FAMILY PEER SUPPORT WORK

A Review of Irish & International Literature



Written By

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Executive Summary

Introduction

The present report details the methodology and results of a comprehensive review of Irish and international literature on family peer support in the context of mental health difficulties, including addiction. The review seeks, firstly, to investigate and outline the practice of family peer support internationally, and secondly, to identify and collate the best available evidence in relation to family peer support work. The review will inform the development of a Family Peer Support Worker Toolkit, which will guide the implementation and practice of family peer support in Irish mental health services. The project was funded by the Family Peer Support Worker Toolkit Working Group, established under the HSE Mental Health Engagement and Recovery Office.

Results

The availability of information on the current practice of family peer support work varies greatly across the six countries. While some countries provide detailed documentation on the scope, values, principles, skills, training, certification, and supervision of Family Peer Support Workers, others – including Ireland - lack such formal structures. Where available, this information is discussed in depth in the body of the report.

Existing research provides great insight into the impact and effectiveness of family peer support. Documented benefits include significant improvements in family empowerment, mental health and wellbeing, self-care, knowledge of mental health difficulties and treatment, and satisfaction with mental health services. Significant reductions in psychological distress were also found. In qualitative research, participants reported benefiting from the information and skills they gained through family peer support, as well as the emotional and practical support provided. Participants particularly appreciated the peer element of family peer support. Receiving support from someone who genuinely understood what participants were experiencing helped them feel more accepted and less isolated and judged.

However, barriers to availing of family peer support are also documented, including practical barriers, insufficient availability, and fear of stigma. Some negative aspects of family peer support interventions have been reported, such as challenges associated with hearing other families' stories in group interventions. From the perspective of Family Peer Support Workers, challenges include lack of clarity surrounding their role, isolation, lack of respect for their expertise, and the complexities of supporting family members of people with mental health difficulties while also being a family member.

Discussion

The discussion synthesises the results, highlighting key points, similarities, differences, and discords within the literature, across 12 areas. The importance of co-production in

family peer support work is addressed first. We then discuss the standardisation of family peer support work across five topics: values and principles; aims and scope; enhancing access to family peer support; skills and competencies; recruitment; specialist Family Peer Support Workers; and supervision. In the following sections, we address the integration of Family Peer Support Workers into services; data collection and measurement; supporting Family Peer Support Workers; and training and certification. On the basis of the available information across these areas, we arrive at 12 recommendations for the Toolkit and broader development of family peer support in Ireland.

Recommendations

The 12 recommendations arising out of the discussion are listed below, in abbreviated form.

1. Place Family Peer Support Workers and family members at the lead of all future developments in family peer support work.

- Partner with Family Peer Support Workers and family members in writing Family Peer Support Workers' role descriptions, requirements, and other organisational documentation.
- Partner with Family Peer Support Workers and family members in producing any national and regional documentation and guidance on family peer support work.
- Partner with Family Peer Support Workers and family members in designing and delivering initial and continuing training for Family Peer Support Workers.
- Partner with Family Peer Support Workers and family members in designing any novel approaches to and methods of providing family peer support.
- Support and fund research into family peer support work that is led by family members.

2. Co-produce a set of core values for Family Peer Support Workers. These values:

- Must be specific to Family Peer Support Workers.
- Will guide organisations employing Family Peer Support Workers in defining job descriptions, tasks, requirements, career progression opportunities, and other structures.
- Will guide any future developments in the field of family peer support work in Ireland.
- Should be reviewed annually, making revisions and changes as necessary.
- Should be complemented by a set of core principles or examples of how these values translate to the practice of family peer support work.

3. Clearly define the aims of the work conducted by Family Peer Support Workers in Irish mental health services. These aims:

- Must be specific to Family Peer Support Workers.
- Will guide the development of job descriptions and role responsibilities of Family Peer Support Workers employed within mental health services.
- Must be aligned with the values and principles of family peer support work.
- Should emphasise the unique contributions of Family Peer Support Workers and clearly distinguish between their role and that of other, clinical staff.
- Should balance specificity with offering enough flexibility to not compromise the client-led nature of family peer support work.

• Should focus on the responsibilities of Family Peer Support Workers with respect to clients.

4. Enhance the accessibility of family peer support work.

- Avoid restricting the availability of Family Peer Support Workers to specific relatives.
- Provide family peer support work through a range of settings and modes.
- Explore the possibility of providing drop-in family peer support sessions at settings such as community mental health services, primary care centres, day hospitals, and GP clinics.
- Expand family peer support work services to all family members of people experiencing mental health difficulties, not just families of clients of mental health services.
- Explore the possibility of establishing an anonymous, online, peer-moderated support forum for family members, including the demand for such a forum.
- Provide both one-to-one and group-based family peer support, to maximise access.
- Ensure that any psychoeducational material provided to clients is written in plain language and available in a range of formats and languages.
- Establish an online, openly accessible directory of resources for family members.

5. Co-produce a Core Competency Framework for Family Peer Support Workers in Irish mental health services. This Framework:

- Must be specific to Family Peer Support Workers.
- Will form a foundation for future developments in family peer support work in Ireland
- Should reflect the values and principles of family peer support work.
- Should be reviewed annually, making revisions and changes as necessary.
- Must exercise caution with regards to the inclusion of psychological or clinical approaches.

6. Co-produce standardised guidelines for the recruitment of Family Peer Support Workers in Irish mental health services. Within these, recommend that services:

- Co-produce all recruitment materials with Family Peer Support Workers and family members.
- Clearly define the role requirements and responsibilities of Family Peer Support Workers.
- Ensure that existing Family Peer Support Workers are involved in recruitment.
- Include a requirement for prospective Family Peer Support Workers to have lived experience of recovery. As recovery is unique to each person, the assessment of this should be individualised.
- Provide applicants with emotional support following the interview.
- Avoid requiring that prospective Family Peer Support Workers have a minimum level of education. Assess literacy and numeracy directly, instead of using education as a proxy.

7. Develop accessible training programmes and certification mechanisms for Family Peer Support Workers in Ireland, led by family members and existing Family Peer Support Workers.

- Develop accredited introductory and ongoing training for Family Peer Support Workers.
- Develop opportunities for ongoing training for experienced Family Peer Support Workers, to support the further development of their skills and enhance career progression opportunities.
- Develop certification mechanisms to provide Family Peer Support Workers with a pathway to receiving formal recognition of their skills.
- Align training and certification programmes with the Core Competency Framework...
- Minimise the costs of training and certification programmes for Family Peer Support Workers, providing scholarships, grants, and subsidies to those who cannot cover the costs.
- Ensure that any training and certification programmes are as accessible as possible.

8. Explore the possibility of recruiting specialised Family Peer Support Workers, with specific lived experience or from specific backgrounds or communities.

- Engage with family members, existing Family Peer Support Workers, and marginalised communities to establish whether there exists a need for such services.
- Consider existing knowledge on groups facing higher risk of mental health difficulties and greater barriers to accessing care, to establish who may benefit from these specialised roles.
- Consider the varying needs of family members of people with different mental health difficulties and consult with family members to assess the need for specialised Family Peer Support Workers with experience of specific mental health difficulties.
- Ensure that the potential recruitment of specialised Family Peer Support Workers is culturally appropriate and led by members of the relevant community.
- Ensure that existing staff at mental health services are prepared to invite specialised Family Peer Support Workers onto their teams.
- Support specialised Family Peer Support Workers in conducting outreach with their communities.
- Provide additional supports to specialised Family Peer Support Workers, including emotional supports as well as supports in reporting instances of discrimination within the workplace.
- Work with relevant communities and member-led organisations to create further guidelines and structures for the recruitment and employment of specialised Family Peer Support Workers.

g. Provide Family Peer Support Workers with regular, appropriate supervision.

- Employ experienced Family Peer Support Workers to supervise other Family Peer Support Workers.
- Provide regular supervision sessions to Family Peer Support Workers, ensuring that they are given "protected time" to attend these sessions.
- Provide additional supervision sessions on an "as needed" basis.
- Ensure adequate supervision, training, and support for supervisors.
- Where possible, employ experienced Family Peer Support Workers as managers for newer Family Peer Support Workers.

10. Support the integration of Family Peer Support Workers into mental health services by actively addressing unhelpful attitudes and cultural factors.

- Provide co-produced training on family peer support work, including its approach, unique contributions, and benefits, for all existing staff and clinicians in mental health services.
- Continue and further support efforts to reform Irish mental health services towards a more person-centred, empowering, holistic, and family-friendly approach.
- Continue and further support efforts to meaningfully include the voice of people with lived experience and their family members into service design, planning, provision, and evaluation.
- Create roles for people with lived experience and their family members at every level of mental health services, including in leadership positions.
- Explore the possibility of introducing allies to Family Peer Support Workers into
- Integrate training and information on Family Peer Support Workers into handover and onboarding materials.
- Explore the possibility of integrating Family Peer Support Workers into multidisciplinary teams, through consultations with stakeholders and considering all potential risks and benefits.

11. Standardise data collection across all family peer support work services nationwide.

- Record the number, type, and duration of Family Peer Support Workers' contacts with clients.
- Collect and record comprehensive demographic data on clients
- Explore the possibility, feasibility, and acceptability of introducing quantitative measurement tools into family peer support work services.
- If such tools are introduced, ensure that the selected questionnaires are valid and reliable.
- If such tools are introduced, take care not to compromise the person-centred nature of FPSW.
- Systematically record qualitative information on client outcomes, including various aspects of their wellbeing, available supports, and day-to-day life and functioning.

 Conduct regular nationwide surveys of the Family Peer Support Workforce in Ireland, collecting data on their demographic characteristics, experiences, and needs.

12. Ensure that Family Peer Support Workers employed in Irish mental health services are adequately supported.

- Provide flexible working arrangements to Family Peer Support Workers.
- Accommodate, as much as possible, any needs that Family Peer Support Workers may have regarding their work arrangements.
- Provide additional leave arrangements for Family Peer Support Workers, in the event that they need to take time off to support their relative experiencing mental health difficulties.
- In addition to any existing Employee Assistance Programme, offer Family Peer Support Workers confidential, one-to-one psychological and/or counselling support.
- Establish a nationwide professional Family Peer Support Workers network.

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List of Abbreviations

Table A. List of abbreviations used in the report

Abbreviation	Meaning
CVS	Community and Voluntary Sector
FPSW	Family Peer Support Work
FPSWr	Family Peer Support Worker
FREDLA	Family-Run Executive Director Leadership Association
GRAMHS	Galway Roscommon Adult Mental Health Service
HSE	Health Service Executive
NGO	Non-Governmental Organisation
NHS	National Health Service
PSW	Peer Support Work
PSWr	Peer Support Worker
RQ	Research Question
SAMHSA	Substance Abuse and Mental Health Services Administration

Glossary

Academic database: Online directory of academic literature and publications, e.g. articles published in academic journals, theses, dissertations. Academic databases can be specific to a field or type of literature, or more general.

Academic literature: For the purpose of this review, "academic literature" refers to articles published in academic, scholarly, or scientific journals.

Community Health Organisation: The provision of public health services in Ireland is organised by region. Within this system, Ireland is divided into nine "Community Health Organisations". Each organisation is responsible for the provision of primary care and community-based healthcare services within their area.

Data extraction: In the context of a literature review, "data extraction" is the process of carefully reading through sources to identify information relevant to the review, and then organising that information to make it easier to read, understand, and analyse.

Family carer: A family member or significant other of a person with a chronic condition or disability (including mental health difficulties), who provides unpaid care to the person. This may include support in everyday activities, emotional support, helping with personal care or hygiene, supporting the person to appointments, managing housework on their behalf, and any other activities that the person may be unable to do independently.

Family peer support: Support offered to family members of people with mental health difficulties, by other family members of people with mental health difficulties. This can take a range of forms, including informal and formal support, information sharing, mentoring, support groups, emotional support, and others. The key element is the supporters' use of their own lived experience to uplift, empathise with, and connect with the person seeking support.

Grey literature: Literature published outside of traditional academic publishing pathways, i.e. academic journals. Examples include theses, dissertations, reports published by governmental and non-governmental organisations, policies, frameworks, guidance documents, and others.

Inclusion and exclusion criteria: In the context of a literature review, this refers to the conditions for a source (e.g. article, thesis, document) to be included in the review. Inclusion criteria outline the requirements that must be met for the source to be eligible, while exclusion criteria outline aspects that make the source ineligible. The terms "inclusion criteria" and "exclusion criteria" are also used in research to refer to the conditions that must be met by a potential participant in order for them to participate in the research.

Keywords: Academic databases and other search tools (e.g. Google) typically have a search bar that words can be typed into to find results relevant to your search. The words typed into this search bar are known as "keywords".

Mental health condition: Also known as "mental disorder", "mental illness", "psychosocial disability", "psychiatric condition", and similar descriptors. Defined by the World Health Organisation as "a clinically significant disturbance in an individual's cognition, emotional regulation, or behaviour ... usually associated with distress or impairment in important areas of functioning". There exists a range of mental health conditions. Some examples include depression, anxiety disorders, eating disorders, bipolar disorder, schizophrenia, and post-traumatic stress disorder. The definitions and diagnostic criteria for mental health conditions are set within the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2022) and the International Classification of Diseases (World Health Organization, 2019).

Mental health difficulties: This term covers the wide spectrum of challenges associated with mental wellbeing, from milder or short-lived difficulties that do not meet the criteria for a mental health condition, to severe and enduring diagnosable mental health conditions. For example, persistent feelings of anxiety may be seen as a mental health difficulty. However, for a diagnosis of generalised anxiety disorder to be given, these feelings must last for at least several months and come with a number of other symptoms.

Qualitative research: Research based on non-numerical, often written or verbal data, e.g. interviews, focus groups, blog posts, social media posts, journal entries. The data is usually analysed by looking for patterns, themes, and meanings in its content.

Quantitative research: Research based on numerical data. This data is analysed using statistical tests, e.g. to look for relationships in the data.

Randomised controlled trial: This is a type of quantitative experiment where participants are randomly assigned to two or more groups. The aim is to test the effectiveness of an intervention, such as a new medication, psychotherapy, or other form of support. One group ("experimental group") receives the intervention that is being tested. Another group ("control group") receives no intervention, a different intervention, or placebo. The groups are then compared over time to see if the intervention received by the "experimental group" had an impact. When done well, randomised controlled trials are considered the gold standard for assessing the effectiveness of interventions.

Reflexivity: Reflexivity involves reflecting on and questioning the ways in which you as a researcher influence, and are influenced by, the research you carry out. To conduct reflexive research, the researcher has to critically think about how their experiences, biases, emotions, and positionings in society impact their work. The concept of reflexivity first arose in qualitative research, but is sometimes used in quantitative research too. It is an important quality check in qualitative research, which is inherently more subjective. The aim is not to try to remove this subjectivity, but to take it into account when doing research and recognise how it impacts your work and findings.

Statistical significance: In quantitative research, "significance" refers to the likelihood that a certain effect was a result of random chance. Significance is assessed using certain statistical tests. For example, in an experiment looking at the impact of an intervention on anxiety levels, the researchers will compare the participants' anxiety levels before and after the intervention. It might seem like there is a difference by just looking at the scores,

but to check if this difference is meaningful, the researchers would need to carry out tests of statistical significance. If the differences are significant, this means that they are very unlikely to have been caused by random chance, and very likely to have been caused by something meaningful, such as the intervention. If the differences are not statistically significant, this means that the intervention had no impact on anxiety levels.

