inclusive User Involvement: An Equality of Condition Framework**

Issues of empowerment are at the heart of equal involvement for people with experience of the mental health services. Service user definitions of empowerment show that for them, empowerment is indivisibly linked to increased authority over decision-making. An 'Equality of Condition' framework can help to explain power inequality through a set of related dimensions of inequality: cultural resources, economic and time resources, physical and mental resources, respect and recognition, and love, care and solidarity. 'Equality of Condition' refers to "enabling and empowering people to exercise what might be called real choices among real options," and "roughly equal enabling of each person to influence the decisions that affect their lives" (Baker, et al. 2004, p.34). Research shows that people with a diagnosis of mental illness experience inequality along all six dimensions.

### **Methodology**

This research has been conducted using participatory action research methodology. As a qualitative methodology similar to ethnography, it does not claim to represent the views of all service users. However, it does authentically evidence a range of experiences of user involvement. It also covers views from different regions, different ages and both men and women, as well as the views of people with different levels of education. A total of 16 service users were interviewed, of whom 13 participated in a pilot training programme. The majority of participants had a diagnosis of schizophrenia or a related psychotic disorder, and all of the participants had long-term engagement with the mental health services. In addition, these interviews were triangulated with five interviews with service user leaders in Ireland. The research was carried out in five phases: pilot interviews, introductory workshop, pilot training programme (the action element), analysis, and triangulation.

### **Barriers to Equal and Inclusive Involvement**

#### **Inequality due to lack of cultural, physical, mental, time and economic resources**

Participants identified a range of cultural barriers to involvement. These included:

- difficulties with context-specific language and terminology
- lack of knowledge of the subject matter or policy history
- lack of valuing of service users' experiential knowledge
- not knowing committee rules and procedures
- not knowing the hidden 'rules of the game'

Participants described how the physical and mental impact of their condition could hinder their involvement:

- difficulties with concentration
- lack of motivation
- lack of energy and stamina

A large number of participants referred to anxiety or stress as part of the involvement experience. Service users described situations of isolation while on committees. Participants also identified their inequality in terms of time resources and economic resources.

### **Inequality due to Prejudice/Stigma**

Seven participants, four leaders and one pilot interviewee raised stigma as an issue during their interview. The negative public attitudes experienced by participants led a number of them to be cautious about participating in public advocacy.

The difficulty about speaking in public puts people with a diagnosis of mental illness at a profound disadvantage in effecting their desired social change. Mental health organisations have a duty to ensure that they do not contribute to the ghettoisation of service users within mental health services. This requires supporting service users to achieve their wider social justice goals, including prioritising combating social stigma and changing public attitudes. It also means ensuring that people with mental health difficulties are treated with respect within the mental health services.

### **Unequal Power in Committees**

Participants had experienced difficulties with getting their issues of concern onto the agenda, with medical professionals' interests dominating the discussion, and with simply being outnumbered on committees.

*“The first problem is the numbers game, you know, I have plenty of confidence and plenty of knowledge around service user issues, but I find myself on advisory groups where we have, for example, four consultant psychiatrists, one service user, one person from the HSE, one person from the Department maybe. There’s a clear imbalance in favour of the psychiatric profession at the moment with mental health issues... The impact is that, for people who need to learn a bit more about themselves even, and perhaps how to participate, it’s very difficult for them unless they already have the kind of confidence that really they need to build.”*

(Male leader, aged 52)

### **The Experience of Empowering Involvement**

Many participants described positive experiences from being involved in collective advocacy. Service users described:

- affirmation of their own competencies
- feeling respected as an equal

- helping others
- having an impact

Having prior education, having previous experience as a professional, and being a determined person were identified as factors influencing their ability to be involved.

Those with experience of involvement emphasised the value of support for initially encouraging and sustaining their involvement. This included family support, peer support and the support of medical and other professional allies.

### **Defining an Ethical Framework for User Involvement: Service users' recommendations for supports and enabling structures**

Service users recommended the following structures and supports to assist their involvement:

- Training in how committees operate, how to read and analyse policy documents, how to gather evidence, how to negotiate, how to use the internet to search for information, how to write effectively and how to avoid burn-out
- Clarifying technical language during the meeting and providing a glossary of terms
- Providing accessible, summarised information
- Providing enough background information to be able to participate
- Providing clear terms of reference for the committee
- Designating time during the meetings for service user input
- Flexibility, including breaks during meetings, alternate/substitute committee representatives and the ability to 'take a break' from the committee
- Respecting and listening to service users' views
- Negotiating fair payment for participation
- Valuing participants' time
- Putting service users in a position of authority on the committee
- Providing an opportunity to frame the agenda
- Ensuring proportional membership of the committee between service users and professionals
- Providing mentors and access to peer group support
- Supporting families to encourage user involvement
- Supporting capacity building of peer support
- Encouraging and recognising ally support
- Addressing prejudice and stigma

In addition, service users going forward to participate have a right to be protected from physical and mental harm as a result of their involvement. Professionals conducting research have long recognised the need to operate within agreed

ethical standards in order to ensure that their research does not cause harm to research participants. Yet the issue of ethics is rarely raised with regard to organisations inviting service users to participate in decision-making. Service users in this research clearly articulated experiences of stress while participating on committees. This demonstrates the need to develop an ethical framework for user involvement which would set out minimum standards to prevent harm.

*“When they invite service users to the table, they need to give them support and training. But I think there are many service users sitting around the table without being given support and training.”*

(Female pilot interviewee, aged 60)

## **Conclusion**

The appointment of a service user onto the Area Management Team of every local area, the establishment of a national Service User Executive and the presence of service users on the Mental Health Commission are profound steps toward greater equality in the mental health services. But service users' experiences tell us that a simple equality of presence (the right to be present in decision-making forums) will not ensure equal participation. This research revealed practices of tokenism, disrespect, lack of influence, constraint on speaking in public, ineffectualness, isolation and stress experienced by users in the process of involvement. In order for mental health services to effectively and more equally involve service users in planning and managing the mental health services, a radical shift in approach is needed. Service users require supports, accommodations and re-balanced structures to enable their full involvement. Establishing an 'ethical framework for user involvement' is more likely to promote not only the presence of service users in planning and management structures, but their empowerment within the mental health services and in Irish society.



## **1. Introduction**

User involvement is not always a means of empowerment. It is also a process which can disempower mental health service users (Croft & Beresford 1995). If, as is recommended in Ireland's new policy document *A Vision for Change* (Department of Health and Children 2006), user involvement is to be extended to all levels of the mental health services, and if it is to go beyond the exceptional few, it is necessary to put in place a framework for equal and inclusive involvement.

For people with experience of mental distress<sup>2</sup> who enter into the planning or advisory committee situation, the experience can be daunting and intimidating. Service users faced with a group of professionals can find themselves ignored, sidelined or belittled. They may be made to feel that they are ignorant in comparison with well-educated professionals or that their knowledge which is based on experience is less valid than professional knowledge. They may feel lost in a situation where they do not understand the language, the subject matter or the history. They may find themselves ineffectual in a process in which the rules and procedures or the organisation's decision-making structure are not explained. They may feel frustrated at not being able to put their issues onto the agenda or not being able to get service user issues taken seriously. These experiences can combine to disempower service users on committees.

Service users want to participate in decision-making on how the mental health services are run and they feel capable of participating:

*"I think that they should wake up and see that there are service users all over this country who are quite capable of sitting on committees, quite capable of effecting change, and this fear that health care professionals have I think needs to be really seriously challenged."*

(Male leader, aged 40)<sup>3</sup>

*"Well, I just think that maybe if more people were offered an opening, if more people had a voice, we might be heard."*

(Female participant, aged 52)

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<sup>2</sup> This paper will use the terms service user, person with experience of mental health services, person with experience of mental distress and person with a diagnosis of mental illness interchangeably. The designation of this social group is contested, with different opinions on the appropriate terminology expressed within the research group. The author has felt that a mixture of terminologies would best reflect this diversity. The term service user appears more often only for the sake of brevity. Service user in this context does not refer to relatives as carers.

<sup>3</sup> Throughout the document, "leader" refers to a service user leader in Ireland, "participant" refers to a participant in the participatory action research group, "pilot interviewee" means a service user who took part in a pilot interview but did not participate in the research group. Respondent text appears in italics; researcher text appears in normal font.

However, they face a range of disadvantages relative to the professionals on planning committees, including unequal access to economic, social, cultural, and physical and mental resources, lack of authority over decision-making, deficits of knowledge and skills, lack of respect and recognition both in Irish society and within the mental health services, and the need for emotional support.

This paper reports results from a Participatory Action Research (PAR) project with long-term mental health service users in Ireland to explore their views on user involvement in planning and/or advisory committees. The research is unique in Ireland in examining user involvement in committees from their own perspective. The results show that while involvement can be an empowering experience, there are also systemic risks of disempowerment of service users in involvement. In order to enable more equal involvement, a framework of structures, accommodations and supports needs to be developed to address their unequal position. In addition, organisations inviting users onto committees have a responsibility to protect service users from harm during the involvement process. I suggest below that there is a need for an 'ethics of participation' which, similar to ethical standards in research, would define an organisation's responsibilities towards the service users it invites into ongoing involvement.

## **2. The Irish Context for User Involvement**

### **2.1 Introduction**

Mental health service user involvement is a relatively new phenomenon in the Republic of Ireland compared to its close neighbours, Northern Ireland, England, Scotland and Wales. While user involvement in England took off in the 1980's, Ireland's first user-run advocacy groups were not established until the late 1990's, most significantly when the Irish Advocacy Network received funding from the health service to provide peer advocacy services in a number of regions. Scattered attempts at involving people with experience in planning occurred during this time with research projects, including two notable Participatory Action Research projects on the views of service users about services (Western Health Board 2002, 2003). The Mental Health Expert Group engaged in user-led research to obtain user views on services (DOHC 2005). Some mental health service users were invited to form advisory committees to local services, participate on regional planning committees, and participate on national advisory committees to government agencies. Two people with experience of the mental health services were appointed to the Mental Health Commission in 2002, and service users were invited onto the mental health advisory committee of the National Disability Authority. So too, when the Government announced a review of mental health policy in 2003, a person with experience of mental distress was appointed to its national steering group. Nevertheless, these attempts at user involvement are very recent and have, until now, lacked any coherent policy, guidelines or standards.

The discursive shift towards greater user involvement in planning is evidenced by two major health service policy documents. In 2001, Government published a new strategy for the health service. *Quality and Fairness: A Health System for You* emphasised person-centred care and accountability. It envisaged community involvement in planning through consumer panels and regional forums. Secondly, the recently-published new government policy on mental health: *A Vision for Change* recommends user (and carer) involvement at every level of the mental health services (Department of Health and Children 2006, p.24) and initiatives to develop user-run services, education programmes to enable service users to represent themselves and others, and establishment of a National Service User Executive (Ibid., p.26-27). *A Vision for Change* is underpinned by the 'recovery' approach to mental health which prioritises people's participation in their own treatment.

