

A SEAT AT THE TABLE



A Report on the Views of People with Self-Experience of Mental Health Difficulties, their Supporters, and Service Providers in the Dublin 10 area, on the Inclusion of People with Self-Experience and Their Supporters on Decision-Making Bodies.

WE WOULD LIKE TO THANK
OUR PROJECT PARTNERS.



A SEAT AT THE TABLE



To reference this report: Dermody, A., Ní Chaoláin, S., & Gardner, C. (2015) *Our Service, Our Say: A Report on the Views of People with Self-Experience, their Supporters, and Service Providers in the Dublin 10 area, on the Inclusion of People With Self-Experience of Mental Health Difficulties and their Supporters on Decision-Making Bodies*. Dublin; Ballyfermot Partnership.

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FOREWORD

I am very pleased to introduce this report on the views of all stakeholders in the Dublin 10 area on the inclusion of people with self-experience of mental health difficulties, and their supporters, on decision-making bodies both within mental health services and in the broader community.

The project, "Our Service, Our Say", aims to develop the confidence, skills, knowledge and experience of people with self-experience of mental health difficulties, and their supporters, in order for them to participate effectively in decision-making fora.

This research was overseen by a working group called 'The People with Self-Experience/Significant Support Person Initiatives Working Group'. This group was set up by 'D10 Be Well', an inter-agency forum focused on the mental health needs of the Dublin 10 local community.

We received a grant from Genio in 2014. This essential funding has enabled us to carry out this research. Ballyfermot/Chapelizod Partnership and the HSE Community Rehabilitation Service would also like to thank Rainbow Clubhouse, Shine, Irish Advocacy Network, a number of individuals with self-experience and the local Carers' group for their enthusiasm, input and support for this project.

This study has provided us with an in-depth understanding of the needs of this community. People with self-experience of mental health difficulties, and their supporters, have had the opportunity to identify and communicate their needs and the challenges they face when they consider participating, or when participating, in management teams. Service-providers in the area have also been consulted to elicit their perspectives. This information is vital to enable local services and stakeholders to effectively support the development of collective advocacy.

This report shows that there is an appreciation and understanding of the wealth of knowledge that people with self experience and their supporters can contribute. There is strong support for their inclusion in the management teams and decision making fora. It also highlights many barriers and the need to develop a coherent strategy to properly utilise this knowledge. The report includes a number of recommendations which will inform the next phase of the project and help to foster sustainable and true representation.



Nicole Murphy
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HSE, Dublin, 2015

HOW TO READ THIS REPORT

WHAT IS IN IT?

The first section of this report is a summary of the findings and recommendations from this action research project. The main body of the report begins with an introduction and overview, followed by a chapter which provides an outline of the methodology and a description of how the researchers collected information and developed recommendations. A context in literature and policy is then provided.

This chapter provides a summary description of what is already known about this topic, including the state of service user involvement in Ireland and what is considered good practice in other countries.

The next chapter presents all of the findings of the research, including people's opinions on what is needed to make the involvement of people with self-experience and their supporters on committees meaningful and effective.

The following chapter provides a profile of the research participants and supporters. This includes people's experiences of committees and their relevant strengths and skills. Recommendations are offered in the final chapter. These recommendations are all directly connected to the findings, and are supported by the literature review in chapter three.

TERMINOLOGY

The term '**people with self-experience**' refers to people who have mental health difficulties and use mental health services. This is used interchangeably in the report with the acronym **PWSE** or occasionally '**representatives**'.

The term '**supporter**' refers to a person who provides care and support to a person with self-experience of mental health difficulties. This might be a parent, sibling, partner, spouse, extended family member or friend.

The term '**stakeholder group**' or '**stakeholder**' is a general term used to describe a group of people with interest in the project. In this report, there are two stakeholder groups: people with self-experience and their supporters, and mental health professionals.

The term **participant** is sometimes used and refers to any person, either with self-experience, their supporters or mental health professional, who took part in an interview for this research.

QUOTES

To help readers identify who certain quotes are from, each quote is written in *italics* in the centre of the page and is followed either by a (*PWSE#*), which means this is a quote either from a person with self-experience or supporter, or by a (*PR#*), which means this is a quote from one of the mental health professionals who took part.

SUMMARY OF FINDINGS AND RECOMMENDATIONS

OVERVIEW

This research, undertaken with 41 people in the Ballyfermot area, sought to understand the needs and concerns of people with self-experience of mental health difficulties, their supporters and of mental health professionals, in relation to the participation of people with self-experience and their supporters with decision-making bodies in mental health services.

This report provides a detailed breakdown of their responses. Presentation of headlines from the report in relation to the findings and the recommendations are followed by the main body of the report, which includes detailed findings and recommendations. The report also features an overview of relevant literature, the methodology, and a profile of people who took part in the research.

SUMMARY OF FINDINGS

1. There is strong agreement across all stakeholder groups that **people with self-experience and their supporters should sit on decision-making bodies** of services provided for them. **Professionals and people with self-experience/supporters wish to work collaboratively** in Dublin 10.
2. Most participants, including mental health professionals and people with self-experience /supporters, had previous experiences of being on committees where there was service user involvement. Their **experiences were mainly positive, but there were some challenges** that can provide valuable learning for the future.
3. A number of **concerns** on the part of both stakeholder groups should be considered, anticipated and planned for, including:
 - o Lack of clarity in the way that services structure, committees and individual professional roles work
 - o Lack of clarity in the role of the representatives on committees
 - o Concerns about negative attitudes of professionals to service user representatives on committees
 - o The potential for a representative role to be tokenistic and not meaningful
 - o The lack of a representative structure or peer group for people with self-experience and their supporters in the Dublin 10 area
 - o A potential imbalance of certain knowledge and skills between professionals and people with self-experience /supporters who are on committees together



4. There was a general agreement that **mental health difficulties can arise for representatives**. Both people with self-experience /supporters and professionals had experience of this happening previously on committees. However, participants also generally agreed that people becoming sick in work is commonplace, and that having appropriate processes in place can ensure **it can be managed well if it arises**.
5. There are a number of **steps that committees can take to promote success**. Generally, the committee members advocated engaging in dialogue in advance of someone coming on to the committee. This means having conversations both internally on the committee as well as with potential representatives or a peer group prior to the representative joining the committee. Specific steps identified for the committee were:
 - o To be provided with **clear information** on the representative role: rationale, role description, remit, responsibilities etc.
 - o To foster **enthusiastic buy-in** from the whole committee in advance
 - o To have service user issues as **standing item** on agenda
 - o To **provide training or induction** to the committee for new representatives
 - o For existing committee members to **undertake some training**, reskilling or upskilling in service user involvement
 - o To generally foster a **service user friendly atmosphere**
 - o To ensure a **clear terms of reference for the committee itself**
 - o To ensure meetings are **run well and regularly**
 - o To **regularly and collaboratively review the effectiveness** of the committee
 - o To **invest resources** for remuneration and training There are a number of **supports for people with self-experience and steps they can take to promote success**. The two most popular supports were training and the development of a peer group, while the options of having a mentoring support was also highly valued
 - o To **establish a peer group** in the area from whom representatives can be drawn
 - o To **provide information on relevant committees**, structures, services professionals
 - o To provide **skills training** on committee participation, negotiation, conflict management, professional communication
 - o To provide **mentoring support** where needed to support the PWSE/supporters to plan and review their participation
6. There is general **support for remunerating (paying) PWSE/supporters for their role** to promote equality among committee members and acknowledge the contribution of their time.

SUMMARY OF FINDINGS AND RECOMMENDATIONS

SUMMARY OF RECOMMENDATIONS

These recommendations were developed and based on suggestions provided by research participants and good practice identified in other research and guidelines. A group of professionals and people with self-experience /supporters then reviewed these recommendations in a workshop where they were asked to state:

- o If they felt the recommendation would be valuable and useful
- o What would make this recommendation succeed?
- o What would make it fail?

The feedback of the group was used to refine the recommendations to ensure they would be as ambitious and as practical as possible.

- 1 Develop a **local plan, co-designed and agreed by PWSE and supporters, and statutory and voluntary mental health services**, for promoting involvement of PWSE in the area. This strategy should:
 - a. Involve all relevant partners with enough seniority to ensure buy-in and implementation
 - b. Establish clear goals, objectives, timeframes and an agreed oversight structure
 - c. Be linked to national policy
 - d. Identify expected standards for committees wishing to involve people with self-experience and mechanisms by which committees can evaluate themselves in relation to this issue
 - e. Identify other committees or groups where the

service user voice is absent and may potentially be interested in having a service user representative (e.g. outside of mental health services)

- 2 Establish a **representative/peer group** of people with self-experience/supporters, **led by people with self-experience and supporters**, with appropriate and sufficient support provided by local professionals to peer leaders to get this off the ground and promote sustainability. The group should establish procedures for the identification, nomination and election of representatives, as well as a clear role description and length of service (see following recommendation).
- 3 In line with national strategy, the **Representative/Peer Group**, with support from relevant professionals, should **develop a role description for the PSWE/supporter representative role** which includes:
 - a. Key activities and responsibilities
 - b. Reporting requirements to
 - i The representative group
 - ii Committees
 - c. Duration of term
 - d. Mechanism for addressing concerns by other representatives/PWSE
 - e. Mechanism for stepping down from the role at an earlier point than scheduled
 - f. Range of supports available
 - i Mentoring
 - ii Training opportunities
 - iii The representative peer group
 - iv Remuneration arrangements

This role description should aim to be in line with national standards.

4 Develop a training and information programme for PWSE /supporters. This should be an applied participatory skills module. It should be accredited, meaning there is an optional assessment for those who want accreditation. This training and information programme may involve:

- Knowledge on mental health services, structures, roles and strategies
- Committee skills
- Leadership and communication skills
- Professional negotiation and conflict resolution skills
- Understanding outcomes, impact and assessing success of committees and strategies
- The application of learned knowledge and skills to committees and the development of agreements

Such a model will require partner organisations:

- **HSE/Mental Health Services:**
 - To input on the development and/or delivery of the training module
 - To involve PWSE/supporters on their committees in line with local agreements outlined in recommendation 1
 - To commit one member to act as a key contact or support for the PWSE/supporter and provide an applied learning environment
- **Adult Education Service:**
 - To accredit the training module

5 Develop an information pack and training options for committees. Information packs may include:

- A background in national strategy, and local and national practice
- A full and detailed description of the service user role, responsibilities, remit, expectations and limitations
- A copy of the local plan for the engagement of PWSE /supporter involvement (as outlined in recommendation 1)
- The standards of good practice for committees wishing to involve PWSE/supporters
- Descriptions of potential support options, including required time and resources, that can be provided by the committee to a PWSE/supporter in order to promote meaningful and effective engagement
- A self-assessment or readiness tool for committees to review where they are at, and what steps they may need to take in order to meaningfully and effectively engage a representative
- A collaborative committee review tool which addresses key good practice points for engaging service users

Other preparatory supports for committees may include:

- Information sessions
- Options for collaborative preparatory work, such as Trialogues, to support effective induction and on-going engagement
- Facilitated sessions to analyse and challenge committee culture, personal bias, etc.

1 INTRODUCTION

1.1 OVERVIEW

Service user involvement in the development, delivery, and evaluation of services is becoming an increasingly important way for health care services to improve what they do across much of the developed world. In recent years, mental health services are moving away from institutionalised care to community care.

This movement is driven by and facilitates a focus on recovery led by people with self-experience. People with self-experience are experts by virtue of their experience in mental health services, and the importance of this role is increasingly acknowledged.

These trends create fertile ground for the involvement of people with self-experience in their own mental health care and in the development of services provided to them and their peers. In Ireland, *A Vision for Change*, our national mental health strategy, acknowledges that mental health services benefit from greater involvement of people with self-experience.

The report highlights that in recent years Ireland has experienced an exciting increase in activity in this area with the growth of Dialogues, leadership programmes and capacity building programmes focused on supporting involvement of people with self-experience in service planning and review.

This report is the result of an action research project which involved people with self-experience and their supporters in the development of the research brief, as research participants, in the reviewing of the report, and in the co-design of recommendations. The findings

and recommendations in this report were generated from research involving 41 people in the Dublin 10 area, including those with self-experience of mental health, their supporters, and professionals who serve them. The research sought to understand what is needed to support greater involvement of people with self-experience of mental health and their supporters on decision making bodies, such as management groups and committees.

This research aims to inform the development of a programme of supports to build the capacity of people with self-experience and service providers to meaningfully engage in management teams together. The D10 Be Well Group, who commissioned this report, hopes that by providing a range of supports, including training, information, and on-going professional support, there will be effective, meaningful engagement between stakeholders in the D10 area. This process builds on the considerable work that has been undertaken previously by people with self-experience and organisations that support them such as the D10 Be Well Group, Shine, EVE, the HSE, the National Learning Network, the Irish Advocacy Network, and DCU.