1.Introduction

1.1 Context

The present report details the methodology and results of a comprehensive review of Irish and international literature on family peer support. The review seeks to, firstly, investigate and outline the practice of family peer support on an international scale, and secondly, identify and collate the best available evidence in relation to family peer support work (FPSW). In addition to Ireland, the review focuses on five other primarily English-speaking countries: the United Kingdom (UK), United States (US), Canada, Australia, and New Zealand. Both academic and grey literature is included.

For the purpose of this review, the term "family peer support" refers to support offered to family members of people affected by mental health difficulties (MHDs) or addiction, by family members of people affected by MHDs or addiction. There is no singular definition or protocol for peer support. It may take a range of forms, including informal and formal support, information-sharing, mentoring, support groups, emotional support, advocacy, and others. The key element is the supporters' use of their own lived experience to uplift, empathise, and connect with the person seeking support.

Within Western mental health services, the development of peer support is generally attributed to the psychiatric consumer/survivor/ex-patient movement (e.g. Peer Support Canada, 2023; National Health Service [NHS] Health Education England, 2020a). This activist movement is led by individuals who have suffered harm at the hands of mental health services (Morrison, 2013). It attends, among other areas, to the power imbalances and abuses that have historically been common within mental healthcare and seeks to create person-led alternatives to traditional psychiatric care. It highlights the harms caused by the disempowerment and oppression of people availing of mental healthcare, aiming to place power over one's care in the hands of the person receiving it, and emphasising the person seeking support as the greatest expert on their experiences and needs.

Among the fundamental principles of the psychiatric consumer/survivor/ex-patient movement are self-determination, empowerment, and person-centeredness (see Morrison, 2013, for a detailed discussion of the movement). These are thus the foundational principles of peer support. There exists great variation in the range and types of peer support offered to both people with MHDs and their family members. However, all forms of peer support share a commitment to ensuring equality in the relationship between the peer supporter and the supported person, as well as the fundamental right of the supported person to lead and make decisions about their care in accordance with their wishes, needs, goals, and preferences.

The practice of formalised peer support for family members is a relatively new field, compared to peer support for people experiencing MHDs (e.g. Byrne et al., 2021a). Its origins are traced back to deinstitutionalisation, when mental healthcare began to be

moved out of institutions and into the community (e.g. ARAFEMI, 2011; 2021; Reynolds et al., 2021). With this came an increasing recognition of the impact of MHDs on not just the person directly affected, but also their family members, friends, and supporters (hereafter collectively referred to as "family members"). FPSW constitutes one avenue of enhancing the wellbeing of family members, though research in this area is still developing, with findings being somewhat inconclusive. For example, Nesta & National Voices (2015) found substantial evidence that peer support for carers¹ "improves experience and emotions" (p. 9). However, evidence regarding the impact on health outcomes or service use and costs was lacking. Acri et al. (2017) similarly noted that documented outcomes of family peer support programmes are "uneven", showing improvements in areas such as family functioning, knowledge about mental health challenges, and parenting skills, but no impact on areas such as parental stress, perceived burden, and coping.

This review aims to describe the current practice of formal family peer support across Ireland, the UK, US, Canada, Australia, and New Zealand. "Formal" in this context refers to structured, professionalised forms of peer support, delivered within mental health services, community or voluntary organisations, or private services, and led by a Peer Support Worker (PSWr) or similar professional with relevant lived experience. In contrast, informal peer support, such as emotional support or advice exchanged between friends or family members, is not included. In addition, we examine existing research on FPSW within these six countries. This will extend upon the findings of previous reviews by providing a more up-to-date picture of the landscape of international research on FPSW, including evidence regarding its effectiveness.

Family Peer Support Worker Toolkit Working Group 1.2

The purpose of the review is to inform the development of the Family Peer Support Worker (FPSWr) Toolkit (hereafter "the Toolkit"), which will guide the implementation and practice of FPSW in Irish mental health services. This Toolkit will serve as a counterpart to the existing Toolkit to Support PSWrs working in the Health Service Executive [HSE] (HSE, 2021), which aims to support HSE services in developing and implementing peer support for people with MHDs. The development of the Toolkit is led by the FPSWr Toolkit Working Group (hereafter "the Working Group"). The Working Group was established through the HSE Mental Health Engagement and Recovery Office in 2023 and is made up of FPSWrs, representation from supervisors and line management, and the Recovery and Engagement Programme Lead in the HSE.

The development of the Toolkit involves a number of steps, namely:

Reviewing the literature on FPSW to identify the best available evidence in terms of practice and implementation into mental health services;

¹ Where the term "carer" is used, this stems from the discussed literature. We avoid using this term where possible, in recognition of the shift away from this language. However, some international literature uses the term "carer", and replacing this with "family member" or similar language may be inaccurate.

- Consulting with FPSWrs, their supervisors, line managers, and the wider service to identify what they need from a toolkit;
- Liaising with other relevant working groups so that lessons learned from their work can inform the Toolkit.

The aim of this review is to fulfil the first objective.

1.3 Structure

This report begins with a detailed explanation of the methodology adopted in the literature review, including the type and breadth of literature included, literature search, screening and evaluating literature, and collating the findings of the literature. In the following sections, the results of the review are presented. First, an overview of the included sources is provided, looking at their quality and subject matter. These sources are then synthesised across three major categories. The first two sections look at family peer support in the context of mental health services: firstly on the basis of international practice documents, to provide a picture of the provision of family peer support across the six countries; and secondly with a focus on research into family peer support. Sources concerning family peer support in the context of addiction only are then analysed separately and described in their own section. The final section combines these results and applies them to the Irish context, providing a set of recommendations for the development of the FPSWr Toolkit.

1.4 A Note on Language

When writing about mental health, it is important to carefully consider the language used and its broader societal and cultural implications. The terminology we use reflects our values, experiences, and biases. It may serve to empower and express respect and compassion, or, conversely, it may contribute to stigma, marginalisation, and exclusion. What is deemed empowering or stigmatising varies across cultures, from person to person, and over time.

There exists a wide range of terminology used to refer to challenges associated with mental health. These include "mental health difficulty", "problem", "issue", or "disorder"; "(severe and/or enduring) mental illness"; "psychosocial disability"; "psychiatric disorder"; and many others. These terms can be used interchangeably, or they can refer to different, specific points on the spectrum of mental health - from milder, subclinical difficulties, to more severe difficulties. Similarly, the language used to refer to those who avail of mental health supports varies, including "service user", "client", "patient", "consumer", and simply "person availing of supports/services". In addition, some people may prefer person-first language, such as "person with a mental health difficulty", while others may prefer identity-first language, such as "mentally ill person".

In the interest of consistency and clarity, this report uses the term "mental health difficulty" (MHD) to refer to the full spectrum of challenges related to mental health, from brief distress to more severe, long-term difficulties. Persons availing of mental health supports are referred to as "clients", in line with a person-centred and recovery-oriented

approach and consistent with major organisations (e.g. <u>American Psychological Association</u>; <u>WHO</u>). Finally, person-first language is used, for example, "person experiencing MHDs", in accordance with standard practice and guidelines on inclusive language (e.g. <u>American Psychological Association</u>).

In choosing these terms, we seek to be descriptive and not prescriptive. The writing of this report necessitates that we choose a set of terms to use consistently. We recognise that not all individuals who we seek to include will identify with our choice of terminology. No set of terms will account for every person's preferences, but we hope that the terminology we use will reflect as broad of a range of preferences as possible. Above all, we respect and emphasise every person's right to self-identify and self-describe using whatever language they feel represents them best.

2. Methodology

This section outlines the procedure followed, firstly, to identify literature to be included in the review, and secondly, to organise and present the gathered information. Initially, all potentially relevant sources were compared against inclusion and exclusion criteria. These criteria ensured that the included sources were relevant to the review. Any identified research literature was then assessed against an evaluation framework. This examined the quality of the research, such that only the best available evidence would be included. The information and evidence gathered was then synthesised to highlight the most relevant details and facilitate the application of the gathered information to the development of the Toolkit.

2.1 Parameters of the Review

2.1.1 Inclusion and Exclusion Criteria

<u>Table 1</u> outlines the criteria against which sources were evaluated to establish their eligibility for inclusion in the review. Broadly speaking, two types of sources were included: research literature and documentation on the practice of FPSW (e.g. guidelines, frameworks). As these literature types differ in format and content, they require a different approach to defining inclusion and exclusion criteria. For example, research literature involves participants. Inclusion criteria may therefore refer to the participant sample. However, practice documents are not research studies and do not involve participants, so criteria concerning participants are not relevant. As such, <u>Table 1</u> specifies the inclusion criteria for the two types of sources separately, where applicable.

Importantly, literature concerning group interventions which are clinician-led but described as "peer support" were not included. In these supports, the PSW element is limited to clients building relationships with one another. The purpose of this review is to inform the development of a Toolkit for FPSWrs; thus, literature concerning interventions which do not involve a FPSWr or similar role was considered irrelevant. In addition, defining PSW as simply the relationships built between attendees in a clinical intervention broadens the scope of this review too widely. Using this definition, group-based clinician-led psychotherapy would fall under PSW, as clients may also build relationships and support one another in this setting. However, psychotherapy is not a form of PSW.

Table 1. Inclusion and exclusion criteria for the literature review

Catagony	Incl	uded	Excluded			
Category	Research literature	Practice documents	Excluded			
Language	English		Sources not available in English			
Туре	- Meta-analyses- Clinical trials- Qualitative research- Research reports- Case studies- Theses & dissertations	GuidelinesGuidance documentsFrameworksPoliciesGovernance documents	Sources that are neither evidence-based nor practice documents			
Date	2010-2024		Sources published prior to 2010, and/or that have been superseded by newer versions			
Location			Research conducted outside of these locations and practice documents which do not apply to these locations			
Participants	At least one of: - Family members of people with MHDs - People with MHDs - Mental health (F)PSWrs - Mental health clinicians	Not applicable	Research which doesn't involve any of the outlined participant groups			
Topic		co-occurring mental and s or disabilities, as long as alth)	Literature concerning only: - Non-family peer support - Non-peer support (e.g. interventions delivered by clinicians) - PSW for people bereaved by suicide - FPSW in the context of non-MHDs (e.g. FPSW for parents of children with physical disabilities) - FPSW which does not involve a FPSWr or similar role (e.g. online forums without a peer moderator)			

Source: TASC, 2024.

2.1.2 Search Strategies

Two primary strategies were followed to identify sources for the review, using academic databases and the websites of relevant organisations and bodies.

Academic Databases

Research literature was identified primarily through searching academic databases. An academic database is a specialised online library or repository, consisting of a large collection of academic sources, such as research articles, conference papers, theses, and books. Academic databases collate publications from existing scientific journals, allowing researchers to search through a large number of journals simultaneously, rather than needing to check every individual journal separately.

To begin, a list of 15 relevant academic databases was gathered (Appendix 1). These databases were then searched using a list of keywords relating to family, peer support, and mental health (Appendix 2). Keywords were selected to account for a range of family relations and types of peer support, as well as cultural variations in the language used to refer to mental health and changes in terminology over time. Keywords relating to mental health included both general terms referring to MHDs and specific mental health diagnoses. The results of the keyword search were refined further using in-built database filters, on the basis of the inclusion and exclusion criteria, for example, to restrict the publication date or language.

The academic databases were searched for a second time at a later stage, after it was decided to include research on Al-Anon and Nar-Anon in the review. For this search, only the following keywords were used: "Al-Anon", "Alateen", "Nar-Anon", and "Narateen". This was done in recognition of the use of these organisations' names as synonymous with the approach they take and interventions they provide. Also, all Al-Anon and Nar-Anon interventions are family peer supports by definition and therefore do not require the use of additional keywords to ensure relevance. Otherwise, the search process and parameters remained the same.

Websites

A search of the websites of organisations and bodies involved in research on and the delivery of FPSW was conducted (see <u>Appendix 3</u>). This process identified relevant practice documents and grey literature. To facilitate this search, we compiled a list of 224 governmental bodies, public bodies (including health services), recovery colleges, and NGOs across Ireland (19 organisations), the UK (47), US (63), Canada (30), New Zealand (16), and Australia (41), as well as some international organisations (8). Governmental and public bodies were those involved in the delivery, design, regulation, or evaluation of mental health services and services for family members, such as relevant Departments of Health, Mental Health Commissions, the UK NHS, and the HSE.

The website of each of these organisations was then searched. The procedure varied across the organisations, as each website was different in design, requiring different methods of searching. In general, each website was checked for a "publications", "reports", "resources", or "research" section, and these sections were searched where available. In-built search bars were also used, with some of the keywords outlined in Appendix 2 searched for as needed and appropriate.

Citation Chaining

Once the literature search and <u>initial screening</u> was conducted, the references of all identified, eligible sources were checked. Academic articles, reports, frameworks, and other literature often cite other academic sources touching on related topics. As such, screening the cited literature allows for the identification of other sources which may have been missed through the academic database and website search. All sources identified through citation-chaining were then also citation-chained, repeating this

process until the citations of all included sources had been searched and all relevant sources included within these were identified.

Sources from Working Group

Four additional sources were forwarded on to the research team by the Working Group. One of these sources had already been included in the review, having been identified through the website search. The remaining three underwent the same <u>screening process</u> as all remaining sources.

2.2 Identification and Screening of Literature

All sources found through the <u>academic database search</u>, <u>website search</u>, and <u>citation chaining</u> were screened twice to ensure that they meet the <u>inclusion and exclusion criteria</u> and are relevant to the review. <u>Figure 1</u> below is a flow chart showing the number of sources screened and excluded at every stage, as well as an overview of the reasons for exclusion.

2.2.1 Initial screening

The initial screening involved reading the title and summary of each source. The "summary" varied depending on the source type. In the case of academic articles, the abstract was checked. For sources where an abstract was not available (e.g. sources found through organisations) the executive summary, attached press release, or any other available brief description was read. The information contained within the summary was compared against the inclusion and exclusion criteria to establish whether the source was eligible for inclusion in the review. A total of 158 sources were included at this stage (45 identified through academic databases, 71 through organisation websites, 13 through the later search of sources on Nar-Anon and Al-Anon, 27 through citation chaining, 2 through Working Group; see Figure 1). Some of these sources were not relevant to FPSW in their entirety, but featured sections which were of relevance.