Thus several strands of social change have come together to promote greater user involvement in mental health services. A general shift towards more consumer accountability and greater consumer involvement in health care in line with health service developments in other industrialised countries, the demands of service users themselves to have a voice in planning, progressive professionals within the services who piloted user involvement, the influence of 'recovery' and advocacy approaches from other jurisdictions, as well as criticism

of the existing mental health services by NGO's and the Inspector of Mental Hospitals all combined to encourage user involvement.

## **2.2 Power in the Irish Mental Health Services**

Implementation of user involvement needs to take account of the history of psychiatric power in Irish society. In 1961 Ireland reached the unenviable state of having detained a higher proportion of its population for psychiatric illness than anywhere else in the world (Walsh 1968). Finnane's history of the asylum system shows that from early on, medical practitioners worked to establish their authority within the asylum system (1981, p.40), and by 1862, their authority was underpinned by regulations in the 1862 Privy Council rules (Ibid., p.47). So too, the power of psychiatrists became further enshrined in Irish law in the Mental Treatment Act 1945, which gave authority to psychiatrists over involuntary detention to such an extent that they could only be taken to court under civil proceedings if permission was granted by the High Court.

This power given over to psychiatrists in the 1860's was again underscored in the Government's modern mental health policy *Planning for the Future* published in 1984. The document recommended a hospital-based management team system consisting of the Chief Psychiatrist, Senior Administrator and Chief Nursing Officer (Department of Health 1984, p.124). At catchment area, *Planning for the Future* made clear that the psychiatric profession continued to hold ultimate authority:

“The catchment area management committee should be chaired by a Clinical Director/Resident Medical Superintendent/Chief Psychiatrist who will have overall responsibility for the service in the catchment area.”

This policy served to undermine perspectives from other disciplines such as social work, occupational therapy and psychology throughout the late 20<sup>th</sup> century. For example, by putting the responsibility for managing community services in the hands of the psychiatric profession, the policy underpinned a continued emphasis on hospitalisation and medical treatment at the expense of community rehabilitation and alternative therapies. Without authority over the primary locus of care, the acute hospital, other disciplines such as psychology, occupational therapy and social work had little opportunity to influence clinical policy or practice. The relative lack of power of psychiatric nurses is supported by the results of the *Nurses' & Midwives' Understanding and Experiences of Empowerment* research, which showed that nurses and midwives in Ireland experienced 'some' but not 'a lot' of formal empowerment in their jobs (Scott, et al. 2003, p.39)

A recent discussion paper by the Mental Health Commission confirms that this hierarchical organisation of the mental health services continues today (MHC 2005). *A Vision for Change* continues to assign both clinical responsibility and 'vision' to psychiatrists. It thus continues to support psychiatric control of local mental health services. However, at national level, psychiatric professionals are in the minority on the new Mental Health Service Directorate, and the new Care

Group Manager for Mental Health is not required to be a psychiatrist. This opens up the possibility for non-psychiatric leadership at the highest level. The potential for interrupting current power relations is aided by the presence of a service user on both the Area Management Team and the National Mental Health Service Directorate. However, it is not self-evident that a single service user on a committee can have any significant influence over decision-making. The danger of 'tokenism' is demonstrated by early reports on user involvement in the UK (Croft & Beresford 1995, p.64), and by what is documented below in the experiences of service users in Ireland.

### **3. Equal and Inclusive User Involvement: An Equality of Condition Framework**

#### **3.1 The Significance of Empowerment for User Involvement**

Issues of empowerment are at the heart of equal involvement for people with experience of the mental health services (see Bowl & Ross 1994, Croft & Beresford 1995, Hickey & Kipping 1998, Linhorst & Eckert 2003, the Scottish Development Centre for Mental Health 2003, Wallcraft, et al. 2003, Chamberlin 2005 and Hodge 2005). While *A Vision for Change* uses the term empowerment only twice in its 284 pages, the link between user involvement and empowerment is made clear in the introduction to its chapter on partnership in care, when it states that involving service users and carers as active partners in the planning and delivery of mental health services is a “necessary step towards more equal and fair communication between all mental health participants.” (DOHC 2006, p.24). User involvement often refers to empowerment in terms of individual consumer’s power and promoting greater responsiveness of services to individual user needs, such as in sections of the policy document *Quality and Fairness: A Health System for You*. However the discourse in *A Vision for Change* rests on a more democratically-framed conception of involvement. It emphasises that involvement should go beyond consultation and should consist of participation in decision-making at every level of the mental health services (Op Cit., p.25).

Service user definitions of empowerment show that for them, empowerment is indivisibly linked to increased authority over decision-making. Chamberlin’s definition derived from service user research includes elements of power such as having choices and having decision-making power (Chamberlin, et al. 1997). Beresford and Croft’s definition specifies empowerment as, “[m]aking it possible for people to exercise power and have more control over their lives..It also means being able to share power or exercise power over someone else, as well as them exercising it over you.” (Beresford & Croft 1993). This definition is also supported by Peter Campbell (Campbell 1994). Some criticism has been levelled at empowerment theory for over-emphasising individualistic qualities of empowerment such as increased self-confidence and competency development at the expense of structural factors for empowerment (Fondacaro & Weinberg 2002).

#### **3.2 Analysing User Involvement using an Equality of Condition Framework**

An ‘Equality of Condition’ framework can help to explain power inequality through a set of related dimensions of inequality. In their work on egalitarian theory, Baker, et al. (2004) have posited five dimensions of inequality: power, resources, respect & recognition, working & learning, and love, care and solidarity. ‘Equality of Condition’ refers to “enabling and empowering people to exercise what might

be called real choices among real options,” and “roughly equal enabling of each person to influence the decisions that affect their lives.” (p.34).

Much of the research on user involvement has indicated a range of service user needs to enable effective participation. However, typically these are listed without any related analysis of the inequalities people with a diagnosis of mental illness face relative to mental health professionals. The danger is that such lists of needs will be seen as arbitrary and unrelated, and therefore will be addressed in an ad hoc way. By analysing the evidence within an ‘equality of condition’ framework, I hope to demonstrate that disadvantages must be addressed in a co-ordinated way across all categories of inequality in order to enable empowerment and establish more equal relationships in planning committees.

### **3.3 Inequality of Respect and Recognition**

For people with a diagnosis of mental illness, their inequality of power is primarily determined by the pervasive prejudice, fear and ‘stigma’ against mental illness which persists in Western societies. This predominant lack of respect and recognition can lead to a lack of confidence in social situations, lack of willingness to identify as a service user (desire to distance oneself from the mental health services), and lack of willingness to speak out publicly. For mental health service users, past or present, the cultural values attached to their experience are a constant accompaniment to their experiences of social participation. In any mixed social situation where they identify themselves as a mental health service user, their participation cannot be innocent of the general perception that they are ‘other’. The literature on user involvement attests to the negative impact this lack of respect has on participation. Peck and Barker (1997) noted how service users’ views are not valued. Barnes & Wistow (1994) found that the validity of service users’ statements was undermined with claims of their ‘lack of insight’, while as recently as 2003, Summers found that amongst sceptical psychiatrists, users’ views were considered unnecessary and irrelevant to the process of service development. On a broader view, Barnes & Shardlow (1997) discussed how stigma negatively impacts on social inclusion and active citizenship.

### **3.4 Inequality of Economic Resources**

Inequality in terms of resources includes economic inequality, e.g. differences in income and earnings power. Disadvantage in terms of economic resources is well-evidenced. In the UK, unemployment for people with long term mental health problems has been estimated at 79% (Disability Rights Commission (2003)). In Ireland, a recent Quarterly National Household Survey showed 86% of people with “mental, nervous or emotional” health difficulties were either unemployed or economically inactive (CSO 2004). With such a high rate of unemployment, it is self-evident that people diagnosed with a mental illness are

at high risk of poverty. Economic disadvantage also impacts on service user involvement. The literature shows that users require economic resources in order to be able to participate (Linhorst & Eckert 2003, Scottish Development Centre 2003, Wallcraft, et al. 2003, Stevenson, et al. 2005).

### **3.5 Inequality of Cultural Resources**

In addition to economic resources, participants on committees require a range of cultural resources in order to participate. The cultural resources which professionals are able to draw upon begin with their cultural competency gained from third-level education. Professionals also enter the committee meeting situation well-versed in an institutional managerial language, including abbreviations and terms representing elements in the mental health system. They arrive with an understanding of the hierarchy of decision-making authority within the system. And in general they have a knowledge of the policy history, i.e. the context of historical documents and existing policies which frame the context of current policymaking. In general, professionals have an understanding of the explicit and hidden 'rules of the game' of committees. They know how to get issues onto the agenda, the status positions of the members of the committee and their social relationships outside the committee situation. All of this creates a 'cultural competency' advantage for professionals relative to service users on committees.

Service users' cultural disadvantage is a common theme in the literature on user involvement. The literature has highlighted the need for accessible information and language (Beresford & Croft 1993, Linhorst & Eckert 2003, Scottish Development Centre for Mental Health 2003, Stevenson, et al. 2005, Wallcraft, et al. 2005, Chamberlin 2005). Church (1996) showed how service users' attempts to re-define the rules of committees were deemed 'bad manners'. Recently, Marian Barnes has argued that the 'rules of engagement' for citizenship participation in professional/bureaucratic governance are fundamentally biased against people with mental health difficulties because they are based on narrow assumptions of competence (Barnes 2002).

### **3.6 Inequality of Physical and Mental Resources**

In addition to economic and cultural resources, people being treated for mental distress also often have less physical and mental resources with which to engage in the committee situation. Barnes & Wistow (1994) emphasised how the symptoms and side effects of mental distress can make it difficult to speak. Participants in this research project raised issues of poor physical health in terms of energy and stamina. They particularly raised difficulties with poor concentration making it difficult to maintain participation in long meetings or read long policy documents. People with experience of mental distress also have a particular need to minimise stress. Stress is known to be associated with hearing voices (Boyle 2006) and a number of studies show that stress reduction is associated with improved recovery and prevention of relapse (Mueser, et al.



2002). This does not mean that people with experience of mental distress are any less able to engage in collective advocacy, but it does mean that like other people with disabilities, they require some accommodations such as breaks during meetings in order to fully participate.

### **3.7 Inequality of Love, Care and Solidarity**

Finally, one of the consequences of a diagnosis of mental illness is a reduction in existing social networks and an increase in social isolation (Wright, et al. 2000, Goldberg, et al. 2003). Professionals arrive at the committee situation with a range of social supports, including, commonly, intimate relationships, collegial relationships and membership in professional organisations. This network of supports provides professionals with a base from which to organise their collective advocacy and a set of emotional supports for their participation. In contrast, people with a diagnosis of mental illness experience social rejection (Wright, et al. 2000). They experience stigma during interpersonal interaction (Angermeyer 2004). They may also lack access to relationships of warmth and intimacy (Cook 2000). They are likely to have lost their non-mental health-related social network upon receiving a diagnosis. Thus mental health service users are commonly at a disadvantage in terms of the social resources which many professionals may have. While mental health service users may be poorer in confidence and social supports, and are socially excluded, they also have less access to the emotional support which would make such a situation bearable.