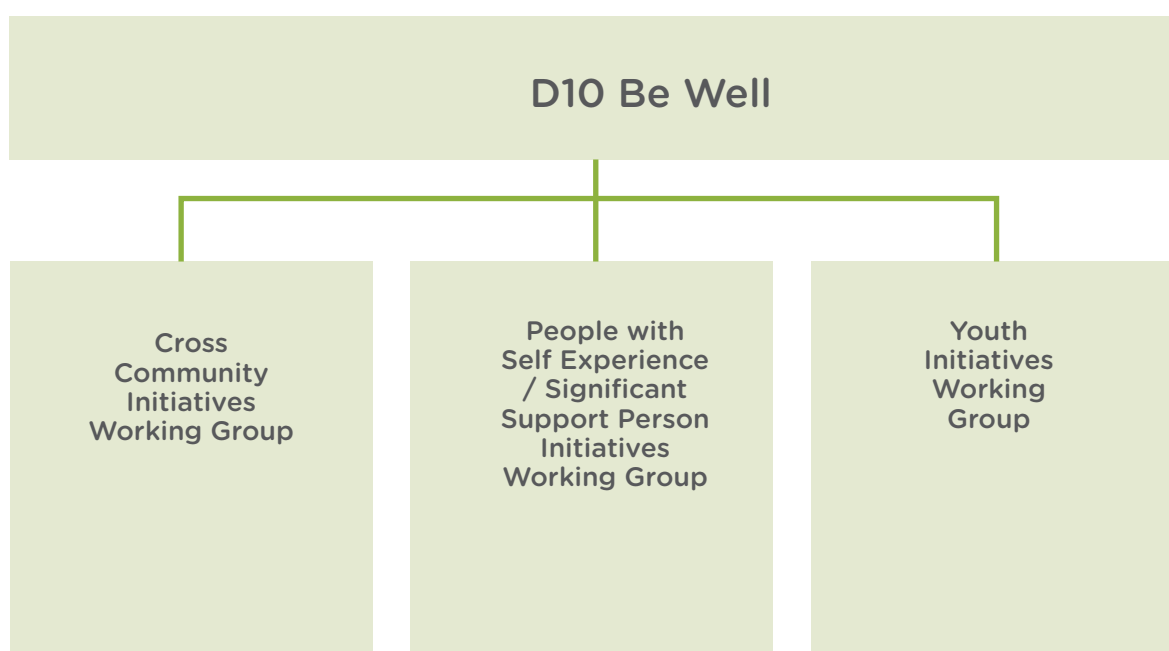


The literature review reveals that with broad consultation, careful planning, transparent processes and a willingness to take risks and learn, people invested in mental health services in Ballyfermot can achieve their shared ambition for the meaningful, effective engagement of people with self-experience in service planning, review, and development in the Dublin 10 area. It is hoped that this research is part of the movement towards this goal.

1.2 ABOUT D10 BE WELL

The D10 Be Well Group is a forum for addressing mental health-related issues in the Ballyfermot area. It consists of people from a broad range of backgrounds and professions from a wide range of health and social care organisations, as well as users of these services. The group consists of one core group and three working groups, as shown in the diagram below. The working group structure reflects the three priority areas identified by the group:

FIGURE 1: D10 BE WELL OVERSIGHT STRUCTURE



The People with Self Experience/Significant Support Person Initiative Working Group oversaw this research. The membership of that group is:

- o Niamh Crudden (Ballyfermot/Chapelizod Partnership)
- o Collette Herra (Friend & Carer support group)
- o Nicole Murphy (HSE Occupational Therapy)
- o Caroline Brogan (Rainbows Clubhouse)
- o Thomas Kenny (Rainbows Clubhouse)
- o Susan Kehoe (HSE Occupational Therapy)
- o Susan McFeely (Shine)
- o James Walsh/Una Kinnane (Irish Advocacy Network)

1.3 THE NEED FOR THIS RESEARCH

The lack of representation from people with self-experience of mental health issues and their family members in decision making fora across the Dublin 10 region was identified as a key concern of the group in 2013 . A working group was established in 2014 to develop initiatives to support people with self-experience of mental health issues and their families to to confidently participate in decision making in meaningful ways at various levels in service management.

The diagram opposite depicts the overall vision and mission of the D10 Be Well Group, as well as the specific goal of the People with Self Experience/Significant Support Person Initiative Working Group:



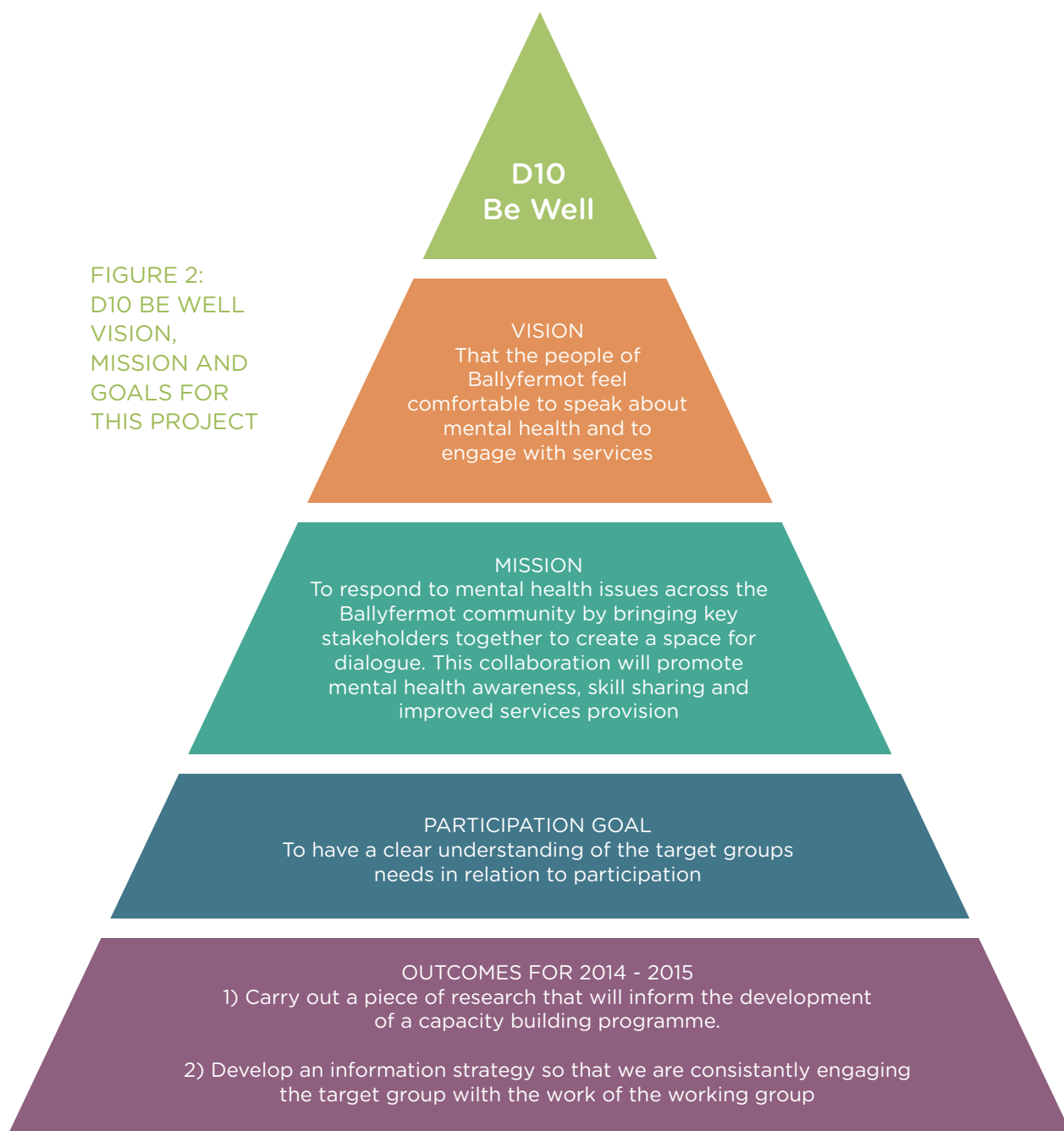


FIGURE 2:
D10 BE WELL
VISION,
MISSION AND
GOALS FOR
THIS PROJECT

This research fulfils outcome one: to carry out a piece of research to inform the development of a capacity-building programme and other supports that will promote meaningful engagement of people with self-experience and family members in decision making fora in the Dublin 10 area.

An aim of the research is to better understand the needs of people with self experience and their supporters in relation to participation within the context of a disadvantaged community. The research will inform the development of a training package which will be delivered to people with self-experience and their supporters, empowering them with the knowledge, skills and confidence to sit on a decision making bodies. This project will support individuals to practice as effective advocates and participate meaningfully within the mental health services and the community. The project, which the group have named *Our Service, Our Say*, successfully acquired funding from Genio in 2014.

2 CONTEXT: LITERATURE & POLICY

2.1 INTRODUCTION

This chapter of the report presents a summary of what is currently known in relation to service user involvement in mental health services.

The first explores different ways that service users are involved in mental health services. A summary of the benefits of service user involvement both for individuals and for service providers is followed by a description of the barriers that prevent service users from engaging in structures effectively.

The final section of this chapter provides an overview of national priorities in Ireland in relation to service user involvement, examining developments to date within Irish mental health service structures and national discourse on mental health, but also the ongoing concerns and limitations of these structures.

2.2 WHAT DOES SERVICE USER INVOLVEMENT IN MENTAL HEALTH SERVICES MEAN?

Service user involvement challenges traditional care models where decisions are made on the service user's behalf. The service user involvement approach frames the service user as an expert-by-experience with a "privileged understanding of their mental distress, what they need for their recovery, and how current service provision is, and is not, providing it" (8). This creates a more equal status between service user knowledge and professional knowledge (9). Service user involvement seeks to increase the direct and real influence of service users regarding their own treatment as well as the delivery of services, generally. It tries to ensure that services are provided in line with service user or consumer needs (10)(2).

Service user involvement in the development, delivery, and evaluation of services is becoming increasingly important within health care across much of the developed world; many countries have implemented changes in law and policy to help service users to regain control over their health care decisions (1)(2)(3)(4)(5). The movement towards service user involvement in mental health has happened alongside a shift toward community-based services and away from institutional care (2). This drive has been largely influenced by the recovery movement which seeks to empower service users to collaborate in their own care and in service development. The recovery movement also focusses on human rights and how they relate to mental health services (7). Tse et al (2011) described service user participation in mental health services as the "hallmark of modern recovery-oriented services" (11).

2.3 THE IMPORTANCE AND BENEFITS OF SERVICE USER ENGAGEMENT

A growing body of research shows positive outcomes from developing a collaborative approach to mental health care (9). The inclusion of service user experiences and perspectives in the development and delivery of services and the development of positive collaborative relationships between service users and professionals has been found to produce better outcomes for service users such as:

- Improved self-esteem and confidence (5)(12)
- Improvement in the provision of information and accessibility of services (12)
- Certain therapeutic benefits (12)
- The development of partnership and advocacy skills and challenging traditional power imbalances between service users and professionals (4)
- Improved staff attitudes to service user participation on mental health service committees and better run meetings as rated by professionals (13)

In a summary of the evidence base for user involvement in mental health, Tait and Lester (2005) summarise why user involvement is important in terms of the following six key factors:

- 1 *Expert patients*: recognising service users' experiences as an important and useful resource that can help improve individual care and services generally
- 2 *Differences of perspective*: different perspectives and priorities of service users and professionals can provide insight that can challenge assumptions and help people to think differently or more creatively
- 3 *Insight into mental distress*: service user experiences can improve understandings of mental distress
- 4 *Alternative approaches*: understanding alternative supports or recovery mechanisms service users have tried, such as complementary therapies
- 5 *Involvement as therapy*: the potential to increase service users' self-confidence and esteem and to learn new skills
- 6 *Promotion of social inclusion*: acknowledging that people with mental illness are amongst the most socially excluded and isolated within society as a consequence of distress and impairment, diminished social roles and networks, perceived or experienced stigma and discrimination, and unemployment (14)
- 7 Understanding the potential benefits of service user involvement for the individual, for the organisation, and at a sectoral level can support buy-in from service users, service providers, and people involved in the planning and development of services. This encourages interested stakeholders to come together, explore the various models for service user involvement, and build one that suits their needs and their structures.

2.4 THE WAYS THAT SERVICE USERS CAN BE INVOLVED

The ways that service users are involved range from participation in decision-making about their own care, to a broader level of participation in service planning, delivery and evaluation, and in training and research (14). Peck et al (2002), drawing upon various theoretical models of service user involvement, described three distinct modes of service user involvement (both in their own care, and at a broader level):

Level 1: involvement as recipients of services

Level 2: involvement as participants within a consultative context

Level 3: involvement as active and autonomous agents (14)

It is worth noting that this research does not focus on **Level 1**, but on **Levels 2 and 3**: the involvement of service users in service planning and review. The World Psychiatric Association (WPA) note a number of ways that service users have been involved in service planning and review in various countries, including:

- Monitoring of services and development of outcome measures in a number of countries
- Training as mental health workers in the UK
- Being part of collaborative committees to plan and manage services in various countries
- Being employed as consumer consultants in Australia
- Being part of a Trialogue approach. This is a forum of shared learning that consists of regular discussion meetings outside of clinical and work environments between three stakeholder groups: service users, family members, and mental health professionals. Organisations in Germany and Austria have found that the Trialogue approach affords an effective yet inexpensive way to learn collaboratively (6)(7).

2.5 SERVICE USER ROLES ON COMMITTEES

The list in the previous section by the WPA identified a number of opportunities for, among other things, service users to participate in decision-making committees. When considering this, it is important to realise that there are a number of ways a service user's presence on a committee can be interpreted: are they there in a personal or symbolic capacity, or are they actually representing a cohort of service users? Pitkin outlines three ways that service user presence can be interpreted (13):

- As a **formal** representative, where formal devices and procedures, such as elections, are used to determine and designate representation
- As a **descriptive** representative, where the service user is seen to be similar to the average person they represent
- As a **symbolic** representative, where the participant may be seen, and may view themselves as symbolising representation, but in fact have no formal constituency to call upon or be accountable to

This issue must be considered in detail by any group considering pursuing this approach. Regardless of the method chosen, anticipating what barriers need to be managed or surmounted is necessary to ensure that any service user involvement is a positive and meaningful experience.