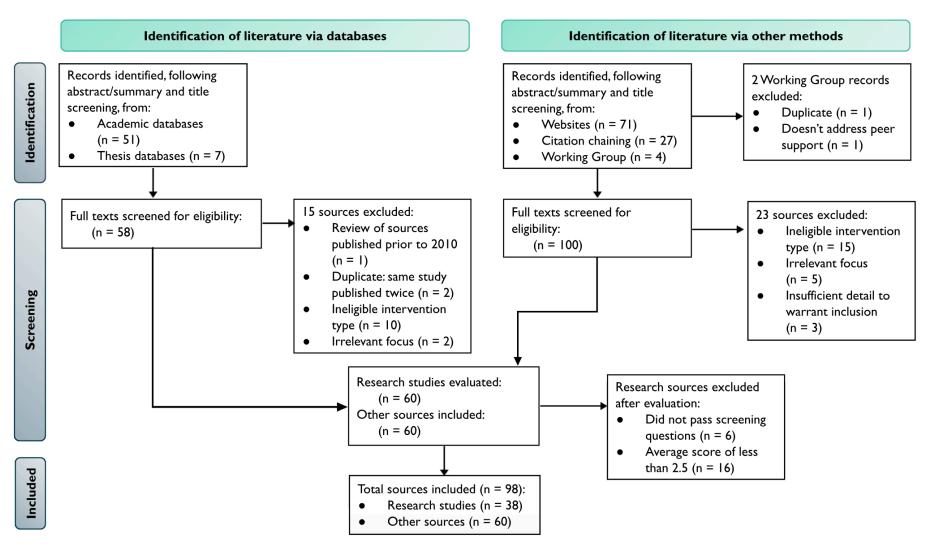
2.2.2 In-depth screening

After completing the literature search and identifying all potentially relevant sources, these 158 sources were then screened for a second time in depth to check whether the source meets the <u>inclusion and exclusion criteria</u>. This involved reading the full text of the source or the sections relevant to FPSW, in the case of sources which were not relevant in their entirety but had relevant subsections. Following this screening, 38 sources were excluded (see <u>Figure 1</u>), for the following reasons:

- duplication, specifically, the same research published across multiple platforms
- intervention type, including lack of a FPSWr (or similar) delivering the intervention (12); interventions for the person experiencing MHDs, rather than their families (11); non-peer support interventions (1); and family peer support in the context of other difficulties, i.e. not mental health or addiction (1)

- irrelevant focus, including using data from family peer support to study the person with MHDs (1) or the experience of being a family member (1), rather than the intervention itself; designing a tool to measure the effectiveness of family peer support (1); discussing the peer workforce and engagement with people with lived experience more broadly, without specific information on FPSWrs (3); and others (1)
- sources that discuss FPSW but in insufficient detail to contribute anything to the review (3)
- literature review of sources published exclusively prior to 2010 (1)

Figure 1. Adapted PRISMA diagram showing the number of sources included and excluded at each stage of the literature search



Source: TASC (2024), adapted from Page et al. (2021).

2.3 Evaluation of Literature

2.3.1 Evaluation Framework

Of the 120 sources that passed the initial and in-depth screenings, 60 were research papers. The remaining 60 consisted of frameworks, guidelines, policy papers, intervention descriptions, literature reviews, and similar documentation. To ensure that the current review is based upon the best available evidence, these 60 research papers were evaluated using an adaptation of the Mixed Method Appraisal Tool (MMAT; Hong et al., 2018). Practice documents were not evaluated as the purpose of including these sources was to describe the current practice of FPSW internationally, separately to any evidence for or against current practices.

The MMAT is a critical appraisal tool designed to support the evaluation of primary research studies across five categories: qualitative, quantitative randomised controlled trials, quantitative non-randomised, quantitative descriptive, and mixed methods. The base version of the MMAT contains two screening questions applied to all studies, followed by five evaluation criteria per each study type. Each source is rated across these criteria as "Yes", "No", or "Can't tell". The authors of the tool advise that a "No" or "Can't tell" answer to one or both of the screening questions may indicate that further assessment is not appropriate or possible. Mixed methods research is rated across all criteria relevant to its methodology. For example, a source which uses quantitative descriptive and qualitative methodologies would be rated on 17 criteria: two screening questions, five quantitative descriptive criteria, five qualitative criteria, and five mixed methods criteria.

The MMAT was selected as an appropriate evaluation framework due to its categorisation of research by methodology, rather than design. Many commonly used frameworks are based upon the exact design of the study (e.g. cohort studies, case studies). Though this allows the evaluation criteria to be made more specific to each design, the range of study designs used in mental health research often extends beyond what these frameworks cover. When checking the suitability of these frameworks against our sources, we indeed found that many of our sources could not be evaluated using these frameworks as they could not be categorised under any of the included designs. The categorisation of studies as qualitative, quantitative, or mixed methods within the MMAT allows for the inclusion of a wider range of research designs under one tool.

However, we decided to adapt the MMAT due to some shortcomings of the framework. Firstly, we felt that the ranking of each criterion as "Yes", "No", or "Can't tell" did not allow for enough nuance. As such, we changed the rating scheme of the non-screening criteria to a four-point scale. Each criterion was rated based on whether the study met it "Very well" (4 points), "Sufficiently well" (3), "Not well" (2), or "Not at all" (1). The "Can't tell" option was also included. Secondly, neither the MMAT nor any other framework we considered incorporated the inclusion of the lived experience voice as a criterion. Similarly, the MMAT and most other frameworks did not attend to the inclusion of vulnerable populations. We decided to add these as additional, universal criteria. Thirdly, we felt that some screening and methodology-specific items were missing from the MMAT and so

expanded upon the criteria to ensure that we address all relevant aspects of the research process. We added two new screening questions, as well as one new criterion to each category except for the mixed methods criteria. These added items were based upon the <u>Critical Appraisal Skills Programme</u> (CASP; 2018) checklists, the Joanna Briggs Institute (JBI) <u>Critical Appraisal Tools</u> (JBI, 2020), and the Research Quality Plus (RQ+) <u>Assessment Instrument</u> (Ofir & Schwandt, 2014). The final items and criteria included in the adapted framework are shown in <u>Appendix 4</u> and include four screening questions, five or six criteria per methodology, and two universal criteria.

Finally, the MMAT does not provide a method of combining ratings across the criteria into an overall result. As the purpose of evaluating the sources was to determine which are sufficiently high-quality to include within the review, we felt that it was necessary to establish this, alongside a minimum score that must be achieved by a study in order for it to be included. Thus, to synthesise the ratings for each source, an average score was calculated based on the scores across all of the criteria (excluding screening questions). The minimum overall (average) score for inclusion was set at 2.5. This is the halfway point between the minimum (1) and maximum (4) possible average score.

2.3.2 Procedure

Before conducting the evaluation, each research source was categorised into one of the five methodologies. Every source was then rated on the relevant criteria by both authors of this review, to enhance the quality of the evaluation. Each author conducted their evaluation individually, unaware of the other's results. They rated each source against the four screening criteria, all of the criteria relevant to its methodology, and two universal criteria, as per section Section 2.3.1 and Appendix 4. Once the sources were evaluated by both authors, their ratings were compared and any discrepancies discussed until an agreement was reached.

This final, mutually agreed upon set of ratings was then discussed in depth by both authors to decide upon sources to be excluded from the review. As mentioned, each source was initially evaluated against the four screening criteria and assigned a rating of "Yes", "No", or "Can't tell" per criterion. On the basis of these ratings, it was then decided whether further evaluation was warranted and possible. There was no set protocol for arriving at this decision; instead, sources were judged case-by-case depending on the number of "Yes" and "No" ratings and, in the case of the latter, the degree to which the source did not meet the criterion. If these shortcomings were so substantial that the research was deemed irrelevant, unreliable, unethical, or impossible to assess further due to missing information, the source was excluded at this point. In total, six sources were excluded following the application of the initial screening questions (one mixed methods, one qualitative, two quantitative descriptive, two quantitative randomised controlled trials). Five of these were not applicable to the context of Irish mental health services, while one source had unclear research questions and contained insufficient detail to assess the remaining criteria. In addition, all six of the sources showed no evidence of ethical approval or oversight.

An average rating per source was then calculated for the remaining 54 sources, as per Section 2.3.1. Upon discussion, the minimum average score for a source to be included in the review was set at 2.5. Any source with an average score falling below 2.5 would be excluded. There was one exception made to this rule: a report titled "An Evaluation of Bealach Nua" (Garavan, 2016). This received an average rating of 2.29, but was included in the review despite this due to its very high relevance, as an evaluation of a FPSW service in an Irish mental health service. As a result, 16 sources were excluded from the review following the evaluation (four mixed methods, four qualitative, three quantitative descriptive, two quantitative non-randomised, three quantitative randomised controlled trials), in addition to the six sources excluded on the basis of screening criteria. This left 37 research sources to be included in the review.

2.4 Data Extraction and Literature Synthesis

As per <u>Section 2.3</u>, data extraction and synthesis were broken up by literature type. A brief overview of the type and scope of the entire body of included literature is available in <u>Section 3</u>.

2.4.1 Addiction

Firstly, the included sources were categorised on the basis of the target difficulty: specifically, MHDs or addiction. This was requested by the Working Group. The results of the review of both research and non-research literature on peer support for family members of people experiencing addiction are described in Section 6. This section is further subdivided into Nar-Anon and Al-Anon, and other interventions. Internationally, Nar-Anon and Al-Anon are among the most well-known and widely available forms of FPSW in the context of addiction. The body of literature on these supports is comparatively large, with their approach being well-documented and established and their effectiveness investigated to a greater extent than other interventions. At the same time, Nar-Anon and Al-Anon function exclusively outside of mental health services and are quite unique in their approach. For these reasons, sources thereon are synthesised and described in their own subsection. Literature on all other peer supports for family members of people experiencing addiction is analysed separately. Four additional forms of support were identified in the literature; each is discussed within its own subsection.

2.4.2 Mental Health Difficulties

Literature on FPSW in the context of MHDs is subdivided into research and non-research literature ("practice documents"). Results of the synthesis of practice documents are described in <u>Section 4</u>, while results of the synthesis of research are described in <u>Section 5</u>.

The aim of <u>Section 4</u> is to describe the current delivery of - rather than best evidence on - FPSW across Ireland, UK, Canada, US, Australia, and New Zealand. As such, research is not included within this section. Initially, we sought to split this literature based on whether it concerns public, community-based (non-governmental), or private supports; however, upon reviewing all of the identified practice literature, we found that this

approach was not well-suited to the information available. Instead, this section is divided by country. The approach then varies somewhat within each country, as the volume of sources and their content also varies substantially. However, for each country, we attempt to address some common, core areas, including the definition and scope of family peer support, values and principles, core competencies, training and/or certification, supervision, and recruitment. Given the relatively limited number of practice documents available for some countries, it was not possible to address each of these areas for every country, but where information on these areas is available, it is included. Where the available information concerns a specific type of support (e.g. public, community), this is specified in the text.

<u>Section 5</u>, the analysis of research literature, aims to synthesise the best available evidence on FPSW in the context of MHDs. Specifically, the section begins with an overview of the types of family peer support investigated in international research. Evidence for its effectiveness is then presented, followed by any identified barriers and challenges in delivering family peer support. Afterwards, we discuss research on clinicians' and FPSWrs' perspectives on FPSW. This is followed by a short discussion of research findings on the training of FPSWrs. The section ends with a review of the gaps in the identified research literature.

3. Overview of Sources

3.1 Literature Focus

Appendix 5 shows a detailed breakdown of the 98 sources (60 practice documents and literature reviews, 38 research studies) included in the review. Among these, 35 are Australian sources, 32 are from the US, 12 are Irish, eight are from the UK, and two are from New Zealand (Figure 2). Additionally, three are international, meaning that they apply to multiple countries. Furthermore, 73 sources concern family peer support in the context of any MHD (in some cases including addiction), 15 concern addiction only, five concern eating disorders, two concern psychosis, one concerns borderline personality disorder, one concerns schizophrenia, and one concerns bipolar disorder and/or psychosis (Figure 3).

Figure 2. Breakdown of sources by country

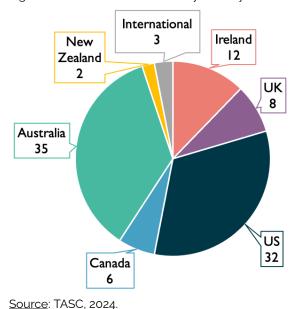
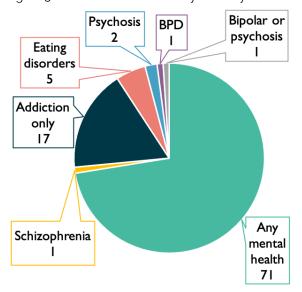


Figure 3. Breakdown of sources by difficulty



Source: TASC, 2024

3.2 Literature Evaluation

In total, 38 research sources were included in the literature review. Of these, 14 used quantitative methods (including one randomised controlled trial), 13 used qualitative methods, and 11 used mixed methods (Appendix 5). Fifteen were conducted in the US, eight in Australia, six in Ireland, four in Canada, three in the UK, and two in New Zealand (Appendix 5).

3.2.1 Evaluation Score

<u>Table 2</u> below displays a summary of the results of the evaluation of research sources, before and after sources with a low evaluation score were excluded (as per <u>Section 2.3</u>). Based on average overall scores, quantitative randomised controlled trials were the lowest performing study type both before and after excluding sources with a score of

less than 2.5. In fact, of the six randomised controlled trials found through the literature search, two were excluded on the basis of screening criteria and three were excluded due to their low scores, leaving only one randomised controlled trial to be included in the review. Qualitative studies were the highest scoring before low-scoring sources were excluded, while mixed methods studies were the highest scoring afterwards. Appendix 4 depicts average scores across the individual criteria.

Table 2. Summary of evaluation results by methodology, before and after excluding low-scoring sources

Mothodology	Before excluding low-scoring sources			After excluding low-scoring sources				
Methodology	N	Min.	Max.	Overall average	N	Min.	Max.	Overall average
Qualitative	17	2.19	3.38	2.75	13	2.63	3.38	2.89
Quantitative RCT	4	2.25	2.69	2.45	1	2.69	2.69	2.69
Quantitative non-randomised	8	2.38	3.17	2.70	6	2.56	3.17	2.80
Quantitative descriptive	10	1.63	3.25	2.55	7	2.5	3.25	2.74
Mixed methods	15	1.43	3.36	2.66	11	2.29	3.36	2.94
Overall	54	1.43	3.38	2.66	38	2.29	3.38	2.86

Source: TASC, 2024.

Note: "RCT" stands for "randomised controlled trial". Minimum and maximum scores refer to the average score received by the lowest and highest quality source within each methodology. The "overall average" is the average of all scores within each methodology. The maximum possible average score was 4, while the minimum possible average score was 1. One mixed methods study falling below the required minimum average score of 2.5 was included in the review due to its high relevance.

3.2.2 Involvement of People with Lived Experience

All research sources were evaluated on the basis of their co-production, that is, the extent to which people with lived experience and/or their family members were involved in conducting the research. In general, we found that studies on family peer support performed very poorly in this area. In terms of average scores across all of the assessed studies, this criterion had the second lowest score out of all 31 criteria within the framework. In other words, there was only one criterion where research studies ranked lower on average than within the co-production criterion. Of the 54 evaluated studies, 38 (70%) received the lowest possible score of 1 on this criterion. Only seven (13%) were judged as performing adequately well (i.e. received a score of 3 or 4), and only one study received the highest possible score of 4. Once the 16 low-performing studies were excluded, 24 (63%) of the remaining 38 received a score of 1. All seven studies receiving a 3 or 4 on this criterion passed the overall evaluation, forming 18% of the final pool of 38 research sources. The source which received a 4 on this criterion was Levasseur et al. (2018), a Canadian study on family peer support in the context of first-episode psychosis. The first author (lead researcher) of this study was a family member of someone experiencing MHDs and an additional family member provided input into certain aspects of the research.

3.2.3 Involvement of Vulnerable Populations

The involvement of people from vulnerable populations in the included research studies was assessed as an added criterion. Assessing this involved looking at the demographic characteristics of the participant sample to assess how diverse the participants were, but also the extent to which the researchers tried to recruit participants from vulnerable populations. A study with a non-diverse sample of participants could still receive a high score on this criterion if there were clear efforts to reach out to vulnerable groups. In addition, the presence of inclusion and exclusion criteria which excluded participants from vulnerable populations from participating, without a sufficiently strong justification, was also considered. This could include criteria such as needing to speak fluent English, or neglecting to provide accommodations that would allow people with disabilities to participate.