### **3.8 Inequality in Working & Learning**

Finally, people with a diagnosis of mental illness typically have less opportunity to develop committee-relevant skills. Symptoms of mental distress normally occur during prime education years from the late teens to early twenties. People with mental disability are less likely to have completed third-level education. The consequences of this are that in general they have lower levels of analytical skills, computer skills, writing skills and presentation skills than professionals.

The constellation of inequalities faced by people with a diagnosis of mental illness are illustrated in the diagram below:

| <b>Dimension of Inequality</b>          | <b>Experienced by Mental Health Service Users</b>  |
|---|--|
| Resources – Economic                    | Lack of Economic Resources   |
| Resources – Cultural capital            | Lack of context-specific knowledges<br>Less formal education                                 |
| Resources – Embodied capacity           | Less physical and mental stamina   |
| Respect/Recognition                     | Stigma and prejudice against people with a history of mental illness<br>Less self-confidence |
| Love, Care and Solidarity               | Social isolation leads to less emotional support   |
| Working & learning (self-actualisation) | Lack of opportunities to develop skills  |

These inequalities combine to militate against equal participation with professionals in the committee situation. It is this full range of inequalities which must be addressed if service users are to be empowered to participate equally with professionals in mental health service committees.

## **4. Methodology**

### **4.1 Overview**

The research was conducted using participatory action research methodology. As a qualitative methodology similar to ethnography, it does not claim to represent the views of all service users. However, it does authentically evidence a range of experiences of user involvement. It also covers views from different regions, different ages and both men and women, as well as the views of people with different levels of education. The research was carried out in five phases: pilot interviews, introductory workshop, pilot training programme (the action element), analysis, and triangulation.

Pilot interviews with five service users were carried out in order to develop the research question. Two of these service users were known to the lead researcher through her work at Schizophrenia Ireland and three others were contacted via snowballing. All of the pilot interviewees had experience of being on a mental health service advisory committee. Several of the interviewees expressed the need for training and support for people who were sitting on advisory committees. It was decided to conduct an introductory training workshop. The workshop was organised by a committee consisting of two service users, the lead researcher and one Regional Development Officer at Schizophrenia Ireland.

The pool of participants for the introductory workshop was developed largely through word-of-mouth within Schizophrenia Ireland, by contacting the Regional Development Officers across the country and asking them to suggest participants. In total, 14 participants from across Ireland participated in the introductory workshop. The workshop was facilitated by a service user who is also a trained facilitator. The workshop consisted of a presentation by a U.K. expert, training and discussion on user involvement and presentations on current Irish legislation. In the workshop evaluation, participants identified the need for further skills training.

The development of a pilot training programme was then pursued through Schizophrenia Ireland's service user Consultative Group. Members of the Consultative Group and interested participants from the introductory workshop became the core pool of participants for the research. In advance of the training, one-to-one semi-structured interviews were carried out by the researcher with training participants. The focus of the interviews was to identify the barriers to user involvement in Ireland. The interviews were analysed with a 'grounded theory' approach using MaxQDA analysis software. A draft interview analysis was presented to the participant group for validation and their comments incorporated into the final analysis. The data from the interviews, introductory workshop discussion and training programme sessions has been triangulated with 5 interviews with leaders in the service user movement in Ireland. Each of the leaders was also given the draft analysis for comment.

## **4.2 Profile of the Participants**

A total of 16 service users and 5 leaders were interviewed, of whom 13 participated in the training programme. The majority of participants had a diagnosis of schizophrenia or a related psychotic disorder, and all of the participants had long-term engagement with the mental health services. While the total number of participants and leaders was small, they covered a wide range of experiences. Participants ranged in age from 19 to 60 years old, while leaders were aged 40 to 59. 10 men and 6 women were involved in the participant group, while 3 men and 2 women were in the leader group. Most of the participants were from the Dublin area, however there were also participants from Galway, Kilkenny and Limerick. Both the participant group and the leader group had relatively high levels of education. In the training participant group four people had Bachelors' level education, while amongst the leader group, four out of five had Bachelors' level education. The participant group consisted of people who are engaged with the support services of Schizophrenia Ireland, a national voluntary organisation for carers and people with schizophrenia and related illnesses.

## **4.3 Reflexive Note**

The research process was profoundly impacted by my pre-existing long-term relationship with a number of the participants. Three of the participants had been employees of Schizophrenia Ireland and worked under my supervision while I was employed as Administration Manager. Other participants knew me casually from my having been an employee at SI while they were active members. With other participants, our relationship developed out of the process of planning the initial workshop, and deepened through the course of the pilot training programme. I left the employment of Schizophrenia Ireland early on in the research and this certainly changed my relationship with the single participant who had, at that time, still been under my supervision. I believe that these good relationships allowed participants to share their views more freely than they might have otherwise.

The research was also influenced by my own experience of mental health difficulties. While never having been hospitalised for mental distress, I have been treated both psychologically and pharmacologically for an anxiety disorder and this allowed me some empathy with the bodily experience of mental distress.

Schizophrenia Ireland underwrote the costs of the training programme and provided venues and personnel support for meetings throughout the project. As part of the research agreement, the text of this article has been submitted to the Director in advance of publication.

## **5. Barriers to Equal and Inclusive Involvement**

### **5.1 Lack of Cultural Resources – Not Having Enough Knowledge to Participate**

As described above, mental health service users face inequality in terms of a range of cultural resources. This is borne out in the results where participants described potential difficulties in being able to understand the discussion in committee meetings.

A participant in the first workshop described “getting too much information, but not good information, not understandable.” During the interviews, three participants and two leaders cited difficulties due to not understanding the language of the committee discussion:

*“Definitely, particularly the language, the language was a real problem when they were talking about CMT’s, LDL’s, all that type of thing...lots of abbreviations and I didn’t have a clue what they were talking about.”*

(Male participant, aged 50)

*“...in that scenario it’s very easy for the professionals, if you like, to use language that excludes the service user.”*

(Male leader, aged 52)

*“Plus, uhm, there’s also an intimidation factor in committees, when they’ll be talking all this high-falutin’ technical stuff, and I won’t understand, you know, I don’t have much education or whatever.”*

(Male participant, aged 36)

Beyond context-specific language, lack of knowledge of the general topic under discussion can be a barrier to participation. Two participants, two pilot participants and one leader identified not understanding what was being discussed in general terms as a difficulty.

*“I felt that I didn’t have the same baseline of knowledge that a lot of the other people who were professionals or people who were managers of disability services - that they had more information.”*

(Male leader, aged 40)

*“But I think a good bit of it was over my head, on the Council, you know that kind of a way, the last time, as far as I can remember.”*

(Female participant, aged 47)

*“I participated, I tried to participate, but I didn’t really know what was going on.”*

(Male participant, aged 36)

So too, a lack of knowledge about the policy process can be a barrier to participation. A service user leader reported this as a barrier from his experience of being on a committee:

*“Because I found a lot of the time that the conversation kind of revolved around issues that some people were very familiar with and other people hadn’t a clue what was going on. And I often think that people with a disability sometimes, uhm, didn’t understand, and I include myself in that, the kind of ramifications of running an organisation, managing an organisation, the overall national policy, how an act and legislation works.”*

(Male leader, aged 40)

Service users, reflecting wider social norms, de-value their own experiential knowledge relative to the vocational training of professionals. A pilot interviewee worried that his knowledge, which is based upon experience, would not be as well respected as other types of knowledge:

*“I might be nervous going into a meeting but it wouldn’t be because of being a service user, it might just be that I might feel out of my depth. My expertise is my experience and that’s not something you get a degree in.”*

(Male pilot interviewee, aged 40)

This view was shared by an experienced participant who raised concern that the basis for his participation was not as valid as that of professionals:

*“The only skill I had was being a service user by experience... That’s the only skill I had. Whereas all the professionals had their mandate by being experts in their field.”*

(Male participant, aged 50)

It is important that service users not be expected to address this lack of context-specific knowledge by themselves. While some participants said that they would not have difficulty asking for clarification of terms, one person stated that her feeling less well in terms of her mental state would hinder her speaking up to ask for information:

*“...you might not be well, you might feel depressed and wouldn’t be bothered asking for clarification of what was being said.”*

(Female participant, aged 47)

So too, a service user leader referred to the embarrassment which someone may feel at showing their lack of knowledge in the committee situation:

*“Well, you either have to say, well, hold on, could you put that into plain English, which I have no problem doing, because I have that level of confidence, but other people perhaps are frightened that they would be showing themselves up or showing their ignorance or whatever.”*

(Male leader, aged 52)

One participant linked the inability to understand the language with being a “token”,

*“Because really, they were using language on that basis about this, that and the other, and the only thing I could contribute was that I felt, really, they should have a good coffee shop.”*

(Male participant, aged 42)

The cultural resources of a situation, its cultural repertoire, include professional technical vocabulary relating to the subject of a committee, such as practices in mental health treatment, rehabilitation social housing. It includes professional vocabulary within the context such as the names of relevant organisations and their remits, the names of relevant projects, the names and content and significance of relevant standards and legislative instruments. It also refers to the policy history which sets the framework for the decisions being made, e.g. previous policy documents and statements by policymakers. Conducting meetings in language that not all participants understand, and referring to knowledges that users do not have is exclusionary. It isolates those without the language and can make it impossible for them to participate.

## **5.2 Unequal Cultural Resources – Not Understanding the Rules of the Game**

A number of participants articulated a disadvantage from not understanding how committees operate. A pilot interviewee suggested that a service user would feel anxious until he or she had ‘gotten used to’ the structures of meetings.

A participant referred to how the professionals on the committee are “used to everything... used to these meetings.” Learning about committee rules and procedures was one of the priorities identified by service users for the training programme. This need to understand the process of committees came through in the open discussion during the preliminary workshop in 2004. So for example, when asked what would have made the experience of being on a committee better, participants spoke of wanting to get training in how committees run, how to chair and how to be more effective on a committee (Notes from the Introductory Workshop).

The need to understand how committees operate goes beyond objective knowledge of explicit standard rules and procedures. The committee meeting is a type of game which operates under a range of taken-for-granted, implicit rules

which are a vital resource for effective participation. A striking example is the process for getting decisions made in one's favour at a meeting. Oftentimes such success depends on building alliances amongst committee members through pre-meeting lobbying. Pre-existing relationships between committee members may facilitate such alliance-building. None of this may be apparent in the recorded action of the meeting itself; yet control of the meeting's outcomes may subtly depend on this hidden social interaction. Service users may enter into the game of 'committee' unfamiliar and unaware of these hidden processes, and therefore be disempowered from effective participation.