Anticipating what barriers need to be managed or surmounted is necessary to ensure that any service user involvement is a positive and meaningful experience.

2.6 BARRIERS TO PARTICIPATION

Although user involvement is a priority goal for many service providers, doing it effectively has proven difficult. Barriers arise in terms of “translating the rhetoric of empowerment and participation into practice”(12), meaning it's easier to describe and discuss it than make it real. The types of barriers to making it work in reality include unequal cultural, physical, mental, economic, and time resources; inequalities in power structures and empowerment; prejudice and discrimination; and a lack of respect for experiential knowledge and expression (15)(12)(1).

McDaid (2009), a researcher who self-identifies as a service user, highlights that in practice, in terms of user involvement within mental health committees, the following barriers may be limitations for the person with self-experience themselves, or limitations on the part of the committee (15):

Lack of knowledge: technical, policy, how committees work

Culture: jargon, power imbalance arising from lack of payment, dominating professional interests, lack of authority in setting the agenda, perceived inappropriateness of emotional discourse

Attitudes: lack of respect for service user views, perceptions of the capacity of the representative by the committee, a perception by the committee that the role is not representative

Personal capacity: stress as a result of participation, lack of time or resources, impaired mental stamina

A **lack of negotiation** between meetings and a lack of support

McDaid highlighted the range of cultural barriers to equal and inclusive participation service users experience, including tokenism, disrespect, and lack of influence, and that equality of presence (that is, the right to be present in decision-making forums) does not ensure equal participation.

McEvoy et al have also identified some structural limitations or barriers which include the need for resources and sustained ongoing support, and for systemic organisational commitment to the facilitation of meaningful participation (16).

It is clear that there are numerous issues that need to be considered and planned for. These may be personal capacity issues for people with self-experience, internal capacity issues for committees, or structural barriers

posed by the organisations in which these committees operate. However, as the following section shows, if these issues are managed well, they are less likely to inhibit effective participation on committees by people with self-experience.

2.7 RECOMMENDATIONS FOR GOOD PRACTICE

In McDaid's research mentioned previously, service users recommended the provision of training in how committees operate, how to read and analyse policy documents, gather evidence, negotiate, conduct and present research, and how to avoid burn-out. They also highlighted the need for clarification of technical language during meetings, provision of accessible summarised information, support of peer capacity-building frameworks, and provision of mentors and peer support were highlighted. Finally, the findings recommended the positioning of service users as respected and authoritative participants within the committee structure with proportional membership to service providers, where service users are protected from physical and mental harm as a result of their participation (15).

Mind, a British mental health organisation, reviewed 15 evaluations of projects that involved service users in service design, planning, development and review. They identified six principles for service user involvement in service design, planning, development and review:

- 1 Taking an assets-based approach
- 2 Building on individuals' existing capabilities
- 3 Establishing reciprocal relationships with mutual responsibilities and expectations
- 4 Peer support networks
- 5 Blurring distinctions between professionals and service users
- 6 Facilitating rather than delivering (17)

The review identified that the strongest projects had each of these principles instilled within their daily practices (17).

The Sainsbury Centre for Mental Health (2010), a pioneering mental health service provider and research organisation in the UK, have evaluated their mental health service user involvement strategy and outlined what they termed 'markers for effective involvement' (18). They recommend services undertaking this firstly acknowledge and promote service users as citizens

with a broader range of human and democratic rights while embedding a core belief in service users as active partners – even if the partnership is unequal. Some specific techniques they mention include:

- Clear aims and limits of involvement, and reviewing progress towards the aims
- Clear and agreed principles reflecting and acknowledging benefits of service user involvement
- Involving front-line staff in promoting service user involvement to support buy in at all organisational levels
- Techniques of genuine involvement should be embedded, continuous and varied
- Service users should be represented directly, collectively, or via peer advocates
- All sectors, practitioners and users should plan for models of user involvement which are not tokenistic, undermining, or damaging to self-esteem or well-being

Research in Ireland on the involvement of service users in practitioner education noted that meaningful and genuine involvement of service users within the mental health sector requires a broad approach. This means involving service users at each structural level in the planning, design, delivery, evaluation, and management of programmes in research and teaching, and recruitment and selection of care providers (4). This report maintains that there are a broad range of factors that must be considered in planning for service user involvement – primarily, and similar to the Sainsbury project mentioned previously, ensuring baseline values and principles are used to create a genuinely collaborative and meaningful process. Practical steps and supports that address as many as possible of the barriers outlined in the previous section of this chapter must be part of this process.

2.8 CAPACITY BUILDING FOR COLLABORATIVE WORKING

2.8.1 OVERVIEW

The previous section highlights that there are a number of barriers that may prevent mental health service users effectively participating on committees or in service planning and review or evaluation structures. One way to proactively manage these barriers can be to support capacity-building of people with self-experience and/or their supporters, and to support capacity-building or cultural change in decision-making structures.

Participation in collaborative structures places unique demands on participants, requiring the ability to adopt different and unfamiliar perspectives, attitudes and effective engagement in new contexts, which requires the development of various skill sets. As the degree of effectiveness of any collaborative effort is influenced by member skills, knowledge, and attitudes, it is important that member capacity is built upon and supported (21). Increasing skills of potential representatives is the primary aim of capacity building programmes. While there is a lack of quantitative evaluations of capacity building programmes and their outcomes, there is a substantial and growing body of research literature highlighting methods and factors that contribute to the success of capacity building programmes. Findings are highlighted in the following sections.

2.8.2 TRIALOGUES

The notion of empowerment is at the heart of the recovery and service user involvement movement – the core of capacity building frameworks which adopt an assets-based focus. In order to work towards achieving a sense of empowerment, those involved must first understand clearly what it entails. Amering, Mikus and Steffen divide empowerment in terms of three key attributes: self-determination, social engagement, and sense of personal competence (19). They describe the use of the Trialogue model (in Austria) for achieving empowerment of service users, family/carers, and empowerment of mental health workers. The Open Dialogue model was developed as an alternative approach to the traditionally psychiatric-focused treatment of schizophrenia and psychosis in Western Lapland (20).

A Trialogue involves participants of various relevant groups, including service users, family/carers, service providers, and advocacy groups; meeting to discuss issues around mental health in a neutral setting, away from the constraints and power dynamics of traditional

mental health settings; and identifying potential barriers and collaboratively identifying potential solutions. Amering et al highlight a growing body of evidence for Trialogues which shows the development of new and effective communication styles, of knowledge by all participants, and of the model's therapeutic benefits. Amering et al further highlight the benefit of the approach in that it can be adopted within many different levels and contexts of mental health work (19). The Mental Health Trialogue Network Ireland (MHTNI) was established to generate proactive communication about mental health in Irish communities through Trialogue, which they describe as a 'powerful open dialogue and participatory process'. Mac Gabhann et al (21), in their review of the MHTNI, highlighted the sense of empowerment, improved sense of self and confidence, and further development of communication skills gleaned from participation in Trialogue meetings. They describe it as a "rich learning experience, an education of each other that enhances how they comprehend others and their own experiences" (22, pg. 3).

2.8.3 PEER SUPPORT, MENTORING AND SELF-ADVOCACY

Peer support and mentoring offers an individual the support of a person who has overcome or lives with difficulties and challenges similar to their own. The UCC UpLift Peer Mentoring programme trained students who have self-experience of mental health difficulties to support and mentor other students experiencing mental health challenges (22). The training programme consisted of educating students about mental health perspectives, such as the biopsychosocial and recovery models, as well as training in certain personal skills and competencies, such as active listening and referring to services (22).

When the programme was evaluated, analysis showed an increase in mentee self-esteem, a reported expansion of social support network by three quarters of mentees, enhanced engagement with campus life, and a decrease in the stress levels of three quarters of mentees (23). Mentors reported an improvement in their communication and interpersonal skills, a sense of accomplishment, increased awareness of their own learning styles, and personal therapeutic benefit as a result of their participation (23).

In an evaluation of self-advocacy training delivered by the Irish Advocacy Network, which provides peer advocacy for individuals experiencing mental ill health, the vast majority of participants indicated that they

believed their level of skills and knowledge of advocacy had improved as a result of the training. They also highlighted increased confidence, self-esteem, and assertiveness (23). Similarly, in an evaluation of the Day to Day Living Programme initiated by Community Mental Health Australia (CMHA), 82% of participants indicated they agreed or strongly agreed that they had gained new information and ideas to take back to the programmes within which they were involved, while 86% indicated that they agreed or strongly agreed they had made valuable new connections through their participation in the programme (24).

The DCU leadership programme, which was linked to the development of the Trialogue network mentioned previously (21), was a programme that created an active, applied learning environment. It combined individualized learning and support with a group forum for discussing how to promote change in healthcare. Service providers played an active role in supporting participants on the programme with a practical change project as well as individualized learning. The content of the learning and capacity-building programme included:

- Healthy systems and social context, and social, political and cultural influences that impact on services and service improvements
- Citizenship and social inclusion
- Leadership, values and principles
- Change and organizational development
- Project planning, process mapping, and project outcomes
- Academic writing

Training, capacity-building and mentorship can provide invaluable support and promote positive outcomes, both for those who receive the support and those who provide the support. Training and mentorship may form an important part of a programme of actions to promote service user involvement in mental health service decision making.

2.8.4 SUMMARY

This section highlights the various factors to be considered and supports that can be provided to service users and professionals to help establish meaningful and effective collaboration in mental health service structures, including, particularly, decision-making committees.

This section also has highlighted the need for committees to support equal opportunity for service users to participate in mental health decision-making structures in a manner that is both empowering and safe. A clear understanding of some of the challenges and barriers to service user involvement and an agreed way of overcoming these barriers can help to inform the development of collaborative working partnerships between people with self-experience and professionals.

A programme of supports targeted at both people with self-experience and committees can help to challenge traditional paradigms and stigmatisation of mental ill health and facilitate a culture change that empowers service users. Promoting service user involvement can help to create context within which the value of the individual (and collective) experience of service users is respected as a unique and authoritative perspective to be heeded.

2.9 THE SITUATION IN IRELAND

2.9.1 STRATEGY

Service user involvement within the mental health sector is a comparatively new development in Ireland. *A Vision for Change: Report of the expert group on Mental Health Policy* (25) reflects the substantial paradigm shift in international standards of mental health service provision, which emphasises a more holistic, socially inclusive, recovery-oriented model where collaborative participation between the service users and professionals aims to empower the user and look beyond mere reduction of symptoms (22)(26)(27)(28)(29).

The National Strategy for Service User Involvement in the Health Service 2008 – 2013 has identified the importance of service user involvement and of providing supports and resources to make this effective (30) as well as a number of other strategies such as The Health and Social Care Regulatory Forum's *Framework for Public and Service User Involvement in Health and Social Care Regulation in Ireland* (36), and by organisations such as HIQA (31), the Mental Health Commission (27), and the HSE Mental Health Division (32).

The Mental Health Division highlights the need for building on the capacity of service users, families, and carers to partake in the design, delivery, and evaluation of services through the delivery of identified necessary training interventions. They discuss the need to establish in full the "Office of Service User Engagement as an integral component of the Mental Health Division", and appoint "a service user member on each area mental health management team" (32).



2.9.2 IMPLEMENTATION

One of the key tasks of the National Service User Executive (NSUE), established in 2007 under A Vision for Change, is to establish a national network of service users (33). The NSUE has published an annual report, *Second Opinions*, since 2009, which outlines response to an annual survey of its members on their experiences as service users in Ireland in terms of the implementation of the recommendations of A Vision for Change (33)(34)(35)(36)(37).

These reports have highlighted that, although considerable improvements have been made, overall progress has been slow. The most recent survey, published in 2013, saw a 6% increase in participants reporting direct involvement in the development of their own individual care plans, representing a 2% rise on the 2011 figure. The report from 2012 acknowledged that “The reality is that significant involvement of service users and their families in the planning and delivery of mental health services at both national and local level is still in its infancy, and mostly noticeable by its absence” (33, pp.9).

As with the NSUE, reports from the Mental Health Commission since 2011 have demonstrated a general dissatisfaction among service users and families about the level of involvement of in-service review and planning (38). They highlighted a need to engage with service users and carers in a meaningful way, to provide training on the principles of the recovery model, and to incorporate collaborative teamwork developed and delivered by service users and professionals (39)(40).

The Inspectorate of Mental Health Services, which is committed to the active participation and inclusion of service users, carers/family representatives, consumer panels, and advocates in the inspection process, published a summary document in 2013 of feedback received at its fourth National Overview meeting (38). Feedback at this meeting included an expressed concern surrounding the difficulty of establishing consumer panels, and a concern that “*patient confidentiality and multidisciplinary teams can offer a pretext for excluding family/friends from decision making*” (38, pp. 6).

2.9.3 CONCLUSION

This literature highlights the fact that not only is it right and fair to involve service users in decisions about their care and services generally, but that service user involvement should be recognized as a measure of quality that improves the effectiveness of services generally. Examination of literature in Ireland shows that, although improvement has been made, it has been slow and fallen far short of objectives set out in Vision for Change, thus placing the establishment of collaborative partnership within mental health structures as an ongoing key objective.