This criterion was the third lowest performing criterion in the evaluation framework. Of the 54 evaluated studies, 30 (55%) received the lowest possible score of 1 and only 4 (7%) received a score of 3 or higher, i.e. were judged as performing adequately well on this criterion. After excluding the 16 low-performing studies, 21 of the remaining 38 (55%) received a score of 1 and only 2 (5%) received a score of 3 or higher: Te Pou (2023) and Visa and Harvey (2018). This is a substantial shortcoming of the available research and raises concerns regarding the generalisability of available findings. For example, studies demonstrating the effectiveness of certain interventions, which do not include participants from vulnerable populations, provide little insight into how effective the intervention is for people from marginalised or minority backgrounds. Such studies also cannot identify any barriers to participating in the intervention that are specific to people from marginalised populations, or shortcomings in their cultural sensitivity. This is a particularly crucial consideration in light of the volume of international research demonstrating an increased risk of MHDs among vulnerable and marginalised populations (e.g. King et al., 2008; Mongelli et al., 2019; Fazel et al., 2005).

4. International Context

The present section synthesises information gathered through the review of practice documents on FPSW, detailing the current practice of FPSW within the six included countries. Where relevant, information gathered from practice documents is supplemented by additional detail noted in the introductions or "context" sections of research studies, but the results of these studies are not addressed here; these are presented in Section 5. Only information on FPSW within the context of MHDs is included here, with information on addiction presented in Section 6. However, in some of the countries covered, addiction and mental health services fall under the same remit and so literature concerning mental health may apply to addiction also. The volume of information and degree of detail provided varies across countries due to substantial variations in the amount of available literature concerning each country, as per Section 3.2. Where possible, we attempt to address areas such as the definition and scope of FPSW, values, principles, core competencies, training, certification, supervision, recruitment, and others.

4.1 Ireland

The available information on FPSW in Irish mental health services is limited, with only two Irish practice documents found through the literature search. The following information is based primarily upon these two documents and supplemented by some information from two evaluations of the Bealach Nua service: Garavan (2016) and Burke et al. (n.d., post-2018). We identified no guidelines, frameworks, or similar documents regarding nationwide provision of FPSW in Ireland, so information such as the scope, values, principles, or competencies of FPSWrs is lacking in this section. Importantly, in the context of Irish mental health services, the support of FPSWrs is only available to family members of adults experiencing MHDs.

HSE Mental Health Engagement and Recovery Office 4.1.1

The need for and importance of FPSW in Ireland is recognised by the Mental Health Engagement and Recovery Office (2023) in the HSE. The Mission of the Office "is to ensure that lived experience expertise and staff inform the design, development, evaluation, and delivery, and therefore the improvement of mental health services" (p. 5). Within the Office's 2023-2026 Strategic Plan, Strategic Objective 3 sets out "to support and enhance the role of peer and family support working in mental health services" (p. 7). Enablers the Strategic Objectives include organisational commitment, communications, data and evidence, and capacity in relation to supporting and implementing a recovery approach in services. As of 2023, 11 FPSWrs had been hired across public mental health services in Ireland, with seven of these located in Community Health Organisation 2 and the remainder across Community Health Organisations 5 and 7. As per Section 1.2, the Working Group funding and supporting this review was founded by the Mental Health Engagement and Recovery Office, as part of its efforts to enhance the delivery of FPSW in mental health services.

4.1.2 Bealach Nua

The greatest developments within FPSW in Ireland appear to have occurred in Community Health Organisation 2, through Bealach Nua in Mayo and later through the Galway and Roscommon Adult Mental Health Services (GRAMHS; see Section 4.1.3). The Bealach Nua service was established in 2015 as a pilot FPSW service in Mayo Mental Health Services. In August 2020, the Bealach Nua model was extended to GRAMHS, and a new FPSW service was established there. In June 2024, a FPSW website was launched by these services. Details of the Bealach Nua service were sourced from two evaluations of the service conducted in 2016 (Garavan, 2016) and post-2018 (Burke et al., n.d.), though results of the evaluations are discussed in Section 5 and integrated into Section 7.

The Bealach Nua service was initially staffed by two FPSWrs who together formed the equivalent of one full-time staff member. The FPSWrs are not part of the multidisciplinary team, to maintain their independence and non-clinical approach (Garavan, 2016). Their support is only available to family members of clients of the adult mental health service, who link in with the FPSWrs through two avenues: at the point of admission of their relative to the mental health unit, or by self-referral. Families receive approximately ten sessions of one-to-one support. Within its first year, 30 families had engaged with Bealach Nua, 25 of which had self-referred. More recent GRAMHS (2022) documentation indicates that since 2015, over 400 families had received support from Bealach Nua.

4.1.3 Galway-Roscommon Adult Mental Health Services

In August 2020, the Bealach Nua model was extended to GRAMHS. As of 2022, the two services had jointly supported 490 families and secured funding for three permanent and four part-time FPSWr posts (GRAMHS, 2022). Of these, 54 referrals and three half-time posts were based in GRAMHS. According to service documentation, the role of the FPSWr involves supporting family members in their wellbeing and in communicating with their team; supporting their communication and relationship with the person experiencing MHDs; and signposting (GRAMHS, 2022). In addition, the FPSWrs support Recovery Colleges and co-facilitate information sessions and support groups. The FPSWrs are not part of the multidisciplinary team. Their support is only available to families of GRAMHS clients. However, families who have no contact with their relative may not be able to avail of the service even if that person is engaging with GRAMHS. Offering the service to these families would confirm that the person is a client of GRAMHS, violating confidentiality. In order to do so, the person with MHDs must consent to this information being shared with the family.

4.2 United Kingdom

The following information is based upon <u>The Competence Framework for Mental Health PSWrs</u> - a three-part document outlining the skills, values, attitudes, and training of PSWrs employed in NHS mental health services (NHS Health Education England, 2020a;

2020b; 2020c). The development of the Framework was led by two professors with experience in developing competence frameworks for other mental health roles. An Expert Reference Group was also established, inclusive of people with lived experience. The Framework concerns PSW for people experiencing MHDs as well as their family members. Only information relevant to FPSWrs is discussed here.

Definitions and Scope 4.2.1

The NHS Competence Framework describes a PSWr as someone who uses their own lived experience to support another person experiencing similar difficulties (NHS Health Education England, 2020a). They foster hope in their clients, support them in gaining a sense of control and satisfaction within their lives, assist them in building community connections and a sense of belonging, and promote their rights. The PSWr does not strive towards predetermined goals, but rather collaborates with their client to achieve their own goals. Interestingly, the Framework also positions the PSWr as an agent of change within their team, who educates other staff, challenges unhelpful attitudes and practices, advocates for more person-centred services, and promotes co-production, equality, diversity, and inclusion. The Framework recognises that PSWrs may work on a paid or voluntary basis in a range of public, private, community, and voluntary mental health settings, though the Framework applies primarily to PSWrs employed in public services (NHS Health Education England, 2020a). The PSWr is assumed to be part of the multidisciplinary team within their mental health service.

4.2.2 Values and Principles

The Framework outlines four values and four principles that should guide the work of PSWrs (NHS Health Education England, 2020a). The principles refer to the application of the values to PSWrs' practice. In particular, PSWrs should work in accordance with values of inclusivity, respect, reciprocity, and mutuality. The value of reciprocity is particularly interesting. Informal peer support is typically reciprocal - for example, two friends mutually supporting one another. However, a key distinguishing feature of formalised peer support is the lack of this reciprocity; the PSWr offers support to their client, but the client does not in turn support the PSWr. In fact, the definition of reciprocity provided within the Framework is perhaps better captured as a value of equality (p.11):

- "1. People benefit from sharing their experience and can learn from each other as equals.
- 2. Everyone learns and everyone's contribution is of equal value."

The outlined principles of PSW are as follows: non-directive, progressive and strengths-based, safe, and supporting self-defined personal recovery. Progressiveness in this context is defined as "helping people learn from their experience and incorporate it and/or move forward" (p. 12). Personal, self-defined recovery is contrasted with clinical and service-defined recovery. Clinical recovery focuses on a reduction in clinical symptoms, regardless of the clients' own perceptions of their wellbeing and desired

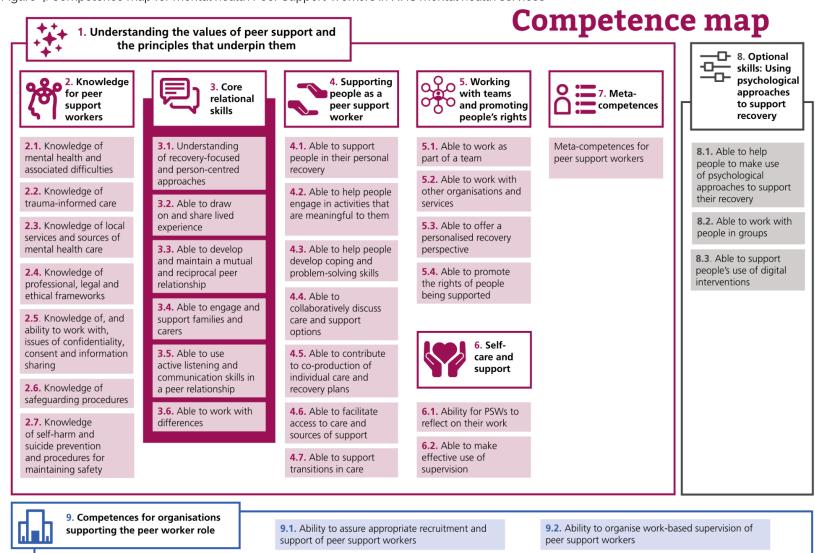
areas of improvement. Service-defined recovery is based upon organisational factors such as targets and guidelines for discharge.

4.2.3 Skills and Competencies

Figure 4 depicts the competencies of NHS PSWrs (including FPSWrs), as well as the organisations within which they work (NHS Health Education England, 2020a, 2020b). The competencies are organised within nine domains, one of which is optional. Rather than discussing each of these in full, a selection is focused on, particularly those which are less self-evident and therefore would benefit from additional explanation. A separate document outlines the training curriculum for enhancing PSWrs' skills within these domains (NHS Health Education England, 2020c).

The graph depicted in Figure 4 provides little insight into Domain 1 ("Understanding the values of peer support and the principles that underpin them"). This domain is based upon the values and principles outlined in Section 4.2.2, defined as "[a]n ability to understand and implement the peer support role in a way that is in line with the values and principles of peer support" (p. 5). Aside from these values and principles, it involves respecting the diversity of each person's experience as well as their experiential knowledge, and enabling clients to utilise their strengths, skills, and strategies. The Framework explains that this Domain is based upon the PSWrs' lived experience and attitudes, and not upon any required formal training or qualifications. As shown in Figure 4, these values and principles span across Domain 2 to 7. Domain 7 ("Meta-competencies") centres around reflection, critical thinking, and judgement, across five areas. These are: attitudes, values, and style of interaction, including the ability to reflect on their impact on one's practice; engagement and intervention, such as knowing when to disclose aspects of one's own experience; support, including knowing when to offer it; ability to respond to feedback; and ability to focus on self-care.

Figure 4. Competence map for mental health Peer Support Workers in NHS mental health services



Source: NHS Health Education England, 2020a; 2020b.

4.2.4 Challenges

The Competence Framework acknowledges that introducing PSWrs into mental health teams may come with challenges (NHS Health Education England, 2020a). A number of potential challenges and suggested solutions are outlined. In general, a culture of reflective practice and openness to change is recommended as imperative to supporting the establishment of PSWr roles. Among the challenges outlined are lack of clarity surrounding the role, isolation due to insufficient contact with other PSWrs, and lack of effective supervision. These challenges can be preempted or overcome through producing a clearly defined job description and role specification, establishing PSWr networks, group supervision, and providing knowledgeable supervisors.

More complicated are challenges concerning lack of acceptance by other professionals, organisational culture, and integrating PSWrs into multidisciplinary teams. Suggested methods of enhancing other professionals' acceptance of and respect towards PSWrs include ensuring clarity surrounding their role, openly addressing and answering any concerns and questions, and training on the value of PSW. Change of organisational culture involves recognising that fostering person-centred practice is not the sole responsibility of the PSWr. At the same time, the PSWr should be provided with supervision and support, such that they can encourage organisational change without experiencing burnout. Integrating the work of PSWrs into multidisciplinary teams is a complex task. Suggested solutions include ensuring commitment to the values and principles of peer support across the team; co-producing staffing and recruitment processes with existing PSWrs; recognising and valuing the contribution of family members and people with lived experience to their workplaces; and providing PSWrs with a physical space to work in.

4.2.5 Response to the Framework

In searching for literature on FPSW in the UK, we encountered substantial backlash to and criticism of the NHS Competence Framework. Though these comments came specifically in response to the NHS Framework, they provide useful insights to consider in the development of new documents concerning (F)PSW. As such, a discussion of these criticisms is warranted.

One key criticism raised against the Framework concerns the lack of co-production in its writing. Though an Expert Reference Group involving some lived experience expertise was involved in the process, the <u>National Survivor User Network</u> notes that the core team responsible for writing the Framework did not include any people with lived experience, PSWrs, or other experts in PSW. The team was commissioned due to their expertise in writing competency frameworks. Engagement with the Reference Group is described as tokenistic, aiming primarily zto add credibility to the Framework. The group was not meaningfully integrated into the process and their feedback was not heard. The authors somewhat acknowledge this when they state that the Framework documents are "not full examples of co-production" (NHS Health Education England, 2020a, p. 3).

Vikki Price, the Managing Director of a peer-led community mental health organisation, argues that the Framework abandons the principles of peer support and does not understand its essence. The CEO of the National Survivor User Network similarly states that the Framework ignores the complexities of peer support. Finally, a major concern raised by critics is the inclusion of psychological approaches as a competency. Though this is an optional domain, the critics argue that this blurs the line between PSW and clinical mental healthcare, as well as being fundamentally in opposition to the equal the PSWr and client. relationship between their Some psychiatric survivor/consumer/ex-patient activists characterise this as indicative of broader efforts within the NHS to use PSWrs to compensate for the under-resourcing of mental health services. Other criticisms of the Framework refer to the absence of attention to the history of peer support, particularly its foundations within the psychiatric consumer/survivor/ex-patient movement.

The Framework underwent a consultation process, where a draft version was published and then edited following feedback from the public. The initial draft was described as "not fit for purpose ... prescriptive and clinical, and far removed from our understanding of peer support" by the <u>National Survivor User Network</u>, as well as "an insult to the survivor movement and everything we value in peer support" by <u>others</u>. The Network recognised that some changes were made following the consultation but noted that the final document remains largely the same. The <u>CEO</u> states:

"The Framework is a product of deeply flawed processes and, as such, a lot of its content is problematic. The wider issue here is who led the Competence Framework ... I would like the failure of the Competence Framework to be led by experts in peer support to act as a catalyst for some of these discussions. Things will not change if we continue to accept invitations to be involved in areas which we should lead. ... I can only echo what others have said: no other profession would have stood by and watched this happen."

4.3 United States

A total of 15 practice documents concerning FPSW in the US were found. These include competency frameworks, best practice documents, documentation on funding for FPSW, standards and directories of certification programmes, and others. In US literature, MHDs are often captured under the label of "behavioural health" and/or "emotional health"; accordingly, this terminology is used within this section. Importantly, this also includes addiction and substance abuse. The present section begins with a brief explanation of healthcare provision in the US, as this differs considerably from the Irish system. Literature on FPSW in the US needs to be situated within this context and understood through the lens of the unique nature of this system. Following this, information gathered through the practice documents is discussed.