*"I never realised that committee members could actually talk about committee meetings before they went into the meeting. I thought you just went in..."*

(Male participant, aged 36)

*"I'm still not completely au fait with how you get things done on committees, how things are decided and how to get things implemented. Those things are really important - that kind of practical knowledge."*

(Female leader, aged 44)

### **5.3 Unequal Physical and Mental Resources**

It is ironic that, despite our being physical and emotional beings, democratic theory rarely refers to the physical and mental capacities required to participate. This blind spot is highlighted through the experience of people with long-term mental health difficulties. Becoming an advocate requires having the physical and mental stamina to engage in challenging social activity on a regular basis. It requires having the ability to concentrate in order to absorb complex information. Three participants and one leader spoke about the challenge of being able to concentrate.

*"I find a lot for myself that, working hard, trying to understand, and sometimes because of lack of concentration or because of my mental health condition I can't do it."*

(Male leader, aged 40)

*"Sometimes we're asked to review documents that might be a little bit heavy reading and that's a challenge as well, because sometimes the concentration isn't very good, so[there is] the challenge of my illness as well as my own set of abilities."*

(Female participant, aged 38)

*"I remember some things and I don't remember some things, and I don't know how I remember some, and not others. And sometimes I find it hard to take in information as well, you know. It just depends on what form I am in at the time."*

(Female participant, aged 47)



*“Because, people with self-experience, their concentration isn't great.”*  
(Male participant, aged 36)

Two participants spoke about the difficulty with not having enough energy to participate.

*“I must try and recognise my limits, and when I'm tired, it's time for me to take a break. I'm learning my limits. I didn't know my limits. At the age of twenty-one I persisted....and I eventually snapped.”*  
(Male participant, aged 47)

The stress of travelling to meetings was particularly highlighted as a barrier to participation:

*“And I'm not going to be involved because national committees, there's just too much work involved because there's too much travelling to Dublin.”*  
(Male participant, aged 36)

*“But there was just too many meetings, and I stopped going to meetings for a while. It was just too much pressure on me.”*  
(same participant as above)

*“It takes an awful lot from people to attend from the country.”*  
(Male participant, aged 33)

Concern over stress from travel was also identified by three of the five service user leaders.

#### **5.4 The Risks to Health from Participation**

If recovery means minimising stress, then clearly there is an extraordinary need to build in structures to minimise stress in the process of involvement. Yet three participants, three leaders and two pilot interviewees expressed anxiety about participation, from a level of nervousness to being ‘terrified’ about participating in a situation with professionals.

How did you feel?

*“Absolutely terrified, and then the guy who was the clinical director of the service and was also my consultant for years was there, and he did a double-take when I walked in.”*

(Female leader, aged 44)

*“You know, a person with mental health difficulties, we would present as quite okay and quite normal, but in actual fact inside it’s like a duck in water, we’re paddling madly.”*

(Male leader, aged 40)

*“When I started going to national meetings, I was very nervous.”*

(Male leader, aged 52)

*“One of the difficulties was that, I think when you are there on your own, I think there’s a certain level of anxiety, you know what I mean. There’s a kind of, more or less, I mean, again, for people who’ve spent maybe the last four or five years steering away from doctors, you know what I mean. Because that can become quite claustrophobic.”*

(Male participant, aged 42)

*“I just kind of felt that it was like jumping into a swimming pool, trying to keep your head above the parapet. Again, the anxiety is there.”*

(same participant as above)

“Okay, but how did you feel walking into that group, and going to the first meeting, and there’s twenty people around the table?”

*Very very nervous.*

And what were you nervous about?

*The professionals. I mean one of them was my own consultant.”*

(Male participant, aged 50)

In addition to describing anxiety, nervousness and fear, two participants and two leaders specifically described participation as stressful.

*“It was stressful going up to Dublin.”*

(Male participant, aged 36)

*“I think actually that it is stressful, I would agree with that and I would agree with the service users comments on that, but I often think that it would be good to have a personal assistant or an advisor to help you get through the raft of bureaucracy. “*

(Male leader, aged 24)

“Did you find it stressful?”

*“Very stressful, but I did a de-briefing afterwards with \_\_\_\_\_ [support worker] and that was very helpful.”*

(Female leader, aged 44)

Of serious concern were those service users who indicated that their stress went unaddressed by the organisation within which they were participating.

*“Yeah, it was increasing my stress. Yes.”*

“Right. And did you feel that you could have said that to the committee, to someone on the committee?”

*“I don't think I could have.”*

“No?”

*“I think I should have, but I just, I don't know what was holding me back.”*

“No one asked.”

*“No one asked. No.”*

(Male participant, aged 36)

Similarly, a pilot interviewee described an experience where she was a member of a committee for over a year without feeling she understood what was happening in the discussions. Eventually, the purpose of the committee was explained to her. Her experience of this, however was that she felt completely unsupported by the organisation.

These comments suggest that one's mental health can be put in danger by participating on committees. There is a need to build in an ethical framework for user involvement that protects service users from harm in the involvement process. Service users have a right to participate in decision-making without risk to their physical or mental health, in the same way that people have a right to protection when they participate in research. The suggested content for this ethical framework is described below in Chapter 7.

### **5.5 Unequal Social Resources – Isolation**

An experience mentioned by one participant, one pilot interviewee and two leaders who have been on committees already is of being isolated within committee meetings. Service users described situations in which they felt marked out as different from the other members of the committee due to their

being the only service user present. One person described being “swamped” through being so outnumbered by professionals:

*“you’d be sitting with a group of maybe 15 people which would include doctors, nurses, social workers, psychologists, and all, and they all knew each other. But you were kind of coming in as a bit of an outsider, you know what I mean, into a situation...and like, to be honest with you, you’re swamped, you’re swamped in a situation like, say for instance, there’s only one of you and there’s fifteen, say [other members of the committee] - you know what I mean.”*

*“Uhm, I don’t know. I think I was kind of a bit swamped. I think I more or less, I think I was an outsider.”*

(Male participant, aged 42)

A professional mental health advocate remarked:

*So I learnt a lot, but I can honestly say that after a year on that committee I left not knowing anyone.”*

(Female pilot interviewee, aged 60)

*“The first problem is the numbers game, you know, I have plenty of confidence and plenty of knowledge around service user issues, but I find myself on advisory groups where we have, for example, four consultant psychiatrists, one service user, one person from the HSE, one person from the Department maybe. There’s a clear imbalance in favour of the psychiatric profession at the moment with mental health issues... The impact is that, for people who need to learn a bit more about themselves even, and perhaps how to participate, it’s very difficult for them unless they already have the kind of confidence that really they need to build.”*

(Male leader, aged 52)

A pilot interviewee raised the need for service users to have support:

*“When they invite service users to the table, they need to give them support and training. But I think there are many service users sitting around the table without being given support and training.”*

(Female pilot interviewee, aged 60)

This was supported by a leader who also raised the difficulty of not having enough support for her work:

*“I would enjoy more support. I’m based in an office where there are other people but they are doing completely different work.”*

(Female leader, aged 44)

The broader social isolation that many service users experience is also a concern. It is articulated by a service user leader who stated:

*“I can see how people with mental health difficulties have been put into that category of loner or avoided. Avoidance is a big thing about mental illness.”*

“You mean people avoiding people with mental illness?”

*“Yeah, oh yeah.”*

(Male leader, aged 40)

And by another service user leader who stated:

*“People don’t want to be associated with mental health service users. Even with social events, it becomes personally uncomfortably to be associated with service users and not be served a drink at a bar and told that you’re supposed to be next door.”*

(Female leader, aged 44)

The social isolation which people with a diagnosis of mental illness experience means that they may enter into the committee situation with less emotional support than the professional committee members. This inequality points to the particular need to build in social supports for mental health service users who are invited to participate on committees. The types of supports suggested by service users are defined below in Chapter 7.

## **5.6 Unequal Time Resources**

Time is an intangible resource which is often ignored in discussions of inequality. Baker, et al. (2004) point out that people need to have the time to be able to participate, if we want to move to a more participatory democracy (p.108). It can sometimes be assumed that mental health service users have a wealth of time to participate in voluntary advocacy activity, yet the issue of time was raised by four participants in the research group. Two of these participants are in full-time paid employment, while a third is in part-time employment. Their comments point to a risk that service users who have recovered and are participating fully in the labour force will not have an opportunity to participate. Baker, et al. (2004) point out that there is a need for a structure to enable employees to be supported to participate in democracy in terms of their time in a way similar to that allowed for jury service. Evidence from this research group corroborates the need for such structured support. This issue also arises for people with caring responsibilities. The fourth participant who mentioned time as an issue pointed out that she was sometimes unable to attend meetings due to her caring responsibility:

*“...then my partner sometimes, he suffers more with mood swings rather than what I do, and uhm, so, there are times when I don't like to leave him*

*alone, and that was actually one reason why I couldn't attend one of the meetings."*

(Female participant, aged 38)

### **5.7 Unequal Economic Resources**

A few participants raised the issue of being paid for participation:

*"You see, this is part of the reason. We're really angry, where the professionals are laissez faire. They're getting paid. And we're not getting paid!"*

(Male participant, aged 50)

*"Money - to be paid!! It can be belittling not to be paid when everyone else around the table is being paid or doing the committee as part of their job."*

(Notes from the 1<sup>st</sup> Workshop)

When participants are paid this can have a significant impact on their overall economic situation:

*"One of the main motivations in the beginning for me was the financial incentive. We were getting a small amount of expenses. That was, to be honest, a motivating factor, because until I started working part-time on a C.E. scheme, it was a significant portion of my weekly income. It was a big chunk that became important."*

(Female leader, aged 44)

### **5.8 Unequal Status – The Disadvantage of Prejudice/Stigma**

People with mental health difficulties learn early that there is something which could negatively impact on them called "stigma". While some participants indicated they would not have any problem speaking about their mental illness in public, seven participants, four leaders and one pilot interviewee raised stigma as an issue during their interview.

*"Uhm, every day, particularly when you hear media and wrong usage of the term schizophrenic, and, uhm, I think everybody who has the illness takes a little bit of that personally, and, uhm, and I have schizophrenia, I have schizoaffective disorder, so every time it's mentioned in the big bad world it has an impact on me."*

(Female participant, aged 38)

So too, a participant said:

*“I was ashamed and that from the stigma attached to depression, as well as schizophrenia, though depression isn't quite as bad now as schizophrenia is with stigma.”*

(Male participant, mid-40's)

*“I think also, the stigma is a huge issue because again, people don't want to be associated with mental health service users.”*

(Female leader, aged 44)

*“We are victims of the ignorance of society, not of the cruelty of society, but in the way that children are cruel to each other, society is cruel to us in its indifference to us, and its absolute need to keep us down due to fear and stigma, due to unfounded and unresearched stigma. And from the point of view, once you start to question fear and stigma, they don't know why it's there.”*

(Male leader, aged 56)

One might think that this perception would be less in a younger age group, however the youngest participant, a man of 19 diagnosed with schizophrenia, also anticipated a negative reaction from people who would learn of his mental illness:

*“I wouldn't like to just say it in a conversation with someone that I just met. It would scare them off.”*

(Male participant, aged 19)

and continuing,

*“...there's such a big stigma, what will the neighbours say, what are they going to say...”*

(same participant as above)

### **5.8.1 How Stigma Deters Public Advocacy**

The negative public attitudes experienced by many participants led a number of them to be cautious about participating in any type of public advocacy.