The benefits of service user involvement have recently begun to be documented, for individuals, for service providers, and for society generally. A worldwide movement towards increased service user involvement is reflected in key Irish policy documents. However, practice on the ground in Ireland shows a need for increased attention to this field at a systemic level, locally, regionally, and nationally.

Considering a broad variety of approaches and techniques can ensure meaningful and effective service user involvement, but demands an understanding of the wide ranging barriers and challenges to effective, equal, and genuine service user involvement. It is an area that requires significant efforts and consideration in order to bring practice in line with policy and strategic aims as well as international standards of best practice.

To overcome the barriers identified in the literature and in local reports, achieving effective service user involvement demands commitment, time, strategic planning. Financial resources and infrastructures are needed to support such an initiative as a sustainable and comprehensive shift from traditional professionally led structures towards a collaborative partnership between service users, service providers, and policy makers (15).

3 METHODOLOGY

3.1 OVERVIEW

This chapter describes how the information for this research was collected, how the different people who took part were recruited, and what steps were taken to ensure that everyone who took part in the research was safe.

3.2 APPROACH

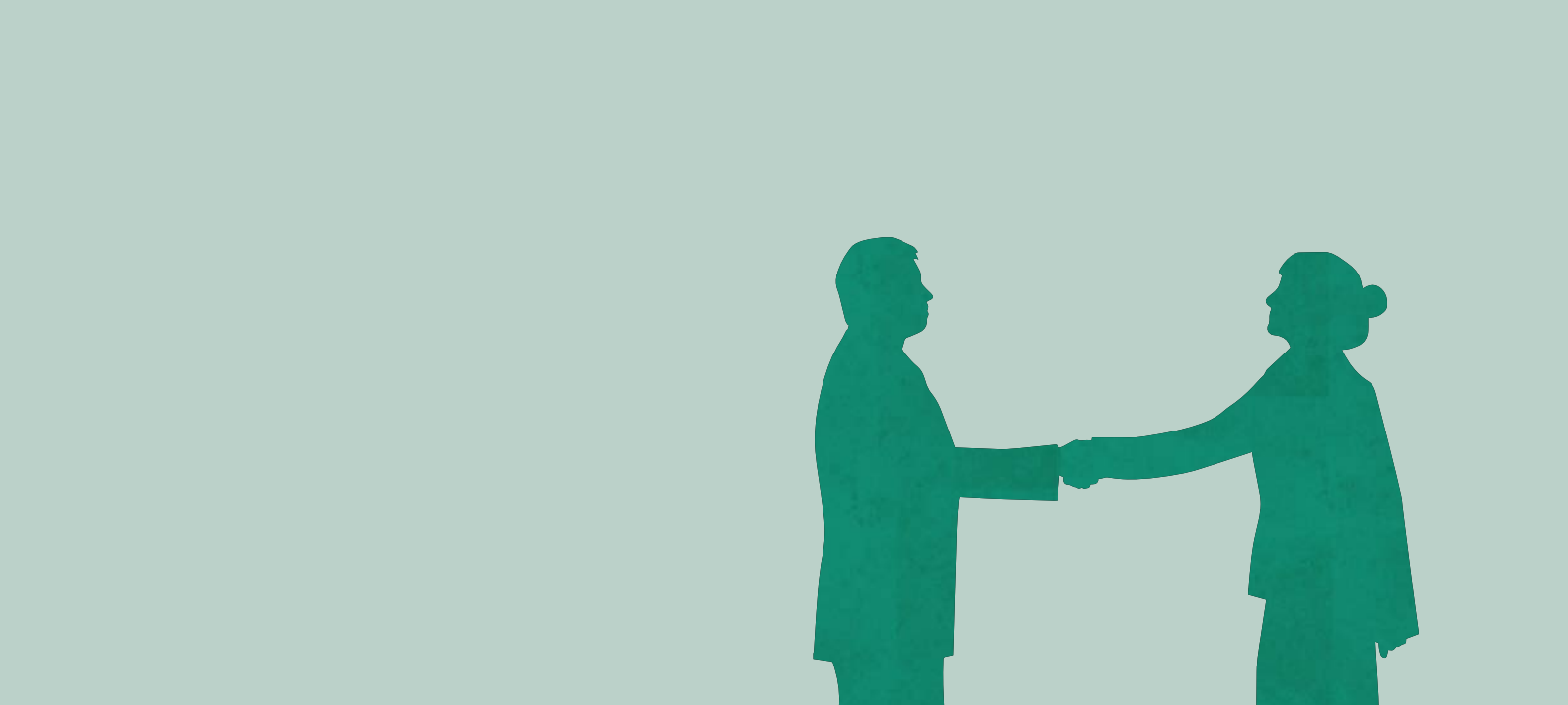
This research was undertaken through an action research approach. Action research is a way of doing research in order to solve real problems in organisations, where academic knowledge is married with the everyday knowledge about organisations and the people involved with them in order to find solutions. It has been described as being "simultaneously concerned with bringing about change in organizations, in developing self-help competencies in organizational members and adding to scientific knowledge [...] it is an evolving process that is undertaken in a spirit of collaboration and co-inquiry". (41 p 439)

This research was undertaken as part of an initiative to promote the involvement of people with self-experience and their supporters on decision making bodies. It involved the collaborative working of practitioners and people with self-experience/supporters at all stages of the research, the development of the research brief, as research participants, in the reviewing of the report, and in the co-design of recommendations.

3.3 AIMS OF THE RESEARCH

The aims of this research were to gain an understanding of:

- The challenges to participation and the supports required for individuals with self-experience of mental health difficulties and their supporters
- The perceptions of relevant professionals of the participation of PWSE/supporters, the potential challenges they may face, and supports they may need.
- Recommendations for the design of a training programme to address the needs of the target group



3.4 METHODS

3.4.1 INTERVIEWS

All information for this study was collected through interviews with people from different target groups, as shown in the table below. In total, 41 people participated. Interviews were conducted either in person in the Ballyfermot Primary Care Centre, in the Rainbow Clubhouse in Ballyfermot, or by phone. Interviews lasted on average 35 minutes.

TABLE 1: STAKEHOLDER GROUPS

Stakeholder Group	Number of Participants
PWSE	23
Supporter	5
Self-Experience and Supporter	2
Mental Health or Healthcare Professionals	11
Total Participants	41

Of the 30 people with self-experience or supporters who participated, the views of 28 were included. One could not be included because the interview ended very soon after it began, as the person was feeling unwell. Another was not included because of a technical difficulty.

3.5 ENGAGING PARTICIPANTS

3.5.1 CRITERIA FOR INVOLVEMENT

The criteria for participants to be involved in this research were that they:

- lived in Ballyfermot or surrounding areas, or,
- worked in mental health service provision or associate service provision in Ballyfermot, and,
- had self-experience of mental health issues, or,
- had supported someone with experience of mental health issues, or,provided relevant services.

3.6 RECRUITMENT

For people with self-experience and their supporters, a multi-faceted approach to recruitment was used, which included:

- Arranging to have 'drop-in' sessions in two mental health services, where researchers met with people using the service that day
- Advertising the research by accessible, engaging posters in relevant local services
- Informing local service providers (gatekeepers) of the research and seeking their support in recruiting suitable individuals by providing accessible recruitment and study information to gatekeepers and service users interested in the research
- For professionals, purposive sampling was used, meaning that key personnel from the area working in mental health were invited by the Steering Group to participate. Targeted professionals included:
 - Those in management positions on the Area Management Team
 - Those working in community voluntary mental health services in the area
 - A number of front line service providers in day and community services

3.7 RESEARCH ETHICS

3.7.1 CONSENT

Consent to participate in interviews was obtained at the beginning of the interview through discussion with the participants. They were fully briefed on:

- The purpose of the research
- The reason they were invited to participate
- The voluntary nature of participation and their capacity to withdraw at any point up until a week before the date of the final draft of the report
- Issues around confidentiality and reassurance regarding implications of non-participation on future service provision, namely that non-participation would not in any way impact on future service delivery (where relevant, e.g. for people using services)

3.7.2 ETHICAL APPROVAL

A submission for ethical approval was submitted by the Steering Group to the St James Hospital and Adelaide & Meath Hospital Dublin Ethics Committee. The ethics application covered all aspects of the research process in detail. Ethical approval was granted for this project.

3.7.3 RESEARCHERS

The researchers have professional qualifications in service provision to vulnerable groups (social care and psychology) with third level research qualifications. Researchers also have extensive experience working with sensitive issues both as service providers and researchers. This helped to ensure that any potentially difficult or sensitive issues would be handled in a professional and compassionate manner.



3.7.4 ETHICAL CONCERNS

Participation in this research involved relatively low risks to the health and well-being of participants. The research involved no administration or withdrawal of treatment or services, no experimental design, and little opportunity for discussion of triggering or traumatic subject matters. In all circumstances, the researcher ensured that participants were fully informed, had a clear understanding of the research, and could confidently and enthusiastically consent prior to starting an interview.

The primary ethical concerns identified for this research included the risk that during the course of the interview, sensitive or difficult issues may arise in the discussion that may be related to an attendant stressor or life issue for participants. Difficult feelings may not manifest immediately in the interview, but could cause distress at some time after the interview. Steps taken to prevent or to support someone experiencing distress included:

- Monitoring levels of distress during the interview by researchers who will regularly check in with the participant throughout the interview using questions such as, 'How is this for you?' and 'Are you feeling OK to continue?'
- Where distress was apparent, offering a call from a gatekeeper to the client within two days of the interview, which only happened in once instance
- Where serious distress was apparent, the client was immediately referred, with their consent, to a mental health specialist identified by the research Steering Group. In only one instance did a participant appear to have a difficulty or trigger to deal with in an interview. The interview was immediately, sensitively concluded and the support staff working with the person were alerted to this with the client's permission.

In addition, there was a concern that participants who were users of services would feel compelled to participate in order to continue to receive services. At all points prior to interviews, gatekeepers and the researchers ensured that the interviewees understood clearly that their potential non-participation in the research would have no impact on their access to supports, and that if they did consent to participate in research that they could withdraw at any point up until a week prior to delivery of the report without it having a bearing on any current or future service provision.

At all points prior to interviews, gatekeepers and the researchers ensured that the interviewees understood clearly that their potential non-participation in the research would have no impact on their access to supports.

4 RESEARCH FINDINGS

4.1 OVERVIEW

This chapter details the findings of the research. The findings are arranged thematically and include the following:

- People with self-experience and supporters should sit on decision-making bodies of services provided for them
- Professionals and people with self experience and supporters want to Work together in Dublin 10
- Previous experiences have been mainly positive but also negative
- There are a various concerns by all stakeholders to consider and anticipate
- Health difficulties may manifest and can be managed
- There are steps committees can take to promote success
- There are a range of supports for PWSE /supporters that could promote success
- There is general support for remuneration and practical supports

4.2 PEOPLE WITH SELF-EXPERIENCE/SUPPORTERS SHOULD SIT ON DECISION-MAKING BODIES OF SERVICES PROVIDED FOR THEM

4.2.1 OVERVIEW

Both professionals, people with self-experience, and their supporters were asked, “Do you think people with self-experience of mental health difficulties and their supporters should sit on committees that make decisions about the services they use?”

Among professionals, the support was unanimous: all professionals felt it was a good idea. The majority of the PWSE group /supporters – 25 people out of 28 – felt it was a good idea. Two people were unsure, and one person did not agree that it was a good idea.

FIGURE 3: PWSE/SUPPORTER VIEWS ON WHETHER PSWE/SUPPORTERS SHOULD JOIN COMMITTEES





4.2.2 REASONS THIS WAS SUPPORTED: PWSE/SUPPORTERS

The following is a list of reasons given by people with self-experience/supporters who felt involving people with self-experience/supporters on committees is a good idea.

- a. **Unique Perspective:** When asked why it was a good idea, the majority of people with self-experience and their supporters (16 out of 28) felt that they have an understanding of services and mental health difficulties from a unique perspective different to that of professionals, and that this perspective could help to improve services. Generally participants felt that without personal experience, professionals would have much more difficulty understanding the concerns of PWSE and their supporters:

We're the ones who know what we need. Decisions are always better coming from the bottom up rather than the top down. (PWSE #6)

- b. **Right to Influence:** Six people said that it was a matter of rights; people with self-experience have a right to influence decisions about the services they use. There was a sense that it was unjust for a range of other people to be making the decisions without the involvement of those people most affected by and concerned with the services:
At the end of the day, it's about us.... We should have our say. We should have the opportunity to ask and understand. (PWSE #25)
- c. **Individual Benefits for the Person on the Committee:** Four people highlighted that it would be good for the representative themselves to learn more about services and structures, or to feel heard directly by people on committees:

They should have their voices heard...speaking up for themselves might make them feel better. Speaking for other people too. (PWSE#27)

- d. **Support New Service Users:** Three people felt that people new to services who may have concerns but are afraid to say them to their individual service provider would benefit from having a representative communicate their concerns and issues up the line anonymously:

For new service users it can take a long time to get comfortable saying your problems and a service user on the committee can access the people who make decisions and tell them the problems. (PWSE #5)

The one person who did not feel it was a good idea felt that it was somewhat redundant, as staff would not respect what the person had to say. This concern was shared by many other participants as shown later in this section of the report.