4.3.1 Context

The US is the only industrialised country in the world without universal healthcare, relying overwhelmingly on private healthcare providers (Vladeck, 2003). In 2022, 92.1% of

the population had health insurance (Keisler-Starkey et al., 2023). Almost two-thirds of these are privately insured, primarily through an employer. The remainder have public coverage, through Medicare (for people aged 65 or older and people with disabilities), Medicaid (for low-income individuals), or specific pathways for veterans. When discussing any form of healthcare provision in the US, it is important to consider access for those on Medicare or Medicaid, as the coverage of these programmes is more limited than that of private insurance. Over 25 million people in the US are completely uninsured, neither privately nor through public programmes. The cost of accessing healthcare is prohibitively expensive without insurance; for example, according to the US government website, a three-day hospital stay costs \$30,000 on average. As such, the majority of the population cannot choose to access services outside of their insurance coverage.

In addition, when discussing healthcare in the US, state-based variations should be considered. Decisions surrounding healthcare are typically made within states, rather than nationwide. As a consequence, the accessibility, availability, cost, standards, and quality of care varies across the country (Radley et al., 2023). Medicaid coverage of services also varies state-by-state.

4.3.2 Medicaid Funding for Family Peer Support

Access to FPSW through Medicaid focuses on family members of youth with emotional and behavioural (including mental health) difficulties. We were unable to find any information on Medicaid coverage of FPSW for family members of adults with MHDs. Each state determines the exact coverage of Medicaid, including the types of support covered, amount of funding, and qualifications the FPSWr must have for their clients to be eligible for coverage.

A 2019 review found that 31 states provided Medicaid coverage for FPSW in the context of youth behavioural healthcare (Schober & Baxter, 2021), compared to 14 in 2012 (Center for Healthcare Strategies, 2012). The types of services covered, amount of funding, and requirements for funding varies across these states. A range of titles for family peer support services were in use, including "peer counselling", "community support services", "self-help services", "family support partner[s]", "parent support and training", and "certified recovery peer advocate". Some services are available for parents only, while others are available to any person acting as a caregiver to the young person. Depending on the state, group and/or individual as well as in-person and/or telephone or virtual support may be covered. The amount of funding varies greatly, for example, from \$6.25 to \$21.97 per 15 minutes for one-to-one services.

In order to be eligible for Medicaid coverage, the FPSWr must meet certain requirements. Again, these vary state-by-state. All FPSWrs must have relevant lived experience, but this ranges from needing to be a family member of a young person with emotional or behavioural challenges, to needing to be their parent, to specifically having experience of the local behavioural health service. In some cases, there is a requirement regarding the length of time since the young person was diagnosed. Some states require training; others require certification; others require a set amount of work or volunteer experience; and many expect multiple of these. Most states require the FPSWr to be

supervised, with various specifications regarding the supervisor's experience and qualifications.

Occasionally, the peer support must include certain components to be covered by Medicaid. For example, in Maine, the FPSWrs must provide assistance in navigating health services and training in self-advocacy. This is in contrast with the standard conceptualisation of PSW, in which the client decides on the type of support, rather than the PSWr entering the relationship with preset goals.

4.3.3 Family Peer Support in the Context of Youth Services

Consistently with the distribution of Medicaid coverage, the majority of identified practice documentation on FPSW in the US concerned youth services. Family peer support is provided in recognition of the importance of engaging the family to the young person's recovery, rather than to enhance the family members' own recovery (Schober & Baxter, 2021; Family-Run Executive Director Leadership Association [FREDLA], 2016; Olin et al., 2016). The benefit to the family members is acknowledged, but this is rarely framed as the primary focus within US literature. The work of the FPSWr involves empathetic and active listening, support in navigating services, information provision, advocacy, skill-building, and facilitating collaboration and engagement between the family and clinicians (Nikkel et al., 2021). FPSWrs may provide services independently of other supports, or form one element of a multicomponent intervention (Nikkel et al., 2021).

One example of a multicomponent intervention incorporating FPSW is the Youth Assertive Community Treatment (ACT) programme (New York State Office of Mental Health, 2024). The programme supports young people aged 10 to 21 who are at risk of entering or are being discharged from inpatient care, with the aim of preventing admission or supporting the young person's transition back to the community. Youth ACT is delivered within the person's home or a community setting, by a multidisciplinary team. The services provided are varied and usually include multiple supports, such as family psychoeducation, crisis intervention, medication management, and PSW for the family and/or young person. As in other US literature, family support is provided "for the benefit of the child/youth" (p. 11). Interestingly, the family and/or youth PSWrs are part of the crisis response team, but only during operating hours; after hours, they are explicitly excluded.

A number of factors have been highlighted as important in providing effective FPSW in US youth services. A key consideration is financing, particularly due to the lack of universal healthcare (FREDLA, 2016). Others include co-producing peer services with youth with lived experience and their families; clear job descriptions, policies, and procedures, highlighting the uniqueness of PSW; supervision for PSWrs; a workplace culture that values expertise by experience; and recognition that family engagement is crucial, not an optional add-on (Nikkel et al., 2021).

Partnerships with existing family-led organisations also may help ensure that services are authentic, effective, and understood by all stakeholders. Such organisations have expertise in the family experience of youth MHDs, often providing family peer support

themselves, and have built trust and connections among people with MHDs and their family members (Nikkel et al., 2021). Stroull (2015) outlines the roles fulfilled by such organisations within systems of care, as well as the ways in which state/public services and these organisations can collaborate to support one another in achieving their shared missions and goals.

4.3.4 Skills and Competencies

The Substance Abuse and Mental Health Services Administration (SAMHSA) is an agency within the US Department of Health and Human Services, focused on enhancing the mental health of the population and treatment of addiction and MHDs. Their 2015 publication, Core Competencies for Peer Workers in Behavioral Health Services, outlines the necessary knowledge and skills of PSWrs. This document was co-produced with a range of stakeholders, including people with lived experience. The competencies apply to peer support for both people with MHDs and their families. SAMHSA (2015) recognizes that drafting separate core competencies for specific PSWrs, such as FPSWrs, may be necessary; their framework may serve as a foundation for this.

SAMHSA (2015) defines a PSWr similarly to other literature. The practice of peer support should be recovery-oriented, person-centred, voluntary, relationship-focused, and trauma-informed. The term "voluntary" in this context means that the clients' participation in PSW is their choice and the support provided is aligned with their preferences. A trauma-informed approach emphasises psychological, emotional, and physical safety, seeking to empower the client and provide them with a sense of control. What is unique to SAMHSA's (2015) document is the framing of a PSWr's role as spanning four major dimensions of recovery: health, home, purpose, and community.

The core competencies outlined within the document fall under 12 areas (SAMHSA, 2015, pp. 4-6):

- 1. **Engages peers** (clients) **in collaborative and caring relationships**, through the use of interpersonal skills, knowledge about recovery, and a recovery-focused approach.
- 2. **Provides support** through validation, encouragement, conveying hope, celebrating accomplishments, and offering practical support in accomplishing self-defined goals.
- 3. **Shares lived experiences of recovery**, including knowing when to share their experiences and doing this in a manner that inspires and supports clients.
- 4. **Personalises peer support** to each client's needs, preferences, personal values, and cultural and spiritual practices and beliefs.
- 5. **Supports recovery planning**, for example, through goal-setting, establishing strategies to achieve those goals, and providing credible, reliable information.

- 6. Links to resources, services, and supports; the PSWr may also accompany clients to activities and appointments, if requested.
- 7. Provides information about skills related to health, wellness, and recovery, including navigating other services.
- 8. Helps to manage crises, including recognising, responding to, and planning for potential crises and distress.
- 9. Values communication: Communicating with clients should involve the use of active listening skills and respectful, person-centred, recovery-oriented language.
- 10. Supports collaboration and teamwork, both in their own work and between the client and other clinicians. Conflict resolution skills are a central element of this.
- 11. Promotes leadership and advocacy: The PSWr should be aware of relevant rights and laws and advocate for their clients accordingly. This competency also involves enacting change within the PSWrs' workplace, for example, through educating colleagues.
- 12. Promotes growth and development, specifically the PSWr's development, including an ability to self-reflect, seek assistance and learning opportunities, and avail of supervision.

Separately to these competencies, the National Federation of Families for Children's Mental Health outlines specific Core Competencies of Parent PSWrs (Purdy, 2010). These are quite different to the SAMHSA competencies. According to the Federation, parent PSW involves applying lessons learned through parenting a child with MHDs, in accordance with ten domains. These are: ethics; confidentiality; effecting change; information about behavioural health treatment and prevention; information about the Individuals with Disabilities Education Act; communication; parenting for resilience; advocacy in and across systems; empowerment; and wellness and natural supports (p. 1). Ethics refers to the awareness and application of ethical and legal principles, as well as the principles of PSW. The ability to self-reflect also falls under this. Effecting change involves the PSWrs' use of a range of tools, such as motivational interviewing, coaching, and relapse prevention, to support the family. Crucially, the aim of understanding behavioural health treatment is not for the PSWr to carry out this treatment, but rather assist the family in understanding their child's care. The PSWr should also be aware of potential parental responses to their child's diagnosis. Parenting for resiliency involves understanding a range of parenting methods and approaches and the impact of these on children. The remaining domains reflect other literature in terms of their content.

A related document from the National Federation of Families for Children's Mental Health (2011), Best Personnel Practices in Parent Support Provider Programs, discusses recruitment practices within peer support and methods of assessing potential PSWrs' skills across these domains. One such tool involves asking applicants to describe their experience of parenting a child with MHDs. This assesses the requirement of lived experience as well as the person's ability to articulate their experiences and the lessons they have learned as a result.

4.3.5 Certification

As demonstrated in Section 4.3.2, the certification of PSWrs is of particular importance in states where the Medicaid funding of PSW depends on the providers' qualifications and certification. Peer support provided by non-certified PSWrs may not be eligible for reimbursement and hence not accessible to most clients. Certification also carries many other benefits. It may enhance the general public's and employer's confidence in PSW, assist the PSWr in finding employment, and improve recovery outcomes for both PSWrs and clients (SAMHSA, 2023b). As such, in 2023, SAMHSA published the National Model Standards for Peer Support Certification. The Standards were developed in collaboration with a range of federal, state, tribal, territorial, and local stakeholders, including PSWrs and FPSWrs. A Technical Expert Group was established to guide the development of the standards, consisting of members from across these stakeholder groups.

The document defines FPSWrs as having lived experience as primary caregivers of children with MHDs (including children of adult age). At the same time, it recognises the importance of PSW provided by, and for, other family members. Each US state is free to determine their own certification mechanisms and requirements (see SAMHSA, 2020, for a state-by-state directory of PSWr training and certification), with the SAMHSA (2023b) standards serving as guidance for designing these. They are closely aligned with the SAMHSA (2015) Core Competencies. Hogge et al. (2020) note that the standardisation of certification enhances consistency across peer workers, promotes ethical practices, and improves consumer protections.

The National Standards (SAMHSA, 2023b) are categorised into domains and based upon the needs of the peer workforce and their clients, in accordance with input from the expert group. Across the standards, there is an emphasis on accessibility, ensuring that the certification process does not exclude people with disabilities, from lower-income backgrounds, or without formal education. Every standard also highlights the importance of co-production. The standards are as follows (p. 5)

- Authenticity and Lived Experience
- 2. Training
- 3. Examinations
- 4. Formal Education
- 5. Supervised Work Experience
- 6. Background Checks

- 7. Recovery
- 8. Diversity, Equity, Inclusion, and Accessibility
- 9. Ethics
- 10. Costs and Fees
- 11. Peer Supervisor

A number of these standards warrant further discussion, as they address important areas not attended to in other literature. The "Authenticity and Lived Experience" standard (#1) refers not only to the requirement that PSWs have lived experience. It also states that the development, adoption, and revision of certification must involve meaningful

involvement of people with relevant lived experience. Assessing a PSWr's lived experience may involve asking about their definition of recovery and how they use their experiences to support others. With regards to family lived experience, the standards state that a FPSWr "should be able to describe their lived experience as a primary caregiver of an individual with a mental health and/or substance use condition, and describe strategies utilized to address associated challenges" (SAMHSA, 2023b, p. 13).

Regarding Standard #2, training should be co-produced with people with relevant lived experience. Recommended content includes areas such as the history of PSW, recovery tools, relevant legal systems, ethics, communication, crisis response, trauma-responsive approaches, and self-care. For FPSWrs, it should also cover systems and laws relating to child welfare and social services, as well as parenting skills and family relationship-building.

Similarly, the standards note that background checks, though sometimes necessary, can needlessly limit the accessibility of certification. This is particularly relevant to the US, which has the sixth highest imprisonment rate in the world, according to the World Prison Brief. Approximately one in three adults in the US has a criminal record (Alliance for Safety and Justice, 2021). SAMHSA (2023b) highlights the large proportions of people engaged with the criminal justice system who live with MHDs or addiction. They note that "a wide range of often disparate disqualifying offences can make obtaining certification difficult for many well-qualified, ethical, and currently law-abiding peer workers" (p. 19). As such, the standards recommend that disqualifying offences are limited to those which may pose a risk to clients, and not drug and alcohol-related or non-violent offences.

The diversity, equity, inclusion, and accessibility standard (#8) consists of recommendations for ensuring that certification is accessible and that certified PSWs are equipped and knowledgeable in this area. For example, training and examination materials should include captioning, interpreters, and braille materials. Remote options should be available. The content of the training should address discrimination, privilege, implicit biases, and barriers to service access for marginalised communities. The costs and fees standard (#10) is tied to this and recommends that the cost of certification is subsidised, with scholarships for those experiencing particular financial hardship.

4.3.6 Supervision

The National Federation of Families for Children's Mental Health (2011) emphasises the importance of supervision in supporting and enhancing FPSW. Supervision may be peer-to-peer, such as group supervision for PSWrs, or clinician-to-peer, where the supervisor is a clinical professional. One benefit of clinician-to-peer is the resulting education for the supervising clinician, who can learn about the value of PSW through supervising PSWrs. However, clinician-to-peer supervision is, by definition, clinical. The guidance provided by the supervisor may not be aligned with the principles of PSW, instead following the aims of traditional supervision, such as discussions of diagnoses,

treatment plans, and clinical progress. A clinical supervisor also cannot provide first-hand guidance on using their lived experience within their work, as this is not an element of their role.

4.3.7 Measuring Outcomes

FREDLA (2016) highlights the importance of measuring outcomes in running a successful FPSW service, for a number of reasons. These include accountability, continuous improvement in service quality, encouraging family members to engage in peer support, as well as facilitating research. In addition, outcome measurement provides evidence of the effectiveness and importance of family peer support to the government, other healthcare providers, and potential funders. This, in turn, can be helpful in securing funding for the development and provision of these services. Though the focus of FREDLA (2016) lies within youth services, these points apply to all peer support services.

Outcomes can be measured through a number of approaches. The first step often involves documenting the number of family members engaging with the service as well as the type, frequency, and duration of contact with families. For more in-depth and nuanced data, existing tools or questionnaires can be used to measure clients' satisfaction with the service or the impact of the service on clients. FREDLA (2016) recommends a number of tools that can be used for this purpose. These include: the Vanderbilt Mental Health Self Efficacy Questionnaire (Bickman et al., 1991), which assesses the parents' beliefs in their ability to influence and partake in their child's care; Working Alliance Inventory (Horvath & Greenberg, 1989), which assesses the relationship between the PSWr and client; and Caregiver Strain Questionnaire (Brannan et al., 1997).

4.4 Canada

Comparatively little literature was found in relation to FPSW in Canada, with only two relevant practice documents². As such, less detail is available on the provision of family peer support in Canada. The following information is sourced primarily from the Canadian <u>Guidelines for the Practice and Training of Peer Support</u> (Mental Health Commission of Canada, 2021) and the <u>National Peer Supporter Certification Handbook</u> (Peer Support Canada, 2023). These documents address peer support both for people with MHDs and their family members; only information relevant to family peer support is discussed here. The Mental Health Commission of Canada (2021) emphasises the importance of developing guidelines and standards of practice for peer support, stating that this "will enhance the credibility of peer support as an essential component of a transformed mental health system" (p. 8).