One participant described how he thought better of participating in a TV interview. Though he had at one point been prepared to go in front of the cameras, when it came time, he decided against it. This participant had gotten advice from his sister that he should not participate, and had himself considered that “the neighbours would know about it and it would be very unwise.”

When asked to explain further, he said,

*"I think the reality is that there is so much ignorance out there that, uhm, people can very easily be stigmatised and abused and prejudiced."*

(Male participant, aged 47)

Another participant stated:

*"Say, I have no problem speaking to a hall of a hundred, two hundred people, doing a presentation, you know what I mean, but as far as T.V. is concerned, I don't think that we've come far enough."*

(Male participant, aged 42)

While a participant who had been public about his experience raised how the stigma can impact on family:

*"My mum and dad weren't big fans of it when I started speaking and talking about what I'd done and the media came and talked to me - they weren't big fans of that because they were afraid. That was their own thing. They were - they were - it came as a big shock to them that that was their son, but I'm nineteen so I'm out of their hands."*

(Male participant, aged 19)

While one participant felt unaffected by stigma himself, he reported that others would find stigma a barrier to public advocacy. He said that there are a lot of people who would be worried about public opinion.

Service user leaders also identified stigma as creating risks for public advocacy:

*"I think it's very difficult for people with mental health difficulties still now. I just say that from the outset. Myself, I'm public, I'm very upfront about my mental health difficulties for the last ten years especially. I feel sometimes there are risks in that as well in that I don't think that society is still ready to accept people with mental health difficulties or mental illness per se in a fully inclusive way. I think there are still fears that people with mental health difficulties are not reliable, are bonkers, you know all about the media stereotypes and all that."*

(Male leader, aged 40)

Nowhere was this issue of lack of freedom to speak in public more profoundly articulated than in the following story relayed by a female service user leader regarding her experience of NIMBY-ism on her own estate.

*"A case of NIMBY-ism arose in the estate where I live. The local services were [planning] to open a day hospital and one of the local residents got wind of it and became extremely active in trying to block it and circulated a letter that was dreadfully emotional and linking people with mental health issues to paedophilia and alcohol and I was limited in bringing it to the*



*attention to the HSE and nobody was interested in challenging it. And indeed I didn't feel safe in drawing attention to my experience in that neighbourhood because of the individuals involved and they were on my doorstep. There were a few particular leaders of that campaign who I felt I didn't want to draw their attention onto me."*

(Female leader, aged 44)

If even a confident and experienced advocate balks at addressing an issue of direct concern to them due to public stigma, as stated above, then how difficult will it be for service users in general to publicly advocate for change? Through public prejudice, people with a diagnosis of mental illness are being denied their most basic civil right to participate in a democratic society through public lobbying and collective public action.

### **5.8.2 The Risk of Ghettoisation within the Mental Health Services**

Three participants also made a distinction between advocacy work on mental health service committees and speaking in public, with regard to stigma. One made clear that he feels no threat at all from participating on health board committees, that he feels, in that context, that he "has nothing more to lose" from professionals, who have already done as much damage during his early experience as they can. Another said:

*"But it's amazing how people who, say, have had a couple of break downs and a couple of relapses will say, who are used to psychiatric services, how they will feel no stigma whatsoever in psychiatric services."*

"Yes."

*"But outside in the community they will feel stigma. You know? That's an interesting point."*

"And why is that?"

*"Because they will think that the nurses and the doctors, they understand that I'm sick, but, uhm, you know other people mightn't understand that it's an illness, that I might be a terrible murderer with this condition, you know, hahaha."*

(Male participant, aged 36)

This same point was made by the participant above when he stated that he would have no difficulty with speaking to a group of mental health professionals or other people directly affected by mental illness, but would not consider speaking on T.V.

These comments have profound implications for the implementation of mental health service user involvement. As will be described below, participants have articulated how involvement in the mental health services can be a positive, empowering experience. They have talked about the positive feeling of having one's voice heard, of making a difference, and of helping others like themselves. Some have spoken of gaining confidence through the involvement process, and of enjoying new social relationships. However, these benefits must not blind us to the limitations of involvement within the mental health sphere. Prominent among issues of concern to users are low income, poor employment opportunities and difficulties getting adequate independent housing. A consistent priority for service users is combating public negative attitudes towards people with mental illness. These are not issues which can be addressed from within the mental health services alone. Thus the difficulty about speaking in public voiced by many service users puts them at a profound disadvantage in effecting their desired social change. Mental health organisations have a duty to ensure that they do not contribute to the ghettoisation of service users within mental health services. Their role in enabling recovery should extend beyond treatment to supporting service users to achieve their wider social justice goals, including prioritising combating social stigma and changing public attitudes.

### **5.9 Unequal Status – Lack of Respect by Psychiatric Professionals**

The unequal status of mental health service users operates not only in society generally but also within the mental health services. A leader described a culture of dependency within the mental health services which makes it difficult for service users to feel like equals with professionals:

*“Because when you think about it, Shari, you go into the psychiatric system and they put you on medication - they don't tell you what the medication does. They don't tell you how it works. They don't tell you what the side effects are, or at least, very, very briefly. You see the psychiatrist probably for five minutes. I'm just trying to extrapolate again, is that you're kept in a position of total dependency within the system. So that when you are on a committee and you are suddenly expected to be just as knowledgeable and open as everybody else, it's just not right. It's crazy. “*

(Male leader, aged 40)

Four participants and two leaders described experiences of lack of respect for the views of service users by psychiatric professionals.

*“Well, it's interesting, like, when we were talking about meeting the clinical teams, it's amazing how narrow-focused they are. They wanted to meet one person with self experience - to meet one person - just to tick off the boxes. They weren't actually. That was called consulting with someone, you know. They weren't actually going to communicate, which we wanted to do. We want to communicate ideas and influence policy, okay, okay.*

*So that's why we're going as a four-strong team. But it's amazing how, you know, consultants get stuck in this mind-set, you know, consulting means asking questions and when you agree with the answers, then tick the box, you know. It's validating [their] own opinions. So things aren't going to change that way."*

(Male participant, aged 36)

*"I'm very interested when I travel around the place and I see, well, oh, we have a service user committee and it meets once a month, and you read the minutes and the minutes are basically a list of what the service users have been told all the changes are going to be."*

(Male leader, aged 52)

Service users' lack of status is also evidenced by how the interests of psychiatric professionals dominate over service users' interests within the committee setting. Two participants, one pilot interviewee and one leader described how professional interests dominated the discussion in committee meetings:

*"Uhm, I said to the other guy [the other service user on the committee]- we both said the same thing - I'm fed up with this shit. I'm not going to do it. We're getting nowhere and they're not paying any attention to us, and they're all at their own agendas and, we had felt that way because of the way the first meeting went. "*

(Male participant, aged 47)

*"What I've found in the psychiatric system is that the service user doesn't seem to be at the core of that service. It seems to be that people are just interested in their own vested interest and power base and, uhm, I think they become complacent in their job."*

(Male leader, aged 40)

*"Very often a strategy is about planning a service for service users, and the staff and the doctors and the I.R. people, so even to come out with "I hear about that but where is the service user in this" is like dropping a bomb. They are all talking about their own interests. I would often feel like saying, if we didn't have service users, you wouldn't have jobs, yet we're not talking about the service user. It seemed to me as if it was rarely about service users."*

(Female pilot interviewee, aged 60)

And while those with experience identified lack of respect for their views within the committee situation, three participants and one leader described lack of respect by their psychiatrist in the therapeutic situation. Thus their experience of lack of respect by a psychiatrist was a background to their participating with a psychiatrist on the committee.

*“Not really being consulted, no. I never got a care plan when I was in hospital, either occasion, you know. And I think that’s wrong. There needs to be change. People need to be respected, which they aren’t being. They’re being treated as biological units, fix with chemistry and they’ll be okay.”*

(Male participant, aged 36)

*“I felt I was coming from a position of inferiority. I was coming from a position where for the years previous when I was unwell and when I was sick, that you had to be complicit to authority, and it was a completely new departure for me that now I was an equal and I was as equal as anybody else within the committee and it was up to me to have the freedom and the breadth to take the challenge on.”*

(Male leader, aged 50)

This lack of respect by psychiatric professionals in the therapeutic situation has also been documented by Brosnan (2006) in her study of the concept of partnership, where participants described not being treated as equals during their treatment.

It is perhaps not surprising that two participants, two leaders and one pilot interviewee identified tokenism as a problem for user involvement:

*“... at the same time I had this feeling of inferiority or tokenistic kind of presentation - that they were only listening to me because it was the proper thing to do.”*

(Male leader, aged 40)

*“I mean, I found that when I was on the \_\_\_\_\_ board that, really, I’m just wondering if I was just there as a token. Because really, they were using language on that basis about this, that and the other, and the only thing I could contribute was that I felt, really, they should have a good coffee shop.”*

(Male participant, aged 42)

*“Oh there’s a lot of tokenism going on, but that will change, it’s bound to change.”*

(Male leader, aged 52)

*“...because I still think there’s tokenism towards service users on committees. I still think there is, mainly because we’re not experienced in a field of expertise.”*

(Male participant, aged 50)

These comments about the lack of respect shown by psychiatrists towards service users both in the committee situation and in the treatment setting poses a key challenge for user involvement. As highlighted above by a service user leader, "...you're kept in a position of total dependency within the system. So that when you are on a committee and you are suddenly expected to be just as knowledgeable and open as everybody else, it's just not right. It's crazy."

### **5.10 Unequal Power – Service Users' Disempowerment in Committees**

Political disempowerment relates to hierarchical power, 'power over', or the power of authority over decision-making. A biblical story illustrates power effectively. The Centurion says to Jesus, "I myself am a man of authority...I tell this one 'go' and he goes, and that one 'come' and he comes." (Luke 7:8). Service users recognise the power of psychiatrists to decide their fate. The psychiatrist can increase their medication and thus change their quality of life for the worse by increasing negative side effects; the psychiatrist can involuntarily detain them in hospital; the psychiatrist can control their experience in hospital; the psychiatrist can decide whether they are referred to counselling or not. Three participants, three leaders and one pilot interviewee identified issues relating to their lack of power relative to professionals.