4.2.3 REASONS THIS WAS SUPPORTED: MENTAL HEALTH PROFESSIONALS

The following is a list of reasons why mental health professionals felt having people with self-experience/supporters involved on committees and decision-making bodies is a good idea:

- a. **Unique Perspective:** As with PWSE/supporters, the most common reason cited by professionals – ten out of eleven people – was that the unique perspective of people with self-experience and their supporters could help to improve services, given the fact that they have experienced both mental health issues and mental health services from a different angle to other people on committees:

When we are making changes to services, it's un-insightful for us to do that without getting their input. It's very real for us and informs our work... Many people with self-experience have so much more than that perspective, they are bringing a whole range of experience, but what's really important for us in this, is that particular perspective. (PR#08)

- b. Help to Focus on Core Issues and Think Creatively:** The second most common reason, named by seven professionals who valued the idea of PWSE and supporter participation, was that at times there was a sense that committees can get mired in discussions on a broad range of matters. Participants felt that having a PWSE or supporter could help to refocus discussions on the core issues that directly affect PWSE/supporters:

My experience tells me that professionals, including myself, can take a business-like perspective... sometimes with a loss of focus on issues that might be most important to service users and families... I've certainly experienced family members or service users come out with a statement or question that makes us stop and think and changes our focus or perspective for the better. (PR#05)

- c. Improve Committees:** The third most common reason, mentioned by five people, was the feeling that the presence of PWSE or supporters would improve practices on the committees, making them more accountable and more professional in the committee space:

It could raise the bar for the behaviour of the entire group, encouraging members to be more respectful in listening to and addressing concerns of all members. (PR#03)

- d. Redress Power Imbalance:** Three professionals highlighted the fact that a power imbalance exists, upheld both by professionals and by PWSE/supporters, which is not ideal. They felt that giving a seat at the decision making table (although not tokenistically, as illustrated in the following section) would help to redress that, consolidate a shared vision between all people concerned, and would support the continued movement of community mental health care towards a recovery model:

Mental health professionals are in positions of power when clients come in at a low ebb and need help. It's an attempt to redress that power imbalance; it will ground us... it redresses the position that we as professionals are put into, as above the patients. (PR#11)

- e. Other:** One professional highlighted the fact that it is beneficial to be in line with national strategy regarding participation of PWSE and supporters in decision making structures, while another person felt that the increased transparency of having someone on the committee would also be helpful.

4.2.4 EXPLORATION OF INDIVIDUAL BENEFITS FOR PWSE /SUPPORTERS

People with self-experience/supporters were asked what benefits they felt they would get from sitting on a committee. Most people mentioned the benefit of gaining a better understanding of mental health services, the views of professionals, and how the system works. The image below shows the most commonly stated benefits.



15

Better understanding of services / structures / professional roles



11

Better understanding of how different organisations / professionals work together



9

Increased confidence in working with professionals



9

A chance to give something back



9

Increased confidence in speaking in public

In addition to those benefits mentioned in the image above, other benefits raised within the interviews were:

- Six people said they would benefit from increased experience of sitting on committees or decision making bodies
- Six people thought they would enjoy an increased ability to advocate for peers
- Three people felt it would be good for their self-esteem
- Two people mentioned it would be good for their CV

As well as this, people mentioned other benefits such as developing a thicker skin and learning about policies.

AWARENESS OF CURRENT PRACTICE: PWSE

While the vast majority of PWSE were in support of the idea of PWSE/supporters participation, less than half of those people with self-experience or supporters interviewed (11 out of 28) said that they knew of a service where people with self-experience or their supporters sat on a committee. One example of such committees is illustrated in the following quote:

It happens here in Rainbow and the Aoibhneas Centre. Members sit together and have their own meeting and then come back and tell the staff what they were talking about. (PWSE #23)

Despite the significant support of and appetite for service user involvement, in the experience this cohort at least, it does not appear to be common practice.

4.2.5 SUMMARY

There was almost unanimous support among professionals and PWSE/supporters for the involvement of PWSE and supporters in decision-making bodies. Most participants felt that the unique perspective that users of services and their supporters can bring to a committee is invaluable and cannot be replaced by any other stakeholder group.

Interviewees stated that the perspective of PWSE / supporters could help to bring real and important focus to committees and consequently to service planning. As well as that, although many PWSE / supporters were not aware of committees where this is happening in the area, it remained a matter of rights, for them, to influence the services that affected them. Participants were vocal about the potential benefits that this diversity could bring to how committees work, to individuals who participate in them, and to individuals who may not attend themselves but whose interests could be represented by a peer.

4.3 PROFESSIONALS AND PEOPLE WITH SELF-EXPERIENCE/SUPPORTERS WANT TO WORK TOGETHER IN D10

4.3.1 OVERVIEW

All participants were asked questions in relation to their interest in further involvement in a project to support increased involvement of people with self-experience/supporters on decision making bodies.

4.3.2 INTEREST IN FURTHER ENGAGEMENT

Participants with self-experience/supporters were asked, "If you were asked to sit on a committee that makes decisions about services, as a PWSE or supporter, would you consider it?" Of the twenty-three participants who answered this question, only six people said that they would not consider it: nine people gave an enthusiastic 'yes' and eight people said 'maybe' or gave a conditional 'yes'. When those who said 'no', 'maybe' or gave conditions were asked if there was anything that would make them more likely to join, answers included:

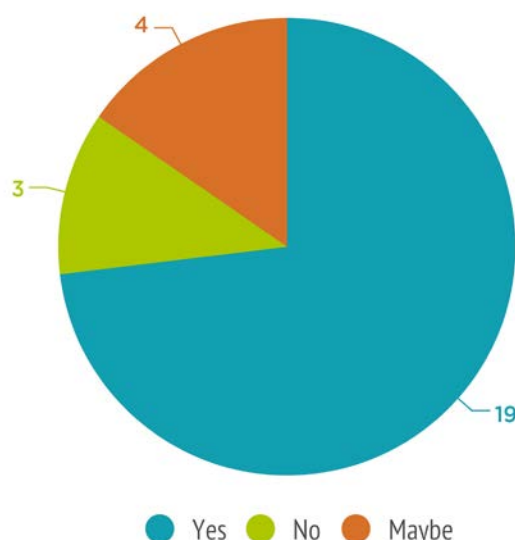
If I thought for one second that I could help someone that even I don't know I'd jump at it. (PWSE #6)

No I just want to look after myself...I wouldn't want to do that; it's not that I'd be afraid. (PWSE#22)

A number of questions were asked of all participants to check their level of interest in engaging in this project further:

- 25 of the 28 PWSE /supporters said they would be interested in hearing more about this project as it develops to support professionals and PWSE / supporters to work together on committees and possibly participating in training
- 23 people said they would be interested in joining a group of peers to develop a pool of representatives (this feedback is illustrated in the graph on the following page)
- All of the professionals, with the exception of one person who would not be able to be involved due to a change in roles, said they would be interested in participating in a focus group to explore recommendations and next steps after this report was completed.

FIGURE 4: INTEREST IN JOINING A PEER GROUP



Of the five people with self-experience who were not interested in joining a peer group, two said they do not enjoy working in groups, two people were not asked, and one was simply not interested.

4.3.3 SUMMARY

There is a genuine interest and engagement by local people, professionals, and PWSE/supporters to progress a project to promote user-involvement in local decision-making bodies.

4.4 PREVIOUS EXPERIENCES HAVE BEEN MAINLY POSITIVE BUT ALSO NEGATIVE ON SOME OCCASIONS

4.4.1 OVERVIEW

This section details experiences shared by both PWSE and supporters of being on committees previously, both positive and negative. The section also details the perspectives of mental health professionals on their previous experiences in sitting on committees where there was supporter or PWSE representative involved. Again, the stories shared were both positive and negative, and all are summarised here.

4.4.2 POSITIVE EXPERIENCES: PEOPLE WITH SELF EXPERIENCE/SUPPORTERS

Positive experiences of committees were discussed by nine of the people with self-experience. Their positive experiences that they referred to focussed on:

- Having people with seniority and authority in services at the table
- Being treated as an equal by others on the committee
- Being remunerated for attending meetings
- Being allowed to empathise with someone about a personal matter, but then get back to the business of the meeting
- Having another person with self-experience there as a support
- Having their voice heard and their abilities recognised
- Here, a person with self-experience reports a positive experience of being on a committee:

It was good to be involved. Enlightening people about mental health. Giving first-hand experience. As a service user it was very impressive to have the consultants and professionals talking to me on a level. (PWSE #19)

4.4.3 POSITIVE EXPERIENCES: MENTAL HEALTH PROFESSIONALS

In the interviews with professionals, eight people discussed previous positive experiences working on committees with people with self-experience /supporter. The types of positive experiences they reported included:

- The person bringing a new perspective and a sense of humour to the space
- The person bringing very useful skills and experience, apart from their perspective as a supporter, to the group
- The person having a clear role, clear boundaries, and an understanding of the committee and its limitations
- A person becoming unwell and having a supportive and transparent process for stepping down from the role with the support of a psychiatrist on the committee
- The person being a representative voice for other people with self-experience
- Where the people in senior positions on the committee were very bought-in to the idea and drove the successful engagement of PWSE on the committee

- Seeing the positive impact undertaking the role had on the PWSE who took the responsibility on

I've worked with committees who are now saying since involving service users and family members on their committees, they will no longer do another piece of work without their involvement. (PR#08)

4.4.4 NEGATIVE EXPERIENCES: PEOPLE WITH SELF EXPERIENCE/SUPPORTERS

A number of negative experiences of being on committees were discussed by nine of the people with self-experience and supporters. These experiences included:

- A person not knowing why they were on the committee or what their role was
- A committee where the representatives only went for the social aspect, and not to work
- A committee that fell apart because there was no funding for the paid staff to be there
- People talking over each other, making it very hard to concentrate
- A person attending meetings whose contribution was not recorded in minutes where other attendees were
- A committee where decision making happened outside the room, so the person had little power to influence decisions

The quote below captures a number of concerns highlighted here, and later in the report:

They needed a rep... It could have been a cardboard cut out of me. I brought a list of issues, but nothing I said went in the minutes. They put one person from the committee in charge of me and her job was to plámás me. Everything was decided before I went into the room. It made me very negative and distrustful of the services. (PWSE#10)

4.4.5 NEGATIVE EXPERIENCES: MENTAL HEALTH PROFESSIONALS

Previous experiences where things did not go so well were discussed by nine mental health professionals. The types of experiences they discussed were:

- Observing the representative putting undue pressure on themselves and experiencing a disproportionate amount of stress in relation to the role
- PWSE /supporter being frustrated by the agenda of the committee, limitations of what they could do, and the pace of change where issues were brought
- Committees not handling criticism brought by the PWSE well and being defensive
- Committees not knowing the best way to engage the PWSE /supporter, and being patronising or tokenistic
- The PWSE /supporter not being representative and becoming stuck on a personal issue or complaint
- Either the PWSE /supporter or the committee not being clear on why the person was there, or what their role was
- The person becoming unwell during their tenure on the committee and everyone being unprepared to manage this well

There's one committee I sat on and when I think about it I cringe, the chairperson, who seemed uncomfortable with the person being on the committee, just kept asking their opinion, very tokenistically. It's too much reverence; we don't need that, we need equal respect for all people at the table. (PR#02)

4.4.6 SUMMARY

The previous experiences of people with self-experience, supporters and mental health professionals provide valuable lessons for planning to promote effective and meaningful engagement in the future. While any change or transition, such as undertaking a new role or adding a new member to a professional team, can be difficult, this section has shown that having clear and agreed roles and responsibilities, a genuine buy-in and engagement from all parties, and an agreed way to manage difficulties or risks can help to equip all stakeholders to manage the inevitable challenges that will arise in bringing these diverse groups to the table together.

4.5 ISSUES TO CONSIDER, ANTICIPATE AND PLAN FOR

4.5.1 OVERVIEW

All participants in the research were asked what concerns they have about PWSE and supporters joining decision-making bodies, or what challenges they anticipate. While a significant minority of PWSE and a minority of professionals did not have concerns, a number of concerns were identified by both PWSE and professionals, with some concerns in common and a number of different concerns identified also.

4.5.2 PEOPLE WITH SELF EXPERIENCE

While seven people (a quarter of the participants) did not have any concerns (a)¹, all others had one or a number of concerns. These concerns are detailed in the table below. As with the expected benefits of joining a committee, the concern most commonly named by PWSE /supporter was that they would be concerned that they would not know how things work, such as the committee, the services, and the professionals (b).