² The relatively small number of Canadian sources may be tied to the restriction of this review to English-language sources, as the official language of Quebec, which houses almost a quarter of the Canadian population, is French.

4.4.1 Definitions and Scope

The Mental Health Commission of Canada (2021) describes a PSWr as someone who not only has shared lived experience with their client, but also has developed the skills needed to support them and is "in a positive state of recovery" (p. 5). The latter is described as equally crucial to the person's lived experience. The Commission states that assessing these requirements (e.g. for the purpose of recruitment) should not be diagnosis-based but instead involve a discussion about the person's experiences, emotions, self-care, and resilience, and the relevance of these to the role. The person's ability to recognise their own stressors and triggers should also be considered. According to the Commission's guidelines, the person is considered to have met the requirement of recovery if they can recognise when they are in need of a "health break" (p. 21).

The PSWr uses their experience of being a family member and their journey of recovery to provide social and emotional support, foster hope, and demonstrate that recovery is possible. Their approach is person-centred rather than illness-centred. This means that the relationship between the PSWr and the client serves as the foundation of the support, rather than a diagnostic label. In FPSW, recovery entails attending to the family member's quality of life and wellbeing, and their understanding of and approach towards the person experiencing MHDs (Mental Health Commission of Canada, 2021). The family member is supported in developing hope and confidence in both their own recovery and that of their relative. It is also believed that their recovery can be enhanced through an improved understanding of their relative's difficulties.

In Canada, FPSW can be provided within a group and one-to-one and is delivered within clinical mental health services, CVS groups and organisations, and other settings. The Mental Health Commission of Canada (2021) emphasises the importance of offering PSW across a variety of settings to ensure accessibility to all who may need it. The Commission also highlights the value of independent, peer-run organisations both in providing peer support and supporting PSWrs, stating that it is "imperative" that their work and contributions are recognised (p. 8).

4.4.2 Values and Principles

The Mental Health Commission of Canada (2021) outlines seven values and 14 principles of practice for PSWrs. The seven values include: hope and recovery; self-determination; empathetic and equal relationships; dignity, respect, and social inclusion; integrity, authenticity, and trust; health and wellness; and lifelong learning and personal growth. The 14 principles are closely linked to these values and attend to both the relationship and interactions between the PSWr and their clients, and the PSWr's own wellbeing and personal development. The same core values are discussed in the National Peer Supporter Certification Handbook (Peer Support Canada, 2023).

With regards to supporting and relating to the client, the principles emphasise person-centeredness, empowerment, recovery-based language, and fostering hope. They refer to the importance of interpersonal communication skills in building an open,

validating relationship with the client, as well as the value of disclosing aspects of the PSWr's lived experience to signify understanding, hope, and the real possibility of recovery. At the same time, boundaries between the PSWr and their clients are crucial. With regards to the PSWrs' well-being, the principles highlight the need for self-care and recognising one's own limits, including when to seek help themselves. Participation in continuous personal and professional development is also encouraged.

4.4.3 Skills and Competencies

The Mental Health Commission of Canada (2021) describes an array of skills, abilities, and personal attributes required for providing formalised peer support. These are derived from and related to the PSWrs' lived experience, interpersonal communication, critical thinking, teamwork and collaboration, and ethics and reliability. Many of these echo the values and principles of PSW, such as having "a strong belief in the possibility of recovery" and "communication and listening skills that encourage honesty, openness, and clarity" (p. 22). For example, one interpersonal communication skill is "an ability to know when the time is right to share aspects of their own lived experience in a manner that provides relevant insight and/or hopefulness while keeping the focus on the peer and their situation" (p. 22). In addition to having lived experience as a family member, the FPSWr must understand when and when and how to disclose aspects of their experience. This requires the use of interpersonal communication skills but also critical thinking, as well as an understanding of the client and the degree to which they feel comfortable with the FPSWr discussing their experiences.

Under teamwork and collaboration, the Commission includes "a clear understanding of PSWr's area of responsibility and expertise compared to the responsibility and expertise of others, such as clinical professionals" (p. 23). This skill is particularly important to maintaining the authenticity of peer support - that is, the peer-to-peer, equal, non-medicalised approach. The PSWr should not only understand the distinction between their role and that of clinical professionals in terms of how it applies to them personally, but also be able to apply this knowledge to working with other professionals and supporting clients in navigating interactions with other professionals.

4.4.4 Training

In line with the values and principles concerning lifelong learning and personal development, the Guidelines recommend the provision of introductory training, ongoing learning and skills development, and a community of practice for PSWRs. Access to a community of practice involves regular meetings between PSWrs to learn from and support one another, as well as "keep each other committed to, and consistent with, the values and principles of practice of mental health peer support" (p. 25).

With regards to introductory training, the Guidelines outline a set of recommended training components for PSWrs, including FPSWrs. These involve fundamental principles of peer support, its social and historical context, and the concepts and methods that promote its effectiveness. The first of these follows the <u>values and principles</u>, with the additional mention of trauma-informed practice. This includes gaining an understanding

of the ways in which a client's trauma may impact their relationship and engagement with the PSWr, and how to respond to this. The social and historical context theme involves training on the philosophy and history of peer support, including the psychiatric consumer/survivor/ex-patient movement. As highlighted within the Guidelines:

"An awareness of the historical context of mental illness serves as a foundation for understanding the legacy of oppression and discrimination out of which current trends in peer support developed." (p. 34)

Training on the identification, understanding, and impact of prejudice, discrimination, and stigma, as well as the importance of diversity, social inclusion, and social determinants of health, is also included within this theme. Finally, the concepts and methods theme again echoes the values and principles outlined in the Guidelines, such as interpersonal communication, resilience, self-care, and boundaries. In addition, training on MHDs and side effects of medication is included here. While PSW is not diagnosis-based, this is considered important in enabling the PSWr to explore these topics with the client and support them accordingly, as and if appropriate.

4.4.5 Certification

Peer Support Canada is the national representative body for PSW in Canada, offering certification (but not training) for PSWrs, including FPSWrs. According to the organisation, certification is valuable to both the individual PSWr and the wider field of PSW. For the PSWr, certification validates their skills, knowledge, and competencies. For the broader field, certification validates PSW as a legitimate profession. It enhances the consistency of peer support delivered across the country and, through this, the quality of care received by clients. In their National Peer Supporter Certification Handbook (2023), Peer Support Canada notes the inaccessibility of university degrees to people experiencing MHDs and their families, especially if they are also marginalised in other ways. Certification eliminates the additional barriers that come with requiring PSWrs to go through university to achieve formal recognition of their competencies.

In order to be certified, the PSWr must demonstrate five standards of practice: lived/living experience, knowledge, acquired experience, code of conduct, and competencies. In accordance with the Guidelines of the Mental Health Commission of Canada (2021), the lived/living experience standard requires not only lived experience, but also being in "a positive state of recovery" (Peer Support Canada, 2021, p. 29). Acquired experience requires that the candidate has at least 200 hours of experience in practising PSW. Interestingly, in previous years, a certified PSWr could seek additional mentor certification. As a mentor, they could support PSWrs through the certification process and act in a managerial or supervisory capacity within their organisation. Mentor certification is currently suspended but recognised by the organisation as valuable and important.

4.5 Australia

Almost half of all identified practice documentation pertained to Australia. The exact topics covered within the literature were broad, ranging from recovery-oriented services to FPSW specifically, and from MHDs in general to specific mental health diagnoses. The types of literature also varied, including guidelines, briefs, frameworks, strategies, position papers, and other reports. Some were produced by government departments and statutory organisations, while others were authored by peer-led organisations or NGOs. Many of the practice documents refer to the "peer workforce" as a whole, that is, anyone employed in a role that is based upon their lived experience as a person with MHDs or their family member (e.g. ARAFEMI, 2011). This could include peer advocates, peer consultants, PSWrs, and others. However, any information included within this section is relevant to PSWrs, specifically FPSWrs.

This section begins with a brief overview of sources expressing support for and calling for the provision of FPSW, demonstrating commitment to FPSW among the Australian government and NGOs. The next subsections are primarily based upon governmental and statutory documents. Priority is given to discussing these sources in depth, as they have greater authority over health services and are thus more reflective of the practice of FPSW in Australian mental health services. When discussing non-governmental literature, the focus is on extracting information that supplements the governmental sources, for example, new or contradictory information.

4.5.1 Support for Family Peer Support Work

Governmental Support

The field of family peer support appears to have been in development in Australia for a long time, as is evidenced by the volume and timespan of the identified practice documents. Some sources trace the origins of Australia's commitment to the provision of peer work back to 1992, when the contemporary National Mental Health Strategy aimed for greater participation of mental health service clients and their carers in the delivery of services (e.g. National Mental Health Consumer & Carer Forum, 2010). ARAFEMI (2011) reports that the first paid family/carer peer roles began to be established in Australian mental health services in the late 90s and early 00s.

With regards to documents identified within this review, the National Framework for Recovery-Oriented Mental Health Services: Guide for Practitioners and Providers (Australian Health Ministers' Advisory Council, 2013) positions family peer support as an essential component of recovery-oriented mental health services. The framework aims to support and enhance the delivery of recovery-oriented mental healthcare in Australia, encouraging cultural change within services as well as greater engagement of people with lived experience. It outlines five practice domains and corresponding key capabilities for a mental health workforce to operate according to recovery principles. Domain 2 refers to person-first and holistic practice. Responsiveness to families, carers, and support people is a key capability within this domain - that is, attending to the needs of families and supporters is seen as a crucial element of person-centred and holistic

care. Within this capability, the Framework calls for greater promotion and employment of FPSWrs. The importance of co-designing FPSW services is also acknowledged. Families and supporters are seen as both crucial to their relative's recovery and deserving of support in their own right.

More recently, the need for greater provision of FPSW was recognised and highlighted by the Royal Commission into Victoria's Mental Health System (2021a, 2021b). The commission was established in 2019 to investigate deficiencies in the Victorian mental health system. In 2021, the Commission published a five-volume final report outlining the findings of its investigation and resulting recommendations. Volume 2: Collaboration to support good mental health and wellbeing (Royal Commission into Victoria's Mental Health Services, 2021a) and Volume 3: Promoting inclusion and addressing inequities (2021b) address the need to expand the provision of FPSW. In particular, recommendation 31 concerns family members, carers, and supporters. It calls for the establishment of family and carer-led centres to, among other aims, deliver family and carer peer support (see Section 4.5.11 for further information). It also recommends establishing a "statewide peer call-back service for families, carers and supporters caring for people experiencing suicidal behaviour" (Royal Commission into Victoria's Mental Health Services, 2021b, p. 68). In addition to expanding the FPSWr workforce, the Commission recommends the development of education and training opportunities as well as "a statewide approach to organisational readiness training" (p. 106) to ensure that public mental health services across Australia are prepared to support PSWrs.

Non-Governmental Support

The need for greater provision of FPSWrs is also recognised by NGOs. For example, the National Mental Health Consumer & Carer Forum (2021) highlights the importance of including FPSWrs within the mental health peer workforce, especially in acute services. They emphasise that PSWrs must be recognised and valued as an essential part of the clients' support teams, providing a unique and specialist expertise, rather than as an optional add-on or method of saving on time or costs. This must include adequate support, supervision, ongoing training, and remuneration for FPSWrs. In addition, the forum recommends that a specialised qualification aimed at FPSWrs should be established to enhance the quality and career pathways of FPSW.

Similarly, Orygen (2019) highlights FPSW as a critical component of family-inclusive practice in youth mental health services, identifying resourcing as the key barrier to its implementation. They call on funding for FPSW both within primary and specialist mental health services. In a separate Orygen report, the lack of and need for dedicated FPSWrs for specific relatives, such as siblings, is also highlighted (Baker, 2020). They recommend the trialling and provision of sibling peer support roles, where the PSWr has lived experience as a sibling of someone with MHDs.

Certain specialist mental health NGOs have also expressed support for the establishment of FPSWrs within specific areas. For example, the Butterfly Foundation for Eating Disorders (2024) recommends that a "carer" peer workforce is developed specifically in the context of eating disorder treatment. As eating disorder treatment is typically family-based, these PSWrs can help family members navigate the complexities, challenges, and dilemmas associated with engaging with this form of treatment, in addition to the universal benefits and aims of family peer support.

4.5.2 Definitions and Scope

In 2021, the Australian Mental Health Commission published a series of National Lived Experience (Peer) Workforce Development Guidelines (Byrne et al., 2021a; 2021b) to strengthen and guide the development of the peer workforce across Australia. These National Guidelines have gone on to shape similar frameworks within specific Australian states, such as the Queensland Health Lived Experience (Peer) Workforce Framework (Queensland Health, 2023) and the Western Australian Lived Experience (Peer) Workforces Framework (Government of Western Australia Mental Health Commission, 2022). A range of lived experience roles are covered within the scope of the National Guidelines. Only information relevant to FPSWrs is discussed within this review. Co-production lies at the heart of the Guidelines, as they were developed through a process of consultation and co-production and emphasise the importance of co-production throughout.

The Guidelines define all peer roles as "distinguished by a commitment to using lived experience to benefit others, uphold human rights and achieve systems transformation" (Byrne et al., 2021a, p. 21; 2021b, p. 4). A number of unique attributes of peer workers are outlined, including, in the case of FPSWrs, having had "life-changing experiences while supporting someone with mental health challenges that have profoundly impacted their life/world view" (2021a, p. 20; 2021b, p. 5). The Western Australian framework (Government of Western Australia Mental Health Commission, 2022) frames this differently, stating that what is key is that the person's experiences "caused life as they knew it to be so disrupted that the person had to reimagine their place in the world and their future plans" (p. 23). Regardless of exact definition, peer workers carry knowledge that only they can possess - knowledge that can only be gained through lived experience (National Eating Disorders Collaboration, 2019b). The combination of this lived experience with adequate training and education forms the "lived experience expertise" that is essential among peer workers.

In addition to and as a result of their lived experience, FPSWrs understand experiences of marginalisation, exclusion, and loss of identity, as well as both hopelessness and the need for hope (Byrne et al., 2021a; 2021b). They are willing to be vulnerable and open about their experiences, and share parts of their stories within their role. They have a greater ability to empathise with other family members and understand the importance and strategies of self-care. They work in a manner that is values-based, recovery-oriented, trauma-informed, and person-centred. Relationships are considered central to all peer roles, including relationships with clients and other professionals. The focus of PSWrs is on the entire person, rather than their diagnosis (National Eating Disorders Collaboration, 2019b). Even the language used by peer workers is important - when engaging with clients, they use the typical, everyday language that is best suited to discussing one's personal experiences and emotions, rather than the clinical, technical,

inaccessible language often used by other professionals in mental health services. Through this, they can also translate the information provided to family members by clinical staff into everyday, clearer language.

workers in Australia, including FPSWrs, are typically embedded into multidisciplinary teams (e.g. Queensland Health, 2023; Byrne et al., 2021a; Australian Government Department of Health, 2019). They function within primary health networks, community mental health services, inpatient services, and community organisations (Australian Government Department of Health, 2019). They may also be found in private services and consultancy (Peer Work Hub, 2016a).