*"Power: Doctors will never give away their power. It's a sick system where only the very sick or the most demanding of service users are the only ones fully cared for by an archaic system. And then I repeat this fact of 2%. I believe this situation has arisen because medical professionals will lose power to rehabilitation units if equality is to occur. Medication should be the only area of doctors' power, the rest to people who know."*  
(Male participant, aged 50)

#### **5.10.1 Potential conflict with one's own psychiatrist**

Evidencing the power of psychiatrists is the concern raised by two service users about coming into conflict with their own psychiatrist. One leader and one participant described the impact of this on their involvement, the first in terms of the committee situation and the second in terms of peer advocacy:

*"I would have felt very uncomfortable having to be in a committee sitting opposite or even beside a consultant or somebody with clinical responsibility who would know my personal record and my personal history. There was certainly fear around that and also having to see him in a personal context as an outpatient again."*  
(Female leader, aged 44)

*"But, uhm, suppose another patient of this psychiatrist has a problem with him and wishes to confront the doctor on that problem. I may be helping them, supporting them - ideally they would represent themselves - but I may come along and support in their meeting with the doctor and whoever*

*else is involved. So I'm not sure if that would rub off on me and my treatment by that psychiatrist."*

"Okay, and if it did rub off, what kinds of things might..."

*"He might start upping my medication."*

"He might up your medication (chuckle). Okay."

*"Hahaha. It's the only thing they can do - or lock you up or something, hunh hunh hunh."*

"I mean, we're joking about it, but is there a certain sense in which there is a real vulnerability there?"

*"There is, there."*

"There is a real vulnerability."

*"Yeah, yeah, yeah."*

"Because ultimately, you can't just say"

*"Because ultimately that's what's happened ... That's what's happening with \_\_\_\_\_ in \_\_\_\_\_."*

(Male participant, aged 45)

### **5.10.2 Power over the agenda for discussion**

Political disempowerment is enacted through preventing service users from setting the agenda for discussion. The issues of not having an input into the agenda and not seeing the agenda in advance were raised as difficulties at the first participant workshop. A pilot interviewee described this situation from her experience:

*"Also, I am meeting service users on a daily basis and what they're talking about isn't being discussed at the meeting. The Service users are talking about a system and very often it's a medical model system, and it's difficult to bring it to the table."*

(Female pilot interviewee, aged 60)

Another participant describes a similar experience while he participated in the strategic planning committee of a health board, where he wanted to raise issues of employment and housing, while all the professionals wanted to talk about was switching from an institution-based to a maintenance-based model of mental health care. This participant links the difficulty with getting service user issues

onto the agenda to the domination of the committee by the interests of professionals:

*“...you’ve got doctors, you’ve got O.T.’s, you’ve got nurses, you’ve got managers, you’ve got assistant managers, you’ve got psychiatrists, you’ve got all these around the group and ... they’re just looking at their own interests. They’re not looking at the broader picture. I keep repeating this and I’m going to keep repeating this until I scream it at them: two percent of service users use up 50% of the budget. I keep repeating it and it doesn’t seem to go into anybody’s head. That money is all going into nurses and managers and psychiatrists.”*

(Male participant, aged 50)

### **5.10.3 Unequal Numbers**

A leader identified the unequal numbers of service users on committees as the primary issue with disempowerment on committees.

*“The first problem is the numbers game, you know, I have plenty of confidence and plenty of knowledge around service user issues, but I find myself on advisory groups where we have, for example, four consultant psychiatrists, one service user, one person from the HSE, one person from the Department maybe. There’s a clear imbalance in favour of the psychiatric profession at the moment with mental health issues. I think that’s one of the things that has to be addressed. If we’re asked to be partners, there should be equal representation on those committees from each group.”*

(Male leader, aged 52)

As can be seen from the above descriptions, service users often enter a situation where they are a very small proportion of a group otherwise dominated by professionals. Frequently, a single service user is asked to join a committee in which all of the other members are professionals or managers, with sometimes a carer as well. The leader speaking above also pointed out the irony that, whereas a committee may have professional representatives from a range of specialities, they will not invite a service user from each speciality. Rather, they will expect a single service user to provide the service user perspective. Two participants with experience on several committees spoke about how having a group of service users on the committee made a big difference. If there are far fewer service users on a committee than other representatives, and they do not have significant role-authority, they will have less control over decision-making.

*“I mean, I am enthusiastic about advocacy, you know, but, like, to be honest with you, you’re swamped, you’re swamped in a situation like, say for instance, there’s only one of you and there’s fifteen, say [other members of the committee] - you know what I mean.”*

(Male participant, aged 42)

*“I think it’s great, but I think that more service users need to come on board. I’m doing the best that I can, but I’m just one person. I would like to see more service users involved in management committees in the health board, in expert groups. I would like to see three or four service users on the mental health commission instead of just two.”*

(Male leader, aged 40)

### **5.11 Summary of Dimensions of Disempowerment**

As service users have articulated, they may face a range of inequalities when entering the committee situation. These include unequal cultural resources in terms of education and the cultural repertoire of policy knowledge and technical language, unequal physical and mental resources, and unequal time and economic resources. They are also at greater risk of being socially isolated and lacking social supports. Service users enter the committee situation marked out as ‘other’, isolated by society and may be afraid to speak out in public about their situation. They are sometimes treated as inferior by psychiatric professionals. They are endangered by the power which psychiatrists hold over their quality of life and their freedom. Finally, they are disadvantaged by their lack of power over decision-making and their lack of numbers relative to professionals on mental health service committees.

While these challenges face service users entering into involvement in the mental health services, the experience of involvement can be empowering. What follows are service users’ descriptions of being empowered and their explanations for their capabilities to be involved.



## 6. The Experience of Empowering Involvement

### 6.1 Describing Empowering Involvement

A total of 5 participants, 4 leaders and 2 pilot interviewees described positive experiences of being involved in advocacy. The types of positive experiences included being listened to, being treated as an equal, being respected, being successful, helping others and having an impact.

*“So fairly quickly I realised that there was a very genuine effort to make positive changes, and I think people were open and ready to listen to what had been reported in Pathways.”*

(Female leader, aged 44)

*“To be quite honest with you, the strategy, they did listen to us, they did listen to us, and they did take on our views.”*

(Male participant, aged 50)

*“Yeah, because they were very supportive. Like, we weren’t there as token people with self-experience. We were actually listened to, you know.”*

(Male participant, aged 36)

Participants talked about the experience of being an equal with professionals:

*“There [were] definitely positives. It made me realise that I was very similar to the professionals.”*

“Really. In what way? Why was that a new thing?”

*“I realised that they were very much human, they could be just as stupid as I could be. Just because they have a degree after their name doesn’t mean that they’re all brains. And also we became great friends, even though we fought with each other all the time, became great friends, and we became very much a team.”*

(Male participant, aged 50)

*"Yeah, we were equal partners, and it wasn't just to be politically correct. We were respected. That's why we were invited onto the committee. It was a positive experience in that respect."*

(Male participant, aged 36)

Two participants spoke about the positive experience of helping others:

*"...but I loved the bit where I was helping people"*

(Male participant, aged 19)

*"Yeah, I think so, because when I was on the radio when \_\_\_\_\_ was here she said she got a call from somebody in Donegal who had heard the interview on Morning Ireland and she was thrilled that someone had come out to speak about schizophrenia who had had the illness"*

(Male participant, aged mid-40's)

The aim of helping others was also named at the first workshop with participants, and by three participants and two leaders, as one of the reasons they would want to participate.

Finally, three participants, one leader and two pilot interviewees discussed the positive experience of having an impact:

*"and so she told her psychiatrist and she got weaned off of it and the anti-depressant, and she's better today. Now I haven't heard from her for a while, but she got better. And it was as a result of coming into contact with MindFreedom."*

(Female leader, aged 59)

*"And I felt that I did, wittingly or unwittingly, directly or indirectly, affect \_\_\_ policy and, unh, no way would I have sat for four years if I didn't feel I was getting somewhere. I would have left sooner. I wouldn't have done it that long."*

(Male participant, aged 47)

## **6.2 Becoming Empowered through Involvement**

It is evident from the quotes above that service users can gain from involvement in terms of experiences of being respected, being treated as an equal, helping others and having an impact. As several participants stated, these positive experiences were important in encouraging them to continue to participate, in gaining confidence and in feeling empowered.

*"I think the most rewarding part of it was getting on the talk show, and when I was at school I was this person, I was being bullied, and I was known by the teachers to be not doing anything with my life, and then suddenly I had this*

*great self-image after asking that question, and maybe I can do something about this and it can get me places and why not go for it.”*

(Male participant, aged 19)

*“You gain confidence when you appear on T.V., it might seem being bigheaded, but you learn and you grow and you mature and you're not afraid to speak out and to speak up yourself.”*

(Male participant, aged mid-40's)

*“Oh, it was terrific, because you felt that people appreciated you. People thought that this was a good thing; it was good for you to speak out. And this gave me the confidence to do it even though I was a very shy and timid woman.”*

(Female leader, aged 59)

*“Yeah, yeah, yeah. I felt I was giving a voice to people who weren't, you know, who weren't in the same position of knowledge of advocacy...so it did make me feel a bit more empowered I suppose, yeah.”*

(Male participant, aged 45)

*“So part of it was getting used to the structures of the meetings and having a voice and getting used to having a voice, but also this other part of getting used to coming out.”*

(Female pilot interviewee, aged 60)

### **6.3 Mediating Factors that contribute to Service Users' Empowerment**

As described above, service users identified the practice and experience of involvement as itself a means towards greater confidence and empowerment. Of the 13 people who participated in the training, 6 stated that they would feel capable of speaking up in committee meetings. However five of these six had no prior experience of sitting on a mental health service committee from which to base this assessment. On the other hand, those with experience pointed out a range of challenges for their participation as described above. Those with experience of mental health service committees identified four factors that assisted them to be able to participate on committees: having advanced education, having professional experience themselves, having support from others and having a confident personality.

#### **6.3.1 Education enabling empowerment**

One participant with experience on a committee and three out of five leaders identified education as a resource which assisted their participation:

*“I found that when I came onto the committees with mental health professionals, well, I suppose I was lucky in the sense that I had gotten back education at that time, so I wasn’t totally phased by their being professionals.”*

(Male leader, aged 40)

*“But I do think that to get that honours degree with the kind of start-stop education I had was more of an achievement than for the ordinary person who had no problems, you know? So in that sense that was a starting point that gave me something to say, well, I’ve done very well.”*

(Male leader, aged 52)

A participant with prior experience on mental health service committees described how his previous training had given him confidence to participate:

*“From the very first year, I was involved in doing, uhm, presentation training with \_\_\_\_\_. He was brought in to train a few of us, myself and \_\_\_\_\_, to do presentations. That was a tremendous boost to my confidence, and it just seemed like a natural link to go on and develop from there.”*

(Male participant, aged 47)

### **6.3.2 Having Previous Professional Experience**

Two pilot interviewees related their confidence to their professional experience.