If you're sitting on a committee for the first time you might feel you don't have the proper skills or experience... you might feel you don't have the same ability as others. You'll probably get over that in time but in the beginning you might feel overwhelmed. Also you fear not feeling heard. (PWSE#1)

TABLE 2: PWSE CONCERNS FOR JOINING COMMITTEES

Concern	Number of people
None	7
Not knowing who people are or how things work	9
Fear of not feeling heard by others on the committee	8
Attitudes of others in the group: (i.e. judgemental, patronising, dismissive)	8
Fear of speaking in front of others/not being able to express myself well	7
Less knowledge than other members of the group	7
Not knowing how and why decisions are made	7
Fear of not knowing enough or saying the wrong thing	6
No experience in committees	5
Not understanding jargon or professional ways of speaking	5
Meeting a professional that I had previously had a difficult time with	4
That it would be 'lip service' or a tick box exercise	4
Lack of time/childcare	3
That it would be boring or not relevant	2
Fear of not being able to concentrate	2
Lack of money to get to meetings	2
Confidentiality	2
Challenges with structures and management on committees	1

¹ The letters in brackets correspond to the concerns detailed in the table in this section

The second two most commonly stated concerns related to the attitudes and behaviours of others on the committee, specifically that there would be negative attitudes towards them and that they would not be heard by others (c & d). The concerns generally revolved around other members of the committee looking down upon the PWSE/Supporters or not understanding their perspective:

The committee would shut them down and be like 'we're at the top'.... they'd have to be very strong willed. (PWSE#8)

It doesn't matter what you say, they tell you it's because of your mental health. They should connect with you, form an alliance and try to find solutions, instead they label you, medicalise you. (PWSE#10)

There is a class difference with the health service staff - you're sitting there with all these people who went to college and have all these qualifications. There would be two different levels - you'd be looked down on. (PWSE#4)

There's a lack of understanding among the committees of our issues...they think we're lazy but we might be lethargic (PWSE #19)

After this, the most commonly cited concerns were people's concerns about their own capacity to communicate, and their lack of knowledge about certain key issues relating to the committees (e, f, g & h):

I'd have to have the confidence. I'd feel out of place completely. I wouldn't be able to help (PWSE#7)

Four people each were concerned that it would simply be lip service without really achieving anything and that they might encounter professionals that they had a difficult time with in the past (k&l):

It can be hard to pin down what you're going to achieve, what you've delivered, what your outcomes are. Will it just be another talking shop? (PWSE#15)

The same people who treated me [...] abysmally are still there (PWSE#10)

A number of other concerns identified are outlined in Table 2. One PWSE articulated a concern with management structures which closely echoed the primary concerns outlined by many professionals in the following section.

For anybody working in the system, particularly a service user who is not part of a professional group, the deficits in the management structure are so serious that the potential to harness the service user input is severely limited. If you look at the agenda for meetings, they generally deal with staff shortages, the need to integrate areas, directives from head office, troubleshooting e.g. recent suicide/s, legal issues. You drop a service user into that... the benefit of that is severely limited. There is no systematic, adequately resourced process for the service user to be effective. (PWSE#24)

There is a class difference with the health service staff - you're sitting there with all these people who went to college and have all these qualifications. There would be two different levels - you'd be looked down on.

4.5.3 MENTAL HEALTH PROFESSIONALS

The concerns most commonly cited by professionals related to structural issues rather than to any concerns with the capacity of individuals who might undertake the role.

TABLE 3: PROFESSIONAL CONCERNS FOR PWSE JOINING COMMITTEES

Concern	Number of People
Challenges with management or committee structures and culture	8
The role is tokenistic	7
The role is not representative	7
Not strong enough or critical enough	3
Confidentiality issues	3
That the person becomes unwell or is not well enough	3
No more concerns than for anyone else	2
Lack of training or support	2
Attitudes of the committee	2
Service user/provider on same committee	2
Finding someone suitable	1
Slow down the work of the committee	1
That the person cannot name issues diplomatically	1
Practical challenges such as literacy, time, transport and money	1

The most commonly cited challenges were concerns with management/committee structures and cultures, that the role would be tokenistic, and, very closely linked to that, that the role for PWSE or supporter would not be a representative one(a, b &c)².

The types of concerns with management structures and committees (a) included:

- Concerns that a committee may not be willing or able to hear criticism
- Certain committees, such as the Area Management Team, are dealing with very high level issues, so the person might benefit from moving up through the structures at various levels before joining such a high level committee
- That some committees can be male dominated, formal and intimidating
- That meetings within an institution, such as the HSE, can frequently get cancelled last minute and could waste the representative's time

It's important to match the individual to the committee; if it's managing structural change in the HSE, you need someone who can engage with that. I've seen it before, where the person was great and very motivated, and what they had to say was very important, but it wasn't the appropriate forum for that person. (PR#08)

I have a concern about committees in general; they work in a peculiar way within the HSE. There can be lots of cancelled meetings. If you're not here full time, there's a real risk that you could find your time is being used fairly inefficiently; you'll get a call 5 minutes before the meeting to say it's cancelled.(PR#07)

The concerns regarding tokenism and not being representative (b) are illustrated by the following comment:

We should not be seen as ticking a box ... If they are going to be involved they need to have a voice at the meeting and be involved in the meeting... if they are sitting there and just listening to the rest of us chatting on it's not useful. (PR#04)

Other concerns mentioned by professionals were that the person might not be critical, for various reasons such as the fact that someone who provided their treatment or that of their loved one is at the table, or simply because they are grateful to have a place at the table and don't want to upset others (d).

² The letters in brackets correspond to the concerns detailed in the table in this section

Someone could be on a committee with someone providing care to their family member, and they might be soft on things that they could be more critical about. (PR#01)

The same number of professionals were concerned about confidentiality issues (e), which for some meant confidentiality regarding service user information, and for others meant confidentiality about internal structural issues:

There would also be concerns that some things are said in conversations that might leak out. There's an unspoken belief that professionals can hold that information where they don't know or have experience of a service user doing the same. (PR#05)

Two professionals each mentioned their concern about the lack of training or support for people with self-experience /supporters to join committees, the attitudes of committee members, and the concern that a person who had previously or was currently providing a service to someone would be on the committee (h, l & j). All of these concerns were also identified by people with self-experience, as detailed in the previous section. A much smaller number of professionals were more concerned about the attitudes of people on the committee than those of people with self-experience or supporters.

One professional mentioned as a concern that people who were not used to sitting on committees would not have the skills to address concerns diplomatically. Knowing how to 'choose your battles' and vocalize criticism was a key skill identified in section 4.8 in 'supports for people with self-experience' (m).

Other concerns noted by one person included a concern that having to explain things too much to person with self-experience /supporters who is not as familiar with the structures and decision making processes might slow down the work of the committee, that it would be difficult to find someone suitable, and that practical issues such as finance, childcare etc. could prevent someone from being able to participate effectively (k, l & n).

The issue of the health of PWSE was raised, with two people feeling that this was a concern that would need to be managed. This is discussed further in section 7.6 below.

We should not be seen as ticking a box ... If they are going to be involved they need to have a voice at the meeting and be involved in the meeting.

4.5.4 SUMMARY

The concerns stated by the people with self-experience /supporters and the professionals appeared to have very different focuses; the people with self-experience /supporters were most concerned about not knowing 'how things work' and about the attitudes of other committee members to them.

Committee members were most concerned about inadequate structures or working practices on the committee, and that the representative role would be tokenistic or not representative. On reflection, these concerns can be seen as mirroring one another.

They highlighted the need for clarity in structure and function of the committee that can be communicated to representatives in advance of joining, and they clarify the need for reps to be in a truly representative role with clear authority and responsibility on the committee, which may mitigate negative attitudes or perceptions of them. A number of other concerns highlighted by smaller numbers beg consideration for inclusion in any supporting structures or processes.

4.6 HEALTH DIFFICULTIES MAY MANIFEST AND CAN BE MANAGED

4.6.1 OVERVIEW

One issue which came up several times both from professionals and from PWSE/Supporters was the complex issue of how having a health difficulty, particularly an active mental health difficulty, may make it challenging to be on a committee. This section details some of those concerns and how they have been managed in the past.

4.6.2 CONCERNS AND RESPONSES

When asked what qualities would be required for someone to be on a committee, two PWSE/supporters and one professional mentioned that the person should be in good health. Both stakeholder groups also said that the person would need to be resilient or strong (five PWSE and two professionals mentioned this). Two professionals mentioned that they would have concerns regarding the potential impact undertaking such a role might be if the person was not in the right space to do so. However, one professional and one PWSE noted that this is a workplace issue that is not exclusive to this situation:

“It’s a very good idea to have a group of people coming together, including service users, to plan this. You can ask really hard questions in a polite objective way.”

If you’re not 100%, it might not be the best place to go. I don’t know how you’d approach it to tell you the truth; you’d need to have an agreement that someone else can step up. It makes me laugh though, people go out to work every day and go home unwell... it’s normal that people sometimes can’t do things that make them unwell. It’s not that big a deal. (PWSE#02)

One professional recalled a time where this had happened on a committee they were on and it had been managed well, while another professional discussed the important role of supervision and support in ensuring that a person can anticipate, prevent, and respond to health challenges:

It has happened in the past where someone who was unwell, and their ill-health manifested as confrontational, which was challenging to work with. Most of the time though, the person themselves has highlighted if they feel they are becoming unwell. When I have done this previously, I have provided monthly supervision to someone and this helped to anticipate it. (PR#08)

4.6.3 SUMMARY

While being in good health, and managing workplace stress were acknowledged by some participants as an expected part of any role, there was a concern raised by a significant minority of all stakeholder groups that if a person is not in a positive space in relation to their mental health, this may not be an ideal role for them to undertake. However, professionals and PWSE / supporters identified some preventative techniques that could ensure that if this does arise, the representative and a supporter are prepared to manage it, including mentoring and having an agreed process for handing over the role where needed.

4.7 STEPS COMMITTEES CAN TAKE TO PROMOTE SUCCESS

4.7.1 OVERVIEW

Mental health professionals were asked, ‘What preparation or supports do you think need to be available, to either committees or people with self-experience /supporters, either before or during their joined working, for it to be successful?’ While this question was not directly asked to people with self-experience / supporters in relation to committees, many had ideas around this. The views of both groups are contained in this section.

4.7.2 GENERAL

A number of committee members felt that apart from taking a number of specific actions to prepare individual PWSE/supporters and committees, it would be most effective if it was part of a larger cultural shift in health services towards the involvement of people with self-experience and their supporters as par for the course.

Preparation for the role was also identified as a key factor. Committee members generally felt that there were some things they could do in advance, both as a committee or together with a cohort of people with self-experience/supporters, to promote effective and meaningful engagement.

An open and frank discussion in advance Engagement, discussion and identification on both sides, what we both feel is needed in order to support the person and allow us all to get benefits from it. (PR#04)

It's a very good idea to have a group of people coming together, including service users, to plan this. You can ask really hard questions in a polite objective way. (PR#03)

The importance of dialogue in advance of embarking on a project to promote inclusion of people with self-experience /supporters on decision-making bodies was also noted by two PWSE/supporters. Apart from dialogue, other advance preparations mentioned by mental health professionals included:

- The need for a build-up within the committee
- The need for preparation by one person from the committee with the representative to help induct and acclimatise them

4.7.3 SPECIFIC PREPARATION/CHANGES

Mental health professionals identified a number of supports or preparation needed *for committees* in order to make PWSE/supporters involvement effective and meaningful. A number of committee members felt that it was important to highlight that they felt that the committees they were on would be a good space for a PWSE/supporter representative, although there were additional steps that could be taken. These are detailed in the table below, and a number of the issues are highlighted in the quotes that follow:

TABLE 4: SUPPORTS OR PREPARATION NEEDED FOR COMMITTEES (IDENTIFIED BY MENTAL HEALTH PROFESSIONALS)

Supports or Preparation Needed	Number of People
To be provided with clear information on the representative role: rationale, role description, remit, responsibilities etc.	7
To foster enthusiastic buy-in from the whole committee in advance	5
To have service-user issues as standing item on agenda	5
To ensure there is a clear terms of reference for the committee	3
To be available to provide training or induction on the committee for representatives	3
To regularly review the effectiveness of the group/processes regularly, and collaboratively	3
To generally foster a service-user friendly atmosphere	3
To undertake some training, reskilling or upskilling in service-user involvement	3
To ensure meetings are run well and regularly	2
To Invest resources for remuneration and training	1

They need to address the issue, if it's not coming from national level, as to what provision we make in our sector to enable the service user/families to participate practically and what will we do about it... they need to be bought in. Teams need an implementation pack which spells out all the details of the role and how it will work, a rationale for the role, relevant policies, the supports the individual will need, the authority they have, their role with respect to governance of each of the sectors, their role with respect to confidentiality and clinical issues with regard to each sector. (PWSE#24)

Possibly a bit of training; how we can run our meetings to be more inclusive. The dynamic needs to change if there was a service user there and we need to consider how we can change. (PR#06)

In relation to fostering a friendly environment for people with self-experience/supporters, while many of the other changes identified previously would support this to some extent, three mental health professionals mentioned in particular being knowledgeable of pace, jargon and the impact of mental health difficulties on the individual. One PWSE highlighted the importance of good minutes for helping the representative to process the issues after the meeting and communicate back to peers.

4.7.4 SUMMARY

While it was generally felt that many committees could be respectful and accessible places, a number of things were identified that could help to ensure that committees can practically and reasonably accommodate people with self-experience/supporters so that all parties can fully avail of those benefits and prevent those concerns so clearly articulated in previous chapters.

The recommendations range from simple procedural issues, such as creating dedicated space on agendas for service-user issues, to challenging deeper cultural issues through reflecting on dialogue and attitudes. More far-reaching and ambitious recommendations relate to embedding an approach across mental health services and reviewing the management structures of the HSE to promote accountability, transparency, and support monitoring of progress and outcomes.

4.8 SUPPORTS FOR PWSE THAT COULD PROMOTE SUCCESS

4.8.1 OVERVIEW

People with self-experience/supporters were asked to rate how useful a number of different support options might be, ranging from 'very useful' to 'not useful'. These supports included practical ones, such as remuneration and training, to mentoring and the development of a representative network. Participants rated these supports and identified others, as detailed in this section. In addition, mental health professionals identified a number of supports that could be useful for people with self-experience/supporters, which were very similar to those reviewed by the people with self-experience/supporters, all of which are detailed in this section.