The National Guidelines (Byrne et al., 2021a; 2021b) also note the potential value of specialised PSWrs, who - in addition to the above lived experience - are part of a marginalised community or have other unique lived experience. This could include people with specific disabilities, survivors of abuse, or people from minority groups. These PSWrs have enhanced insight into intersectionality and can additionally connect with their clients surrounding shared experiences of marginalisation. Similarly, Mental Health Families and Friends Tasmania (2023) note that the provision of PSWrs with specific experience of being a young carer or supporter may alleviate the isolation, confusion, self-blame, and guilt often experienced by this under-recognised population. Though research on specialised PSWrs is limited (Australian Government Department of Health, 2019), the Guidelines note that there is likely to be great value in investigating these roles further. The Australian Government Department of Health (2019) recommends that if specialised PSWr roles are put in place, they must receive additional supports due to their added vulnerability to discrimination.

4.5.3 Values and Principles

The National Lived Experience (Peer) Workforce Development Guidelines (Byrne et al., 2021a; 2021b) outline ten core values of peer work: hope; equality/equity; mutuality; empathy; choice: authenticity; belonging/inclusion; respect: interdependence/interconnectedness; and justice/human rights. Belonging/inclusion means understanding the importance and impact of inclusion, as well as respecting intersectionality and diversity. Interdependence/interconnectedness refers to the importance and impact of relationships and social networks in recovery. The justice/human rights value states that the PSWr should understand the impacts of social justice and inequality, in general and specifically on recovery. They should also be aware of the psychiatric consumer/survivor/ex-patient movement and the links between this and other civil rights movements.

Resulting from these values is a set of guiding principles underlying the practice of peer support. These include practising in a manner that is recovery-focused, person-directed, strengths-based, relational, trauma-informed, humanistic, and voluntary. The "voluntary" principle refers, in part, to the commitment of peer workers to eliminating involuntary treatment and coercive practice. The "humanistic" principle refers to the relational nature of peer support, with human connection at its core. Self-determination and lived experience as expertise are also included as principles.

Alternative, co-produced guiding principles of PSWrs are defined within the Western Australian Framework (Government of Western Australia Mental Health Commission, 2022). These are: authenticity, diversity, humanity, mutuality, human rights, and connection. Diversity involves an appreciation of different experiences and backgrounds and "understanding that each person's way is the right way for them" (p. 16). Humanity means believing that all people are inherently valuable and worthy of respect and compassion. Mutuality refers to the two-way, equal relationship between the peer worker and client, in contrast to the clinical professional-to-client relationship.

While the above values and principles underpin peer work itself, the Guidelines also outline core principles of the authorities and systems involved in the development of peer workforces. Employers, policy makers, and public bodies seeking to expand and support peer workforces should work in accordance with the following principles (Byrne et al., 2021a, p. 10; 2021b,)

- 1. Co-production
- Maintain the integrity of peer work
- Create the conditions for a thriving workforce

- 4. Respond to diversity
- 5. Reduce coercive and restrictive practice
- 6. Support systemic change and professionalisation

Co-production must involve an equal and respectful partnership, as well as a sharing of power, between lived experience expertise and clinical expertise. It should underpin every stage of the process, from co-planning, to co-design, to co-delivery, to co-evaluation. Maintaining the integrity of lived experience work involves working in accordance with its values and principles. The principle concerning coercive and restrictive practice is perhaps less relevant to FPSWrs; in any case, peer workers must not be expected to be involved in the use of restrictive practice. This is closely tied to maintaining the integrity of their work. Finally, supporting systemic change involves investment in peer workforces. Professionalisation must be led by the peer workforce itself, to ensure that its essence is not lost in the process.

4.5.4 Skills and Competencies

No core competencies and skills are outlined within the <u>National Lived Experience (Peer) Workforce Development Guidelines</u> (Byrne et al., 2021a; 2021b). However, Queensland Health (2023) lists a set of core competencies of peer workers within their framework. These include ethics, relational competencies, professional competencies, leadership, recovery, a lived experience perspective, and systems change. The ethical skills are closely tied to dignity and respect. Relational competencies centre around relationship-building and interpersonal skills. Professional skills refer to accountability, responsibility, and engagement in professional development. The systems change competency echoes the National Guidelines and international documentation, in that the PSWr is expected to advocate for cultural change within their organisation.

4.5.5 Developing a Peer Workforce

The National Lived Experience (Peer) Workforce Development Guidelines (Byrne et al., 2021a; 2021b) describe four crucial stages that an employer must undertake when developing a peer workforce: clarify; commit; co-develop; and continuously learn. Each of these stages includes actions across leadership, culture, policies, and planning. Clarifying involves building an understanding of the uniqueness and value of peer roles across the organisation. Any training provided within this area should be co-produced by people with lived experience and peer workers. Commitment involves seeing peer workers as essential, ensuring adequate resourcing, and moving towards recovery-oriented systems. Workplace adjustments are also essential, to ensure that peer roles are accessible to all, including people with disabilities. Examples of reasonable accommodations for peer workers may include flexible working hours, options to work part-time or on adjusted schedules, access to support, and special leave arrangements (National Mental Health Consumer & Carer Forum, 2010). Co-development requires the embedding of peer roles across all levels of an organisation, as well as the development of allies (see Section 4.5.6). Continuous learning and the embedding of these learnings into the organisation can happen once peer roles are successfully integrated into the organisation. Over time, any remaining barriers are challenged, the peer workforce becomes more diverse, career progression opportunities are provided, and a culture of safe sharing of lived experience across the entire workforce begins to develop. Information on example actions in each of the four stages is available in Table 3 below.

Table 3. Employer actions for lived experience workforce development

Ş 3 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	Preparation: Clarify	Preparation: Commit	Implementation: Co-develop	Transformation: Learn and grow
Leadership and culture	Build Leadership understanding of: • Lived Experience workforce • Recovery-oriented practice • Diverse perspectives and needs Strengthen commitment to diversity and inclusion	Prioritise Mission statements recognise Lived Experience work as core business Build whole-of-workforce commitment to lived experience	 Identify champions and allies for the Lived Experience workforce Partner with lived experience to develop and implement workforce strategy Consider opportunities to develop Lived Experience leadership roles 	 Embed Lived Experience roles represent diverse culture and perspectives Person-directed and recovery-oriented service delivery and practices are established Safe sharing of lived experience is prioritised for the whole workforce
Policies and planning	Review Identify the gap between current practices to recovery-oriented practice standards Current levels of diversity in service users, workforce and community	Review HR and other policies for flexibility to support Lived Experience work Outline a Lived Experience workforce strategy Include Lived Experience in long-term budgets and plans	 Plan Develop an implementation plan Develop position descriptions and recruitment processes Budget for sufficient numbers of roles and Full Time Equivalent and all necessary supports and training 	 Crow Lived Experience roles are employed at all levels sufficient to meet needs Career pathways are available for Lived Experience workers A range of supervision and training options are available to Lived Experience workforce
Development	Whole-of-workforce about Lived Experience roles and the value of diversity People accessing services and their families about Lived Experience roles Provide service users with information on peer support services in the region		Equip Ensure access to appropriate supervision and training for Lived Experience workers Consider Lived Experience apprenticeships/traineeships Enable connections for Lived Experience workers with Lived Experience networks	Review and evaluate the impacts of and remaining challenges to embedding the Lived Experience workforce Evaluate to contribute to a lived experience informed evidence base

Source: Adapted from Byrne et al., 2021a; 2021b.

In addition to the National Guidelines, in 2016, the State of New South Wales published an Employer's Guide to Implementing a Peer Workforce (Peer Work Hub, 2016a; 2016b). This toolkit assists employers intending to integrate a peer workforce (such as FPSWrs) into their organisations. It guides them through a six-step planning process, supplemented by worksheets and checklists to assist with each step. The guide was

published a few years prior to the National Guidelines, but there are similarities between the two.

The first step of the process involves assessing the readiness of the organisation through defining the goals and objectives of establishing a peer workforce, the scope of the workforce, and any constraints and risks. These steps resemble the clarification and commitment steps of the National Guidelines (Byrne et al., 2021a; 2021b). Organisational readiness refers to readiness for change and cultural readiness, that is, the extent to which the service adopts a recovery, strengths-based, trauma-informed approach. In the following steps, the employer should engage with relevant stakeholders and define the peer worker roles, in conjunction with experienced peer workers. This is aligned with the clarification step of the National Guidelines. Importantly, peer workers shouldn't be asked to do anything that increases the power imbalance between them and their clients, for example, completing assessments or coercing the client into accepting treatment. Once these first two steps are completed, the employer must manage change through communicating with and educating their existing workforce. Staff must be prepared to work with peer workers, for example, through availing of peer-led training on the definitions, origins, values, and benefits of PSW. At this point, the organisation can begin recruitment (see Section 4.5.7). The final steps involve managing performance, evaluating organisational practices, and revising practice accordingly.

The Tasmanian Peer Workforce Development Strategy (Mental Health Council of Tasmania, 2019), also provides a set of priorities for developing a peer workforce in Tasmania "that promotes both recovery for consumers and appropriate supports for families and friends, resulting in better outcomes in their mental health journeys" (p. 21). These are:

- Governance and Advocacy, including administrative arrangements, policy commitments, resources, guidelines, and regulation.
- Peer Connections, including peer networks, peer supervision, mentoring, and leadership. This is essential to ensuring the wellbeing and development of peer workers.
- Organisational Readiness and Culture, including stigma-reduction efforts, flexibility, and role design. The organisation must be prepared to accept a peer workforce, through fostering a culture that is inclusive, recognises their value, and does not stigmatise.
- Training and Professional Development, such as qualifications and training. Training should cover the core competencies of the role, best practice, legislation, and advocacy.
- Workforce Development, including HR management and clear role descriptions, to support and strengthen the existing workforce as well as attract new PSWr candidates.
- Career Progression, including remuneration, awards, and career development.

4.5.6 Allies

Similarly to other international documentation, the National Lived Experience (Peer) Workforce Development Guidelines (Byrne et al., 2021a; 2021b) frame peer workers as important agents of change. Encouraging their organisations and colleagues to adopt a more recovery-oriented and person-centred approach is seen as a core element of their role. This is echoed in other Government documentation (e.g. Australian Government Department of Health, 2019). However, the Guidelines simultaneously recognise that this should not be the sole responsibility of the peer workers. They call on the identification and development of allies to peer workers.

Allies are individuals who are not peer workers themselves, but who actively support and promote the peer workforce. They recognise and act upon their responsibility to advocate for systemic change. They support peer workers vocally and practically, throughout the initial and ongoing development of the peer workforce. This includes recognising and removing barriers for the peer workforce, from practical and bureaucratic barriers to unhelpful attitudes and workplace culture. Examples of actions considered essential to effective allyship are (Byrne et al., 2021a, p. 28):

- Actively opposing discriminatory language, policies and practice
- Actively and vocally supporting the work of the Lived Experience workforce
- Deferring to and stepping aside to credit lived expertise and share power
- Facilitating opportunities for lived experience leadership
- Advocating for lived experience roles at multiple levels

Allies should exist at all levels of the organisation and may be external or internal. Training for allies should be co-produced by peer workers and experienced allies. Continuity, handover, and succession training is important such that the expertise of allies is not lost due to staff turnover.

4.5.7 Recruitment

The National Lived Experience (Peer) Workforce Development Guidelines (Byrne et al., 2021a; 2021b) recommend that existing peer workers are involved in the recruitment process of additional peer workers. Expanding on this, the Queensland Health Lived Experience (Peer) Workforce Framework (Queensland Health, 2023) and New South Wales toolkit (Peer Work Hub, 2016b) recommend that peer workers are present on the interview panel. Beyond this, the National Guidelines do not contain much guidance on recruitment, though state-based documents offer slightly more detail. For example, the Queensland Health (2023) Framework recommends that candidates for peer roles are shortlisted not only on the basis of their lived experience, but their ability to articulate how these experiences inform their ability to fulfil the requirements of the role. Interview questions should be designed to elicit such responses. Since disclosure of personal experiences is highly likely during interviews, the panel should be skilled in creating a safe space for this to take place and support should be made available for the applicant following the interview.

4.5.8 Supervision

Supervision is considered crucial both within national (Byrne et al., 2021a; 2021b) and state-based guidelines (e.g. Queensland Health, 2023; Peer Work Hub, 2016b), as well as by community organisations and NGOs (e.g. Tandem, 2015). Hodges et al. (2022) recommend that supervision is embedded into practice standards for peer workers, to enhance funding. A peer worker's line manager should ideally be an experienced peer worker, though this may not be possible in organisations with relatively new peer workforces (Byrne et al., 2021a; Peer Work Hub, 2016b). However, supervision for peer workers must be carried out by more experienced peer workers (Byrne et al., 2021a; Peer Work Hub, 2016b; Butterfly Foundation for Eating Disorders, 2024). Where this is not possible, the organisation should partner with an external peer-led organisation or experienced lived experience contractor, rather than providing non-peer supervision. Supervision should be provided on a regular basis and additionally as needed.

The Mental Health Peer Supervision Framework, produced by the Lived Experience Workforce Program of the Mental Health Coalition of South Australia (2022), provides further guidance on supervision of peer workers. The Mental Health Coalition is an NGO and the Supervision Framework is specifically aimed at supervision of peer workers within NGOs. Nonetheless, it can offer some valuable learnings for public services. The focus within the framework is on peer supervision, that is, supervision offered by peer workers to peer workers.

According to this Framework, the peer supervisor should have extensive experience of peer work practice, in a similar role to the supervisee. At the very least, they should work on the basis of the same lived experience perspective, that is, personal or family. This shared personal and professional experience allows them to relate to the specific difficulties and ethical dilemmas faced by their supervisee. Supervision sessions should be co-produced by the supervisor and supervisee. The physical environment should also be considered and agreed upon mutually, such that the location and venue is accessible and suitable to both. Peer supervisors should themselves receive ongoing supervision and training. Regular evaluation is also recommended, taking into account the effectiveness of the supervision, the supervisee's development and feelings of being supported in the relationship, the supervisee's overall satisfaction and willingness to continue engaging with supervision, and the supervisor's ability and effectiveness in providing supervision.

An alternative approach may involve group supervision. This comes with a number of advantages. The collaborative element may facilitate better problem-solving and sharing of knowledge. Group supervision fosters a sense of connection and community, building peer networks. From an organisational perspective, it is more cost effective. On the other hand, group supervision may lead to confidentiality issues and produce conflict among colleagues. Peer workers may not feel safe sharing their experiences in a group, and some voices may dominate. The group also offers less flexibility and less room to reflect on personal practice and discuss one's experiences in depth.

4.5.9 Training

At present, the main training course for PSWrs in Australia, including FPSWrs, is a Certificate IV in Mental Health Peer Work (Australian Government Department of Health, 2019; Peer Work Hub, 2016a). Core areas covered within this one-year course include working with diverse populations, trauma-informed care, promoting self-advocacy, promoting wellbeing, peer work practices, workplace health and safety, and applying one's lived experience to one's work. Elective modules are also available, with some options specific to FPSWrs. Placement is included within the course, and there are no entry requirements. The requirement for PSWrs to carry this qualification is supported by NGOs, such as Tandem (2015). However, both Tandem (2020) and the National Mental Health Consumer & Carer Forum (2021) recommend the co-production of specialist training for FPSWrs. Additionally, Hodges et al. (2022) recommend the provision of tiered training opportunities for PSWrs, from short courses to university-level qualifications, to support their career progression. All training options for peer workers should offer flexibility, including hybrid learning options, to enhance accessibility and completion rates (Hodges et al., 2022).