*“I have work experience in a professional manner, as a designer I used to have to attend a lot of meetings and meet a lot of people and meet clients, so I have that professional work ethic, but also a street knowledge”*

(Male pilot interviewee, aged 40)

The importance of education and prior professional experience articulated by service user leaders indicates a potential barrier to ensuring that service user committee participants are indeed representative, in terms of being typical, of the users of mental health services. People from lower class backgrounds are several times more likely to be admitted to hospital for psychiatric illness in Ireland than any other socioeconomic group (Walsh & Daly 2004, p.86). Given this fact and the experiences documented here of the benefits of education for enabling participation, the question arises of how to ensure that the views of service users from lower class backgrounds, who represent the majority of inpatients, are represented on mental health service committees. User involvement programmes should not ignore the cross-cutting social inequalities experienced by mental health service users.

### **6.3.3 Being a Confident, Determined Person**

Two participants and three leaders identified their personality as a significant factor in their ability to participate:

*"I'm fairly confident in myself as well"*

(Female participant, aged 38)

*"I did personality typing...and my particular type is a natural born leader anyway, like my mother said, he just walks into a room and takes over."*

(Male participant, aged 47)

*"And of course, my personality is to be a sticker. When I start something I usually stick it through. Once I start something, it's my way that I would like to see it finished."*

(Female leader, aged 44)

*"...and at the end of the day I suppose I was always a bit of an argumentative type and my experience of having mental health difficulties taught me how to fight and to struggle and learn, you know, and fight through fairly tough odds."*

(Male leader, aged 40)

While the ability to participate in advisory forums is affected by a range of social factors as identified above, it is evident from discussion with some of the participants that their involvement depends to a degree on their personal characteristics of determination and leadership. Service users who do not have these inner personality characteristics, and those in whom the services and society have damaged their confidence, will need a greater level of support and encouragement in order to participate. This leads to the need to be emotionally supported in the process of involvement. However, it is important to keep in mind that six participants in the research group felt fully capable of participating.

## **6.4 The significance of support for empowering mental health advocates**

Five participants, four out of five leaders and one pilot interviewee identified support as important. Those participants with experience of advocacy described how emotional support from various sources, family members, peer group networks, friends, supportive professionals and allies had contributed to their being able to participate. Two participants described how lack of support from their family deterred them from taking up opportunities for public advocacy.

### **6.4.1 Family Support**

Three out of four leader interviewees and two participants discussed the importance of support from family and friends. It is particularly significant that those with the most experience of user involvement spoke about their need for

family or friend support. One leader described how her move into advocacy would have been impossible without the support of her partner:

*"...and Jim, as you met there, was finding it hard in the beginning, but as time was going on Jim was realising what was going on as well. At the beginning it was hard for him, because you see, he came with me a bit reluctantly in the beginning, but as time went on, with more and more enthusiasm, and now he's nearly more enthusiastic than myself. And he would come with me the first time I spoke and he was there with me, and he would speak with me if he was needed."*

"And you think that you would have done it if your husband hadn't been supportive?"

*"No, no. it would have been very difficult. We probably would have had very major marital problems and it would have been very difficult."*

(Female leader, aged 59)

While another female leader stated that lack of family support would have been an additional barrier:

*"Certainly having had the support of the family could have made some things a bit different for me. I think my family also succumbed to the whole stigma and they didn't have the resources to take care of financial problems that were arising."*

"So there was a time when you weren't getting the support from your family?"

*"Yes, but then it changed and emotionally, they're very affirming now and quite proud of how things have turned around for me."*

(Female leader, aged 44)

A young participant described how lack of support from his family deterred him from speaking out more often in public:

*"I got a whole lot more opportunities and my family, they were having none of it. So I think it would have gone further if I had of got support off my family, but I hadn't at the time, and I still don't..."*

(Male participant, aged 19)

A participant with experience of speaking to a group of professionals described the family and friend support she got through that situation:

*"well my mother was outside, and she was very encouraging...and \_\_\_\_\_ [her partner] was very encouraging."*

“And did that make a difference to you, or would it have not made any difference?”

*“It did make a difference, because they are close people telling you that you can do this...”*  
(Female participant, aged 38)

#### **6.4.2 Peer Support**

If support by one's family was considered a baseline necessity by those with extensive experience of involvement, the emotional support gained from peers was the most widely identified type of support recommended by all participant groups. Four participants, three leaders and one pilot interviewee identified peer support as valuable, while peer support was also identified in the first participant workshop.

One leader emphasised the importance of the encouragement she received from internationally-known survivors:

*“I realised from reading Toxic Psychiatry that there were a whole lot of survivors in America and other places, but I didn't think that there were too many in Ireland. And I thought, I want to get in touch with them. I really wanted to feel - because it sounded really powerful from the book, you know, and I heard mention of David Oaks, the director of MindFreedom International, and I thought, wow, he sounds like a brilliant man, and people like Judi Chamberlin, and all these people, and at that time I didn't have a clue how to use the computer, and we had a student at the time and she knew how to use it, and I asked her, could she put something out and ask if there are any survivors out there, could they get in contact with me, but it didn't work. But in the meantime, a great psychotherapist got in touch with me named Greg White, because he heard that there were a few people in Cork coming out, recovering, and somebody told him about me, so we got together and he told me then about MindFreedom International, and at that time there was a hunger strike on in America. David Oaks and some of the other survivors, challenging the American Psychiatric Association to give the evidence that all these things actually exist. And, of course, this, to me, was fiercely exciting that all these people were actually going out on hunger strike to ask these questions. So then I knew that there was actually a movement called MindFreedom International and that you could get in touch with these people. So with many efforts, because our own computer wasn't working very well at the time, I went down to the library a few times, and eventually I actually got in touch with David Oaks. And from the word go, again, this man was encouragement all the way, and he was the very same as Terry Lynch, and this man again, now, he is a huge man in the world as a survivor in the movement, and I said, isn't this fantastic - I was only a small woman here in Ireland.”*

(Female leader, aged 59)

Another leader described how peer support helped her to cope with the stress of meetings:

*“Part of the process at that time was that the service users would meet separately to discuss issues about the process, so at that meeting I would have had a chance to sound off about how difficult the committee meetings were.”*

(Female leader, aged 44)

A male leader described how the peer group can be a back-up to the service user on a committee by providing information and encouragement:

*“I think the value of the group is the support you can get from the group that if you’re unsure about something, you can call and find out, you know, you can get information...in terms of backup, the help, the confidence as well.”*

(Male leader, aged 52)

While two people highlighted the overall support from being involved with an organisation:

*“I feel that being involved with something like Schizophrenia Ireland, that when you’re part of an organisation, within that there’s a lot of support, you know what I mean?”*

(Male participant, aged 42)

*“I do think you should distinguish in your research between professional service users, and because I am a professional I am getting outside help from the Irish Advocacy Network (IAN) and training from IAN, but the vast majority of service users are not.”*

(Female pilot interviewee, aged 60)

### **6.4.3 Professional Support**

Three participants and four out of five leaders with experience of involvement also highlighted the value of support they had received from medical professionals and other allies. This was related in particular to the early experience of involvement, when service users are often nervous and daunted by the experience. At the early stages, the value of allies and positive professionals was described as particularly important.

*“I wouldn’t have gone if it hadn’t been for her [the development worker’s] support. If I hadn’t gone in and left with her I don’t think I would have*



*taken it on. I felt that I had an ally, and somebody very supportive and she constantly pointed out the importance of what I was doing and that even if I didn't speak that my very presence was important."*

(Female leader, aged 44)

*"...and if I didn't have somebody like Terry Lynch supporting me as well, from the establishment. Like, I felt he was a doctor, a former doctor, and I needed things like that at that time. Now I wouldn't need them, but then I did."*

(Female leader, aged 59)

*"When I look back and if I had had somebody like you as a mentor, somebody who I could go to if I was confused about this situation, in terms of policy, in terms of how society works and operates and how boards operate, that would have been of great benefit to me."*

(Male leader, aged 40)

*"As most service users do not have a third level education, professionals have to build up our self-esteem, to build up communications skills, to build up negotiation skills, to build up an ability to interpret what's being said and what other's are saying, to see these committees as a changing tool, a way forward."*

(Male participant, aged 50)

*"I'm sure \_\_\_\_\_ did mention the fact that she's giving the talk... and the researcher there has worked, I think he's met her at least four times since it was suggested that she would do the talk to the group of people with mental health problems, and uhm, so support is great."*

(Male participant aged 33)

## **6.5 Summary of Empowering Involvement**

It is clear that involvement can be an empowering experience for mental health service users. Service users can receive affirmation of their own competencies, their value as human beings in being able to help others and their potency in being able to have an impact. Service users also gain competency through involvement. This point was highlighted by those who had experience of involvement, the two more experienced participants and three out of five leaders. Participants also named those factors related to themselves as individuals which, in their experience, had facilitated their ability to be an advocate. These were their higher education and training, having previous experience as a professional in any field and having personality characteristics such as determination and self-

confidence. Finally, those with experience of involvement emphasised the value of support for initially encouraging and sustaining their involvement, including family support, peer support and the support of medical and other professional allies. As one leader put it, there are many service users all over Ireland who are capable of advising on committees. They should be given the opportunity to do so. What is evident from those with experience is that they simply require the skills, knowledge, resources and supports to enable their participation.

## **7. Defining an Ethical Framework for User Involvement: Service Users' Recommendations for Supports and Structures to Assist Equal Involvement**

### **7.1 Introduction**

As previously discussed, organisations inviting mental health service users into involvement have a duty to protect service users from harm in the process. This section outlines the range of supports that participants identified to assist their equal participation. The supports address the six dimensions of inequality that people with experience of using mental health services face: cultural resources, physical and mental resources, respect and recognition, economic and time resources, power, and the need for emotional support.

### **7.2 Addressing unequal cultural resources**

Participants identified a range of ways to address their unequal cultural resources:

- **Training**

Training was suggested by 6 participants, 3 leaders and 1 pilot interviewee. It was also requested by the participant group at the introductory workshop. This led to the development of a pilot training programme in which 13 people participated (McDaid 2005). The skills areas identified were:

  - How committees operate (including committee rules and procedures, and the unwritten 'rules of the game')
  - How to read and analyse policy documents
  - How to gather evidence to support your case, including internet searching and identifying useful resources
  - How to negotiate
  - Computer skills
  - Writing skills
  - How to prevent burn-out
- **Clarifying technical language during the meeting.** One participant and two leaders mentioned how they would seek clarification of unknown language during a meeting. It is important that meeting chairpersons provide opportunities for terms to be clarified. It was also suggested that service user members be provided with a glossary of terms, e.g. CMHT means Community Mental Health Team.

*"Asking for information to be given in plain English, and during a meeting, for statements to be made in plain English"*

(Introductory workshop group discussion)

- **Providing accessible information.** Participants in the pilot training programme with experience on committees raised the need for clear and concise information about the issues under discussion on the committee. Participants wanted summarised information, and information in straightforward language.