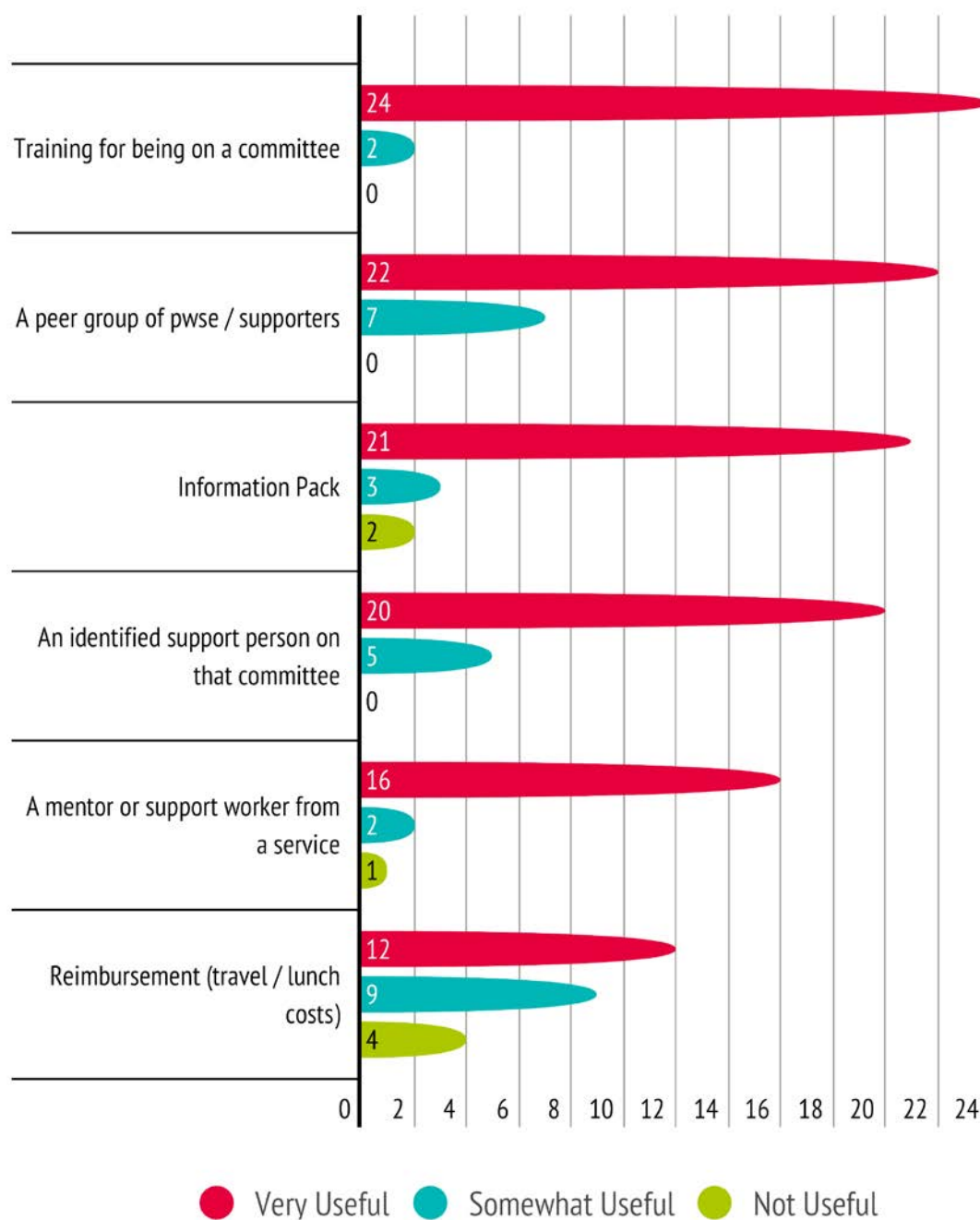
While it was generally felt that many committees could be respectful and accessible places, a number of things were identified that could help to ensure that committees can practically and reasonably accommodate people with self-experience/supporters so that all parties can fully avail of those benefits

4.8.1 GENERAL RATING OF SUPPORT OPTIONS

There was almost unanimous agreement that the following three measures would be useful support options for people with self-experience/supporters: training for being on a committee, a representative group of people with self-experience/supporters, and a support person either on the committee or elsewhere.

A small number of people did not feel that an information pack, reimbursement, or a support person outside of the committee would be a useful support. This is illustrated in the graph below.

FIGURE 5: RATING OF SUPPORT OPTIONS BY PWSE



4.8.2 TRAINING AND/OR INFORMATION PACK

Along with establishing a peer group, detailed in the following section, this was the most highly rated support. The 26 PWSE/supporters who rated this said training would be very useful or somewhat useful, with nobody rating it not useful. One PWSE here recalls the value of training he had received previously:

We talked about structure of the meeting, roles (chair etc.), sub groups, report writing... It was well-organised. (PWSE#2)

The following lists all of the issues mentioned by PWSE/supporters that they felt should be included in training:

THE COMMITTEE

- Who will be at the meeting
- What their job is
- What the agenda is
- Generally, how the committee works
- What common barriers are (e.g. jargon, noise etc.)
- Confidentiality issues

THE ROLE

- What is expected of the role
- How to run a meeting
- Conducting yourself in meetings
- Talking to people about difficult issues in meetings and challenging others respectfully
- Understanding when to sit back and when to fight
- How to express yourself in a professional space
- Being prepared in what to say and what points to make
- Being able to manage expectations of other PWSE and supporters
- How to write notes quickly and in shorthand

RELEVANT ISSUES

- What plan is the committee working from, and how are they measuring success?
- Relevant policy, and what is coming down the line in the mental health sector
- Mental Health Issues and Mental Health Services

Knowledge of the system and how it works and how decisions are normally made, as that would give me insight to how the process could be improved. (PWSE#6)

The provision of training was also supported by seven mental health professionals, who addressed many similar issues to those listed above:

I'm new to the team and my sense is that I'm trying to play catch up; there might be a similar experience for any new member of the team, including a service user rep. If the service user is anxious or maybe isn't used to the corporate or business world... this might be a challenge for them. I think it's important to give them some training in how business meetings are run. (PR#10)

Mental health professionals also supported the development of clear information on the role, responsibilities, remit, limitations etc.

People need specific jobs and roles so that they know their role in an environment which could be overwhelming. This is important for staff too. The way the jobs are organised, the tasks they are involved in and the boundaries need to be clear. (PR#07)

4.8.3 PEER GROUP OR REPRESENTATIVE GROUP

Along with training, this was also the most highly rated support by PWSE/supporters. As indicated previously, there was unanimous agreement that a peer group would be somewhat or very useful, with the vast majority, 22 people, saying it would be very useful and nobody saying it would not be useful. Participants were also asked, 'Would you join a peer group for PWSE/supporters or have you previously been on one?'

The majority of people who responded said that they would join and thought it would be beneficial.

Having a committee or consultative service user group gives you strength, helps you feedback... it can really work well. If the service tried to set it up in the beginning and there were a number of people who wanted to become more involved, it would be a good idea. (PWSE#1)

Of the three people who did not want to be part of a group, two of them said that they did not like working in groups, and one person said they were new to services and would not like to be part of a group. Additional points to consider in setting up a peer group were raised by people with self-experience /supporters:

- That it should be linked to a national network such as Mental Health Reform and/or Seechange³

³ These are both national networks representing the interests of people with experience of mental health difficulties in Ireland

- That the group should be independent of the HSE; the HSE can help to set it up and promote it, but should step back once that is done
- The group shouldn't be run by the services; they should help set it up and advertise it, and then back out

The importance of having a group or collective of peers to represent was also highlighted by mental health professionals. Eight of the eleven professionals discussed this and of those, only one person did not feel that being representative was necessary. All others felt it was important, feeling that it compromised the authority of the role if it was an individual speaking on their own behalf, and highlighting the importance of transparent processes for nomination, duration of term, and stepping down:

[A non-representative remit] disrupts the quality of what's being discussed. It lets the committee off the hook of engaging with issues from the broader group. I've seen service user or family reps on a committee get caught up in their own issues; if they were representative of a broader group that might not have happened. Strong meaningful engagement requires representation. (PR#02)

4.8.4 MENTOR/IDENTIFIED SUPPORT PERSON

There was also strong support from PWSE and supporters for having a mentor or support person identified (the support for this was marginally stronger for the mentor being a member of the committee the person was joining). Four people discussed the type of support that might be helpful from a staff or committee member: someone they could meet before they join the committee to help them feel safer when they get there and introduce them to the rest of the committee, a way to help them orientate:

I think one person off the committee could come and talk to that person first and explain what happens on the committee (PWSE#17)

Someone to discuss concerns with and to encourage you when you may be getting used to the role, for instance, was discussed. Both PWSE and mental health professionals emphasised that diplomacy is important, as is knowing where to direct energy, what battles to choose:

You can't come in guns a blazing. You have to be sensitive. (PWSE#5)

One participant who sits on committees discussed a tactic they use to help them focus in this regard, using the support of a mentor:

I feel if I talk in there, they're like... 'We don't need to know this'... so I run it by someone before. (PWSE#28)

There was strong support for the mentoring/individualised support role from mental health professionals; six people mentioned this as a support they felt could be helpful for representatives:

A professional support staff member outside the committee, a key worker type role who can help them work through their ideas, prioritise their issues for the meeting. (PR#10)

4.8.5 SUMMARY

The supports that would be useful for potential representatives from a cohort of people with self-experience/supporters fall under three categories: training and information, a representative group, and support from a professional mentor. There was little dissent among stakeholders about the importance of the range of supports being available to all. However, given the diverse range of skills and competencies highlighted at the beginning of this report, the exact approach to training and mentoring will need some consideration to ensure it reflects the diverse support needs of different individuals who may be involved in this project as it progresses. There is also a question of resources, which will dictate the range of supports to be provided and the need to ensure that any representative group is developed in a way that is sustainable while being appropriately resourced.

4.9 REPRESENTATIVES SHOULD BE REMUNERATED IN THEIR ROLE

4.9.1 OVERVIEW

All stakeholders were invited to give their opinion on whether the role of representative for people with self-experience or supporters should be remunerated. There was general support, although some precautions, as illustrated in this section.

4.9.2 PEOPLE WITH SELF EXPERIENCE PERSPECTIVE /SUPPORTERS

There was general agreement that people taking on representative roles for PWSE/supporters should be reimbursed in some way. Among PWSE and supporters, 21 of the 25 people who answered the question said that reimbursement would be a useful support to those undertaking the role. The support for this idea is captured in the following two quotes:

Your time should be valued; you should be given a reward to acknowledge the value of your time. It can be overlooked. It should be taken as read that they'll need to be reimbursed. (PWSE#1)

If everyone else is getting paid, why shouldn't they? (PWSE#8)

However, one participant felt that it should be approached with caution, as paying someone could compromise the independent nature of the role:

Money changes things... he who pays the piper plays the tune. Once people become dependent on money, you start singing off someone else's hymn sheet. If someone's going in in a paid position, that would be different. But, how would they keep their independence if they're then part of the system. (PWSE#10)

One person also said that he would appreciate a clothing allowance to help him look professional, as he does not have a suit.

4.9.1 MENTAL HEALTH PROFESSIONAL PERSPECTIVE

Ten mental health professionals discussed the issue of compensation with resounding, unanimous support for reimbursing representatives for expenses incurred and large support (seven people) for paying representatives for their time. There were also a number of precautions mentioned regarding the impact of paying someone as an employee or contractor if they are also in receipt of social welfare:

Yes, the person with self-experience may not be in employment and the others on the committees may be attending on their work time and therefore getting paid to attend, equality in this matter is paramount. (PR#09)

There needs to be a level of accountability. There needs to be a job description. Paying them for their time on the committee and doing work outside of it will make it meaningful. Working out the rate of pay for that is complex then. If we're going to do this, then we need to work that out with social welfare, if the person is on social welfare etc... we need to work out all of that before we really talk about paying people (PR#02)

One professional noted that simple issues like transport (e.g. if it takes too much time to get to and from a meeting) could act as a barrier and should be considered.

4.9.2 SUMMARY

Although there is almost unanimous support for remuneration, this is tempered with concerns about objectivity as well as the extent to which people should be reimbursed. Given the high rate of unemployment among the cohort, at least those involved in this research, considerations around impact of payment on social welfare, the need for expenses for taxis, professional attire, and other costs also requires additional discussion. The issue of reimbursement, who should pay it, and how much should be prioritised for discussion in planning this role for the Dublin 10 area.

4.10 LONG-TERM AMBITION: CULTURAL SHIFT AND EMBEDDING OF ROLES

Generally, it was agreed by a number of professionals that a cultural shift was needed within mental health services. A key marker of success would be that the involvement of people with self-experience /supporters would be unremarkable and typical:

Where a service user comes to a meeting and it would be like everyone else coming, it wouldn't be an issue, it would be normal. (PR#06)

In addition to this, two PWSE and three committee members felt that a longer-term goal was also that the presence of people with self-experience and supporters would lead to direct and tangible benefits for the functioning of mental health services, as illustrated in this comment:

If a service user is there and they are bringing difficulties, and we are improving the service based on their feedback and contribution. If it's functioning well, things are improving (PR#11)

“Your time should be valued; you should be given a reward to acknowledge the value of your time. It can be overlooked. It should be taken as read that they’ll need to be reimbursed.”



5 PROFILE OF PARTICIPANTS

5.1 OVERVIEW

This chapter provides an outline of the strengths, skills, and employment status of the participants in the research at the time of the research. This includes the people with self-experience, their supporters, and local mental health professionals.

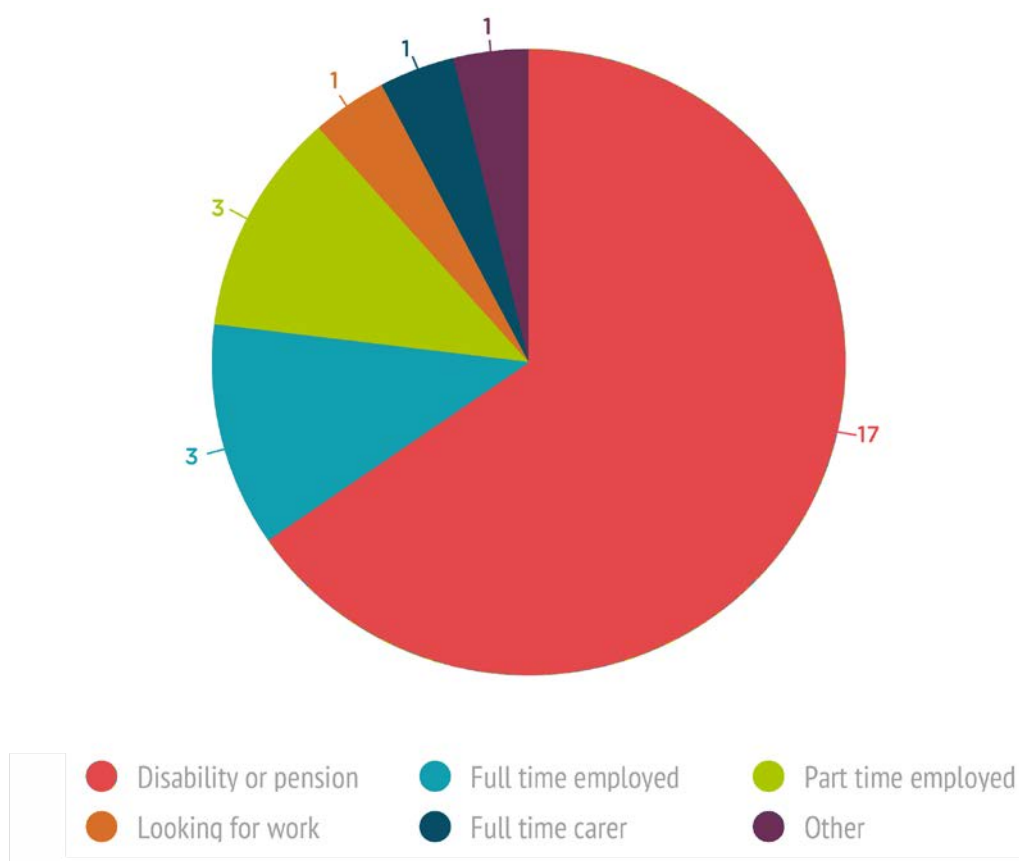
5.2 PEOPLE WITH SELF EXPERIENCE AND SUPPORTERS

In total, 30 people with self-experience or their supporters participated in the research. The experiences of 28 people are included in this research. Of those, 23 were people with self-experience, three were supporters, and two people identified as having both self-experience and a supporting role for another person with self-experience.

In total, six of the 23 people with self-experience and/or supporters who participated were employed. The majority were not working. About half of the participants (12 people) were users of a day service that provides support to people with complex needs, which may explain why there is a higher rate of people with self-experience not working in this research than in the general population⁴.

⁴ According to census data from 2011, available from www.cso.ie, in the general population, people with a disability from a psychological or emotional condition have an unemployment rate of 40 – 45%, whereas in this research, the unemployment rate was 79%, where unemployment means not in paid work.

FIGURE 6: EMPLOYMENT STATUS OF PWSE OR SUPPORTERS



Ballyfermot is a low socioeconomic area⁵, which means that many of the people using mental health services in the area experience an intersection of disadvantage which includes poverty and mental health difficulties. The high rate of unemployment among the cohort in this research would indicate that this may be the case.

⁵ Data from the 2011 Pobal HP Deprivation Index reveals that Ballyfermot has a deprivation index score of -7, which is well below the national average.

5.21 SKILLS AND STRENGTHS PROFILE OF PWSE/SUPPORTERS

FIGURE 7: SKILLS AND STRENGTHS OF PWSE AND SUPPORTERS



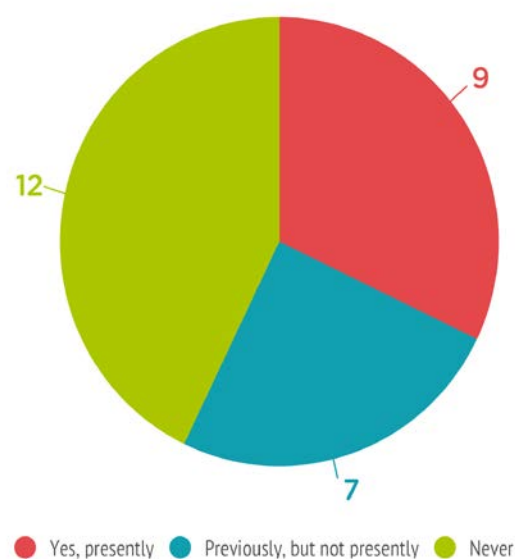
As well as those identified in the graphic above, 15 people identified as having 'other skills'. One or two people had each of the following skills or experience:

- Qualified facilitators, social care workers or other related qualifications
- Practical professional experience working in health and social care settings
- Uncertified training on committee skills and participation

5.22 EXPERIENCES OF SITTING ON COMMITTEES

The majority of people with self-experience and their supporters had experience of being on a committee. The graph below illustrates that at the time of the interviews, one third of the participants were on a committee, with a further 12 having previously been on a committee.

FIGURE 8: EXPERIENCE OF BEING ON COMMITTEES



The types of committees people had sat on ranged from research steering groups in mental health to parent teacher groups in schools.

5.3 PROFESSIONALS

Altogether, 11 currently employed professionals participated in the research. Professionals were mostly from the Health Service Executive, while another two professionals worked in non-governmental mental health support services (one of whom worked part-time for the HSE). The types of roles that the professionals held included:

- Occupational Therapy
- Psychology
- Social Work
- Development Work
- Administration

Of those who participated, seven people either currently or previously sat on the HSE Area Management Team which carries significant responsibility for the planning and operation of mental health services in the larger catchment area in which the Ballyfermot services operate. The professionals who participated sat on six committees each, on average; the lowest number of committees any individual sat on was one, and the highest number was more than ten.

5.4 SUMMARY

People with self-experience and their supporters who participated in this research had a range of skills and experiences that they felt would be a strength to any decision-making body in a mental health service. This ranged from their ability to bring their experience as a mental health service user to the table, their interpersonal communication skills, to harder skills such as relevant educational qualifications and professional experience in the social care sector. Participants from this group also had experience of sitting on committees either at the time of the research or at some point in the past prior to it, although for the most part, there was not a 'culture' of sitting on decision making bodies among their families and friends. There was a high rate of people who were not employed in the PWSE/supporters group. Combined with the strong appetite for involvement in decision-making that is highlighted in the following chapter, this reveals that there is a considerable untapped human resource in the community of people with self experience and their supporters in the area.



6 RECOMMENDATIONS

6.1 OVERVIEW

The literature highlighted the various factors to be considered and supports that can be provided to PWSE/supporters and professionals to help establish meaningful and effective collaboration in mental health service structures and decision-making committees.

It also has highlighted the expectations that must be held of the participating professional and formal structures in order to facilitate and support equal opportunity for PWSE/supporters to participate in mental health decision-making structures in a manner that is both empowering and safe.

These factors, combined with a clear understanding of some of the challenges and barriers to involvement and an explicit detailing of mutually agreed outcome measures, can help to inform the development of effective programmes of preparation and support for PWSE/supporters and professionals in creating a collaborative partnership.

The implementation of such a programme, which needs to adopt an assets-based approach and be established at a systemic level, has been shown in the research to challenge traditional paradigms and stigmatisation of mental ill health. Such an approach would facilitate a culture change that empowers PWSE/supporters, creating a context within which the value of the individual (and collective) experience of PWSE/supporters is respected as a unique and authoritative perspective to be heeded supported in its communica-

tion.

These recommendations were developed based on suggestions provided by participants in the research and good practice identified in other research and guidelines. These recommendations were then reviewed in a workshop with a group of professionals and people with self-experience /supporters. In this workshop, participants were asked to state:

- If they felt the recommendation would be valuable and useful
- What would make this recommendation succeed?
- What would make it fail?

The feedback of the group was used to refine the recommendations to ensure they would be as ambitious and practical as possible.

6.2 DEVELOP A LOCAL PLAN FOR PSWE /SUPPORTER INVOLVEMENT

Develop a **local plan, co-designed and agreed by PWSE and supporters, and statutory and voluntary mental health services**, for promoting involvement of PWSE in the area. This strategy should:

- a. Involve all relevant partners with enough seniority to ensure buy-in and implementation
- b. Establish clear goals, objectives, timeframes, and an agreed oversight structure
- c. Be linked to national policy
- d. Identify expected standards for committees wishing to involve people with self-experience/supporters and mechanisms by which committees can evaluate themselves in relation to this issue
 - i Standards should address issues such as accessible and clear minutes to support the representative to bring issues back to their group
 - ii A role description for a key professional contact or mentor, be they on or off committee, which includes induction and on-going support
- e. Identify other committees/groups where the PWSE/supporters voice is absent and may potentially be interested in having a representative (e.g. outside of mental health services)
- f. Have an agreed monitoring structure (e.g. steering group) for implementing the plan that includes representation from senior HSE management and all other committees where PWSE /supporters will be present
- g. Be linked in to national structures and strategies (communications, support etc.)

6.3 ESTABLISH A REPRESENTATIVE/PEER GROUP OF PEOPLE WITH SELF-EXPERIENCE/SUPPORTERS

A representative group of people with self-experience/supporters should be developed, **led by people with self-experience and supporters, with appropriate and sufficient support provided by local professionals so peer leaders can get this off the ground** and promote sustainability. This group should have agreed lines of clear communication with the strategy group to promote cohesive working, and there should be representatives who can act as a conduit of information between these two groups.

This group should have:

- o A working plan which includes clear aims, objectives and outcomes against which progress can be monitored
- o A clear risk management strategy and process for articulating concerns to ensure that the group can play their role in implementing the local strategy mentioned in the first recommendation
- o Procedures for the identification, nomination and election of representatives, as well as a clear role description and length of service (see following recommendation)

6.4 COLLABORATIVELY DEVELOP A ROLE DESCRIPTION FOR PWSE/ SUPPORTER REPRESENTATIVES

In line with national strategy, the **Representative/Peer Group**, with support from relevant professionals, should **develop a role description for the PSWE/supporter representative role** which includes:

- Key activities and responsibilities
- Reporting requirements to
 - The representative group
 - Management groups
- Duration of term
- Mechanism for addressing concerns by other representatives/PWSE/supporters
- Mechanism for stepping down from the role at an earlier point than scheduled
- Range of supports available
 - Mentoring
 - Training opportunities
 - The representative peer group
- Remuneration arrangements

This role description development should be led by people with self-experience /supporters. In order to promote buy-in, it should be supported or reviewed by service providers locally. Ensuring the role is in line with national strategy and good practice may entail expert input from a relevant professional or organisation (e.g. national service user executive or DCU).

6.5 DEVELOP A TRAINING AND INFORMATION PROGRAMME FOR PEOPLE WITH SELF EXPERIENCE AND SUPPORTERS

Development of a **training and information programme for PWSE /supporters** should be an applied participatory skills module. It should be accredited, meaning there is an optional assessment for those who want accreditation. This training and information programme may involve:

- Knowledge on mental health services, structures, roles, and strategies
- Committee skills
- Leadership and communication skills
- Professional negotiation and conflict resolution skills
- Understanding outcomes and impact while assessing success of committees and strategies
- The application of learned knowledge and skills to committees and the development of agreements
- Such a model will require partner organisations:
- **HSE/Mental Health Services:**
 - To input on the development and/or delivery of the training module
 - To involve PWSE/supporters on their management group for PWSE/supporters, in line with local agreements outlined in recommendation 1
 - To commit one member to act as a key contact or support for the PWSE/supporter and provide an applied learning environment
- **Adult Education Service:**
 - To accredit the training module

Develop an Information Pack and Training Options for Committees When developing an **information pack and training options for committees, coordinators** may include:

- A background in national strategy and local and national practice
- A full and detailed description of the representative role, responsibilities, remit, expectations, and limitations
- A copy of the local plan for the engagement of PWSE /supporters involvement (as outlined in recommendation one)
- The standards of good practice for committees that wish to involve PWSE/supporters
- Descriptions of potential support options, including required time and resources, that can be provided by the committee to a PWSE/supporter in order to promote meaningful and effective engagement
- A self-assessment or readiness tool for committees to review where they are at, and what steps they may need to take in order to meaningfully and effectively engage a PWSE/supporters representative
- A collaborative committee review tool which addresses key good practice points for engaging PWSE/supporters
- **Other preparatory supports** for committees may include:
 - Information sessions
 - Options for collaborative preparatory work, such as Trialogues, to support effective induction and on-going engagement
 - Facilitated sessions to analyse and challenge committee culture, personal bias etc.



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