*“KISS – Keep It Simple Stupid”*

(Pilot training programme group discussion)

- **Providing enough background information to be able to participate.** Participants also sought background information on the topics under discussion, such as the recent history of the policy, previous decisions made and the evidence (prior policy documents and research reports) on which policy had been made.
- **Mentors and peer groups as cultural resources.** One leader described how a service user would value being able to seek information from their peer group. Another leader described the value of ally support, a type of ‘personal assistant’ to explain what was going on in the meetings. Both mechanisms should be offered to any service user committee member, not only at the beginning of their participation but on an ongoing basis so that they can draw on the accumulated cultural resources of peers and allies in order to inform their participation.

*“I think the value of the group is the support you can get from the group that if you’re unsure about something, you can call and find out, you know, you can get information.”*

(Male leader, aged 52)

*“When I look back and if I had had somebody like you as a mentor, somebody who I could go to if I was confused about this situation, in terms of policy, in terms of how society works and operates and how boards operate, that would have been of great benefit to me.”*

(Male leader, aged 40)

- **Terms of reference.** All members of a committee should be provided with the terms of reference for the committee. This is good practice, but it is particularly important for service users who may not have the other cultural resources needed to interpret the committee proceedings. Terms of reference should specify the purpose and scope of the committee, its decision-making authority and its leadership structure. They should also specify a designated liaison person within the organisation to whom service users can speak if they are having difficulty on the committee. Participants also requested information on the background and positions of other members of the committee.

### **7.3 Addressing unequal physical and mental resources**

Some participants emphasised the need to incorporate breaks during meetings in order to accommodate their lesser stamina and concentration levels.

*“Just give lots of breaks, because, people with self-experience, their concentration isn't great.”*

(Male participant, aged 36)

Three leaders also recommended that structures be put in place to allow a service user to resign or take a break from a committee. This may be needed to accommodate a period of mental distress, or if the committee situation itself becomes unduly stressful. The idea of having an alternate was also suggested. This would enable continued representation of a service user perspective regardless of the wellness of any one appointee.

*“I think everybody should have protection from harm but there needs to be the space to be able to opt out. That needs to be built in. People might have good days and bad days and allowances need to be made for that but that needs to be made for everybody. Everybody can have a bad day.”*

(Female leader, aged 44)

*“I think that if there's a very bad, negative energy going on, it's probably best to go away from it, you know, because this isn't productive anyway because if there's too much fighting going on, I mean, you can't have too much happening if you're having meetings and most of it is fighting. What are you going to get out of it anyway.”*

(Female leader, aged 59)

### **7.4 Addressing unequal respect and recognition**

The evidence from the interviews demonstrates the negative impact of both societal and mental health system prejudice on service users' ability to participate. Social stigma can inhibit persons with experience from speaking in public. Mental health professionals' negative attitudes can deter service users from speaking up in committee meetings. If user involvement is to have any moral validity, it must address these broader issues of societal and mental health system 'stigma'. A simple positive measure would be to ensure that stigma is addressed as an agenda item on committee schedules, but to ensure that such a mechanism is effective, it must be underpinned by a broader programme to change public attitudes. Brosnan (2006) recommends that:

“Dignity, respect and equality should be the cornerstone of delivery of mental health services. These values should be incorporated into a vision statement for the services within the reformed HSE structures and built into the service planning process.” (p.38).

Participants in this research also supported the need for an ethos of respect within mental health services:

*“I think people might need different things, but if supports are offered for training and supporting people in the process of growth of confidence that’s necessary to find one’s own voice and to value the experience, the perspective that people with experience can bring, so learning to value that through the support of people who believe it already was vital for me.”*  
(Female leader, aged 44)

*“And then - being on a committee with professionals sharing, what are the challenges to you - and I said - that I be respected, that I be seen as a person with ideas and a contribution like anybody else on the committee.”*  
(Male participant, aged 50)

Mental health services at local, regional and national levels need to lead on changing public attitudes through prominent public messages. They should be supported by clear public leadership from Government. They also need to develop specific programmes to address the stigma perpetuated by mental health service providers, both statutory and non-statutory. Implementing the ‘recovery’ approach to mental health care which sees partnership as a core ethos and prioritises the expertise of people regarding their own recovery from mental distress is one way to move away from the culture of dependency currently persisting in some areas of the mental health services (see Mental Health Commission 2005). Ultimately such an ethos will only succeed, however, in a system which delivers knowledge and power to people with a diagnosis to determine their own treatment.

## **7.5 Addressing unequal economic and time resources**

- **Negotiating a fair payment for participation.** The issue of payment was raised by one participant, one leader and one pilot interviewee, as well as in the introductory workshop. Demographic information obtained from participants showed that their average income is low by Irish standards. Amongst 11 interviewees who answered the income question, 6 had an annual income of less than €12,000.

However, one participant also questioned whether being paid might change the motivation of a service user’s participation.

*“If I was being paid I'd get greedy and I might not put as much into it, I'd be in it for the money then. I'd rather go out and do it, and if there's money there, admittedly, I'd, if it was there and they were offering it to me I wouldn't say no, admittedly.”*

(Male participant, aged 19)

The National Disability Authority's *Strategic Partnership Guide* for working with people with experience of mental health difficulties recommends that payment for participation be negotiated as part of establishing the partnership (NDA 2005). Evidence from this research supports this recommendation.

- **Valuing and accommodating participants' time.** Two participants in full-time employment discussed time as a constraint to involvement. One participant said that she would only participate if it did not become too time-consuming. Another described how he had chosen not to participate at national level due to the time required for long-distance travel. It is therefore important to enable service users, especially those who are in full-time employment, to have sufficient time to enable their participation. It is also important for organisations to recognise the value of participants' time and use their time efficiently. As noted above, Baker et al. (2005) recommend a structure to enable employees to be supported to participate in democracy in terms of their time in a similar way to that allowed for jury service. Evidence from this research group corroborates the need for such structured support not only for employees but also for people with caring responsibilities.

## **7.6 Equalising power**

Participants and leaders made a range of suggestions to improve the balance of power within the committee situation. These include:

- Being put in a position of authority on the committee
- Having an opportunity to frame the agenda
- Having more than one service user on the committee
- Having a regular, designated time slot for service user input

*“So I turned around and I said to them that I really felt that a sub-committee would be a good idea, and to consider rather than having one person sitting there on the board, to have two people with disabilities.”*

(Male participant, aged 42)

## 7.7 Addressing the need for emotional support

Participants and leaders recommended peer, family and ally supports for participation.

- **Family support.** One leader recommended family and friend support as an aid to participation, while two other leaders noted the importance of family support for their continued participation.
- **Peer support:** Participants in the pilot training programme called for the availability of peer groups to support participation. A leader highlighted the value of peer support especially for people starting out on committees:

*“Sometimes you feel a fool, you know, uhm, and it’s hard at times, you know, people will be embarrassed, people will say things that they don’t know or don’t understand. Yeah, there is a danger there, so I think maybe at the start that it’s important to have groups, so that if you’re representing, and it needs to be a very non-judgmental arena, so that you can go back to them and say, so, folks, I really f\*\*\*\*\* up at today’s meeting, you know.”*

(Male leader, aged 52)

Another leader called for much more widespread development of peer forums to enable debate amongst service users:

*“I suppose, a lot more support and a lot more opportunities to discuss things with people. Having service user forums. If the HSE set up these user councils there would be a lot more healthy debate. I think that’s a major lack in the Irish situation that there aren’t forums for people to get together, apart from the Irish Advocacy Network.”*

(Female leader, aged 44)

- **Ally support and encouragement:** Three participants and four out of five leaders identified the value of ally support, meaning the support of mental health and other professionals. For some this had to do with the value of the information that professionals could provide to service users. More often, leaders spoke about the importance of the encouragement they had received from allies during the early stages of their involvement.

*“Encouraging people and fostering a sense of self-belief in people is really important...”*

(Female leader, aged 44)

One leader defined the value of an ally but stated that this role needed further working out.



*“What I would say is that I don’t think it’s really worked out properly in terms of supporting mental health service users who are on committees and boards.”*

(Male leader, aged 40)

### **7.8 Summary of Service User’s Recommendations and the Call for an Ethical Framework for User Involvement**

From an egalitarian perspective, issues of skills and knowledge inequalities, language barriers, the need for group support, the need for more proportional representation and for more say in decision-making and the need to be respected reflect deeper inequalities. The inequality issues for service user involvement cannot simply be wished away; they reflect the unequal position of people with mental health difficulties in society as a whole, and should be addressed coherently and comprehensively.

In addition, service users going forward to participate have a right to be protected from physical and mental harm as a result of their involvement. Professionals conducting research have long recognised the need to operate within agreed ethical standards in order to ensure that their research does not cause harm to research participants. Yet such a view is rarely raised with regard to organisations inviting service users to participate in decision-making. Service users in this research clearly articulated experiences of stress while participating on committees. This demonstrates the need to develop an ethical framework for user involvement. Such a framework would delineate the range of disadvantages/inequalities users may experience in the involvement process, and set out minimum standards to prevent harm. The types of inequality have been indicated in this analysis. Standards for increasing equality and preventing harm should address each of the dimensions of disadvantage, such as improving the educational qualifications of service users and re-training professionals to value experiential knowledge, re-balancing power relations through proportional service user representation and assigned service user authority over decision-making, ensuring adequate financial compensation for service user participants, supporting service user group capacity-building, providing mentoring support, Plain English documentation and a relevant induction programme. Such an ethical framework for involvement should be a pre-requisite for any organisation inviting service user participation, so that all service users can participate safely and effectively without undue risk to their physical and mental health.

## **8. Conclusion**

The appointment of a service user onto the Area Management Team of every local area, the establishment of a national Service User Executive and the presence of service users on the Mental Health Commission are profound steps toward greater equality in the mental health services. Discursively, they represent a paradigm shift towards inclusiveness and away from paternalism. Sociopolitically, they show an acknowledgment by society that people with mental health difficulties, like all citizens, have a right to be involved in the decisions that affect them. In this sense they represent a shift towards basic equality for people diagnosed with mental illness. But service users' experiences tell us that a simple equality of presence (the right to be present in decision-making forums) will not ensure equal participation. The experiences of involvement documented in this research reveal practices of tokenism, disrespect, lack of influence, constraint on speaking in public, ineffectualness, isolation and stress. In order for mental health services to effectively and more equally involve service users in planning, a radical shift of approach is needed. Service users require supports, accommodations and re-balanced structures to enable their full involvement. Such an ethical framework is more likely to promote not only the presence of service users in planning structures, but their empowerment within the mental health services and in Irish society. Furthermore, their experiences have much to teach all of us about the general need for an ethical framework for participation. All members of a community should be supported to participate in decision-making to the maximum of their capacity without fear of harm or stress. To deny this is to enshrine a democracy of the elite.

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