4.5.10 Challenges

Challenges to the provision of peer support, including FPSW, are identified across sources concerning both public services (e.g. National Mental Health Consumer & Carer Forum, 2010) and community-led services (e.g. Western Australian Association for Mental Health, 2014). A number of these are outlined below. Challenges around recruitment, training, and supervision are detailed in the previous sections. The National Mental Health Consumer & Carer Forum (2010) states that failure to address these challenges can lead to burnout among both peer workers and other mental health service staff, compromised outcomes for clients of services, lack of trust and respect between clients, peer workers, and clinical staff, as well as reinforcement of stigma.

Funding

Adequate funding for PSW is identified as a challenge (e.g. Western Australian Association for Mental Health, 2014). This barrier is additionally impactful within the provision of specialist peer support, for example, for people affected by eating disorders and their family members (National Eating Disorders Collaboration, 2019a; 2019b). Secure, multiannual funding is necessary to ensure adequate provision of peer work and suitable pay and conditions for PSWrs. Tandem (2020) recommends significant, recurrent, nationwide investment in the family/carer workforce as a necessary part of the core team of mental health services. Hodges et al. (2022) also recommend targeted investment into training pathways, scholarships, and career opportunities for peer workers. Relatedly, poor remuneration, particularly when compared to clinical staff, also poses challenges (e.g. Tandem, 2015; National Mental Health Consumer & Carer Forum, 2010).

Role Confusion and Conflict

Lack of clarity over the role of PSWrs, including FPSWrs, is identified as a challenge by the Western Australian Association for Mental Health (2014), National Mental Health Consumer & Carer Forum (2010), and Tandem (2015). The roles and responsibilities of peer workers are often poorly defined, with structures such as job descriptions lacking. This can inhibit the effectiveness of PSWrs and trigger stress, boundary issues, and conflicts within teams. Role descriptions for PSWrs must be clearly defined, outlining what is and isn't a part of the role of a PSWr. Peer roles should also be integrated into occupation classification systems, to enhance the understanding of these roles as distinct from other mental health service roles (Hodges et al., 2022).

Preparing the Organisation, Attitudes to Peer Workers, & Stigma

As outlined within previous sections, the success of the peer workforce is dependent upon the readiness of an organisation to accept and adapt to the presence of PSWrs. Existing staff must understand the nature and value of PSW and treat them as equal members of the team (Western Australian Association for Mental Health, 2014). The attitudes of staff towards peer workers, including the presence of stigma and devaluing of PSWrs' expertise (Tandem, 2015), may impact the effectiveness of PSW and the wellbeing of PSWrs (National Mental Health Consumer & Carer Forum, 2010). The expertise of peer workers is sometimes not recognised as valid, while their involvement can be tokenistic (Hodges et al., 2022). One avenue of addressing this is through the provision of co-produced training for non-peer workers, addressing discrimination, stigma, common assumptions and misbeliefs about peer workers, and the role and value of peer workers.

4.5.11 Specific Approaches to Family Peer Support

Within this section, two specific Australian approaches to the provision of family peer support are outlined. These include the Family- and Carer-Led Centres recommended by the Royal Commission into Victoria's Mental Health Services (2021b), as well as the Families Helping Families programme delivered by Orygen (Leggatt & Woodhead, 2016).

Family- and Carer-Led Centres

As mentioned, among the recommendations of the Royal Commission into Victoria's Mental Health Services (2021b) was the establishment of family- and carer-led centres, a number of which have since been opened. The Commission recommends that each centre has both a physical location and an online presence. The centres are to be staffed by at least eight full-time equivalent support workers, offering information about and referral pathways to other supports, providing financial aid, working one-on-one with families, and offering out-of-hours access. Though initially it may not be possible to ensure that all staff members are specifically FPSWrs, this should be the goal and achieved over time. The centres will function within an individualised, strengths-based model in identifying the needs of their clients. They will also support existing family peer support groups in their areas. Importantly, access to these services should not be dependent on having a family member who is actively engaging with mental health services, but simply having a family member with MHDs, regardless of their access to services. No formal referral will be required.

Additional input on the establishment of these Centres has been provided by Tandem (2021), an NGO representing family members, carers, and supporters of people with MHDs. Tandem (2021) recommends that eight categories of services are provided within these Centres: practical support (e.g. respite, financial support, system navigation); wellbeing services; psychoeducation; family therapeutic services; crisis and post-crisis services; specialist support services (to meet the needs of specific groups); outreach services, including home-based services; and after hours support. In addition to these eight forms of support, Tandem (2021) highlights the potential contribution of the Centres to research on FPSW and family services more broadly.

Families Helping Families

Families Helping Families is a FPSWr service aimed at family members of young people who experience psychosis, delivered by the youth mental health charity Orygen (Leggatt & Woodhead, 2016). The training programme for prospective FPSWrs consists of seven 90-minute sessions, interspersed with practical, apprenticeship-style experience. The sessions cover areas such as using one's own lived experience to support families; active listening; working with diverse families; helping families cope with first-episode psychosis; management of illness-related behaviours; supporting families in understanding the mental health system; and managing boundaries.

FPSWrs within the Families Helping Families programme are officially employed and paid. They are part of the Psychosocial Recovery Services multidisciplinary team. New clinicians are provided with orientation and a newsletter describing the role of the FPSWrs. This involves providing face-to-face and telephone support and information to families of clients registered with Orygen.

FPSWrs are offered support to assist them in navigating difficult emotional experiences that may arise during their work, such as personal triggers or concerns about supporting clients. Group supervision for the entire multidisciplinary team is provided in weekly sessions, led by a senior clinician (not a PSWr). Topics commonly discussed include boundaries, self-awareness, self-care, confidentiality, strategies for empowering families, offering advice, and service improvement.

4.6 New Zealand

No practice documentation concerning New Zealand was identified through the literature search. However, a small amount of information was found on the Te Pou website. Te Pou is the New Zealand National Workforce Centre for Mental Health, Addiction, and Disability. FPSWrs are part of the "consumer, peer support, and lived experience workforce". Surveys of this workforce in mental health and addiction services in New Zealand conducted in 2018 and 2020 found that it is made up of approximately 481.5 full-time equivalent positions. This includes those working within NGOs and within

public services. Among these, there are 45.1 full-time equivalent FPSWr roles (referred to as "Whānau support worker", from the Māori term roughly translated to "extended family"). All of these roles are employed within NGOs - not public services - though Te Pou notes that the figures for public services may be inaccurate. All are located within adult services.

More recently, a 2022 survey of the lived experience workforce in New Zealand, inclusive of paid and voluntary staff within public, voluntary, and community services, found that 12%, or 29, of the 242 respondents were Whānau (family) PSWrs (Te Pou, 2022). Of these, 22 worked in NGOs, 4 worked in public services, and 11 worked in Māori-specific organisations, with some respondents working across multiple of these. Furthermore, 2022 data showed a total of 71 FPSWrs employed within New Zealand NGOs, constituting approximately 17% of the total NGO peer support workforce and a growth of 58% since 2018 (Te Hiringa Mahara: Mental Health and Wellbeing Commission, 2023). Equivalent data for public services are not available.

5. Research on Family Peer Support

This section details the findings of research studies identified through the review. In total, 37 research sources are included. Eight concern addiction and are discussed within Section 6, as the focus within this section is on FPSW in the context of MHDs. We begin with an overview of the types of family peer support investigated within the research. Two case studies are provided as examples. Next, research on the impact of FPSW is discussed, as well as barriers and challenges in FPSW. Following this, the focus is shifted to FPSWrs' and clinicians' perspectives on FPSW, followed by the FPSWr training. Finally, we summarise some gaps identified in the existing research.

5.1 Approaches to Family Peer Support

Of the 29 research studies on FPSW in the context of MHDs, 23 focused on a specific intervention. The range of interventions covered was wide, including multi-session group supports (Brister et al., 2012; Grennan et al., 2022; Lucksted et al., 2013; Levasseur et al., 2018; Schiffman et al., 2015; Higgins, 2012; Mercado et al., 2016), single-session group supports (Brown et al., 2022), and one-to-one support (Cottrill, 2011; Reynolds et al., 2022; Mercuri et al., 2022; Radigan et al., 2014; Garavan, 2016; Hopkins et al., 2021; Davis et al., 2011; Davis et al., 2010; Visa & Harvey, 2019; Markoulakis et al., 2021; Markoulakis et al., 2017; Jamison, 2019). Additionally, one study involved a group-based intervention followed by optional one-to-one support (Chiocchi et al., 2019), while another combined online psychoeducation with a peer support forum and text-based one-to-one peer support (Lobban et al., 2020). Another study explored an adaptation of a non-peer-led group intervention, where a FPSWr role was introduced as additional support for clients who had completed the group sessions (Vaswani-Bye et al., 2024). Some supports included a range of components depending on the clients' needs, such as emotional support, information provision, practical support, and advocacy (e.g. Mercuri et al., 2022). Others were focused on specific elements, such as psychoeducation (e.g. Chiocchi et al., 2019) or advocacy (e.g. Davis et al., 2010; 2011). Discussing all of the forms of support addressed within the literature is beyond the scope of this review. Instead, we detail two example case studies below.

5.1.1 Case Study 1: National Alliance on Mental Illness "Family-to-Family"

The "Family-to-Family" programme was launched in 1991 by the US National Alliance on Mental Illness. This is a 12-week course for family members (including partners and friends) of people with MHDs, delivered in-person, in a group setting, and free of charge (Duckworth & Halpern, 2014). The programme aims to enhance family members' wellbeing and understanding of their relative's and their own experiences (Lucksted et al., 2013). Facilitators of the programme are volunteer family members who have themselves completed the classes and a three-day training course.

Sessions are two to three hours long and involve skill-building, psychoeducation, problem-solving, and, overall, providing a safe environment in which attendees feel understood. Each session focuses on a different topic, such as specific diagnoses and associated treatments, brain function and its relation to mental health, recovery, medication, communication skills, self-care, and advocacy (Lucksted et al., 2013). To support the learnings of the programme, over the 12 sessions, attendees receive a total of 250 handouts. While this volume of information may seem overwhelming, facilitators focus on supporting attendees to integrate the lessons into their lives, rather than trying to memorise their content in detail. Distributing this information in paper format is precisely what allows for this, as attendees can easily revisit the information as needed. The handouts may also be shared with other family members and friends, thereby increasing the reach of the programme.

As of 2014, over 300,000 family members had availed of the programme and over 3,500 had been trained to deliver it (Duckworth & Halpern, 2014). Family-to-Family has also been culturally adapted for delivery outside of the US and translated into a range of languages.

5.1.2 Case Study 2: Family Navigation Project

The Family Navigation Project was established in 2013 in Toronto, Canada, to support families of people aged 13 to 26 affected by MHDs and/or addiction (Markoulakis et al., 2021). The aim is to assist families in navigating mental healthcare and related services, and connect them with relevant supports and organisations. Initially, the Project was delivered exclusively by clinician (non-peer) navigators. In 2016, it was expanded to add a new role: Parent Advocates with Lived Experience. These Advocates work alongside the clinician navigators to provide non-navigation peer support.

The introduction of Parent Advocates was informed by Markoulakis et al. (2017), who explored family members' perceptions of and needs regarding this proposed service. Three themes emerged from this. Firstly, participants wished for the Advocate to support them, by encouraging self-care and providing a space to discuss their experiences with someone who can genuinely understand and empathise with them. They noted that the clinician navigators assist clients in linking with services but do not directly support them, and so wished for the Advocates to do so. Secondly, when asked about Advocates' qualifications, participants stated that lived experience would be their most crucial qualification, and other formal education was not necessary. In terms of skills, they felt that empathy, listening, validating the client, and boundaries were crucial, as well as understanding when disclosure of the Advocate's lived experience was appropriate. Finally, participants saw the Advocate as a complement to the navigation service, rather than a replacement. The Advocate would both support them in difficult times and celebrate their successes, as through their lived experience, they understand the importance and value of even seemingly "small" achievements.

The present day Parent Advocates are aligned with these areas (Markoulakis et al., 2022). Families availing of the navigation service are referred to an Advocate if their team feels that they would benefit from additional support. Though they are called Advocates, their

role primarily involves providing emotional support, rather than advocating for clients in interactions with other services.

5.2 Impact and Value of Family Peer Support

The effectiveness and impact of FPSW has been investigated qualitatively and quantitatively. <u>Section 5.2.1</u> summarises the findings of quantitative research while <u>Section 5.2.2</u> discusses the qualitative results. Findings concerning the <u>Family-to-Family programme</u>, the <u>Family Navigation Project</u>, and <u>Bealach Nua</u> are presented separately, in <u>Sections 5.2.3</u>, <u>5.2.4</u>, and <u>5.2.5</u> respectively.

5.2.1 Quantitative findings

Research on group-based family peer support interventions has found evidence for their effectiveness, though results are not entirely consistent. Brister et al. (2011) explored the impact of an intervention similar to the Family-to-Family programme, specifically targeting caregivers of youth experiencing MHDs. They found that participation in the programme resulted in significant improvements in family empowerment and self-care, as well as a reduction in incendiary communication (e.g. shouting). Interestingly, there was no corresponding increase in more constructive, affirming communication. Chiocchi et al. (2019) investigated a group psychoeducation and skills-training programme for carers³ and family members of people attending secondary mental health services, modelled upon the "Family Connections" programme for relatives of people with borderline personality disorder (Hoffman et al., 2005). Similarly to Brister et al. (2011), family members who took part in the programme experienced significantly higher family empowerment. Their mental health and wellbeing also improved. They felt less burdened by their relative's MHDs, in areas such as financial problems, limitations on personal activity, household disruptions, shame, quilt, stigma, and resentment. Brown et al. (2022) assessed the effectiveness of two group interventions for carers of people with borderline personality disorder: a seven-hour workshop and a 2.5-hour information session. Both resulted in significant improvements in participants' attitudes towards and knowledge of borderline personality disorder. The seven-hour workshop - but not the 2.5 hour session - also led to reductions in participants' psychological distress and the extent to which they felt burdened by their relative's difficulties, similarly to Chiocchi et al. (2019).

In an Irish project, Higgins (2012) describes the design, delivery, and evaluation of a group-based, peer-led and peer-conceptualised recovery education programme for family members of people attending mental health services. After participating in the programme, family members reported significant improvements in their knowledge of areas such as their family member's rights, helping their family member become more involved in their community, and supporting family members who hear voices. However, no significant changes were observed in five other domains: participants' general health,

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³ As mentioned in the introduction, where the term "carer(s)" is used, this follows the phrasing used in the research study. While we recognise the criticisms of this term, using an alternative term would be inaccurate, as the research is based upon the experiences of self-identified carers and not, for example, family members more broadly.

self-advocacy, perceived support from their social network, hopefulness, or attitudes towards recovery. Regarding specific components of the programme, 17 of the 18 participants who took part in the evaluation agreed that hearing others' stories was both supportive and an effective way of learning. Fifteen participants felt that group work was an effective way of learning.

Quantitative research on the impact of one-to-one interventions is more limited, with only two such studies included in this review. In addition, both of these explored Family Peer Advocates in youth mental healthcare, rather than more general peer support for family members of people of any age affected by MHDs. Radigan et al. (2014) examined the impact of Peer Advocates on families' satisfaction with mental health services. They found that having access to a Peer Advocate was associated with significantly higher satisfaction with access to, appropriateness of, and participation in services, as well as general satisfaction with services. No association was found with satisfaction with the cultural appropriateness of services or understanding of medication. In addition, caregivers who had access to a Peer Advocate reported significantly higher levels of social connectedness and enhanced outcomes for the young person, in terms of happiness, ability to make friends, and getting along better as a family. However, this is contradicted by the results of Jamison (2019), who found that availing of a Family Peer Advocate did not significantly predict outcomes for the young person.

In addition to these evaluations of more standard models of FPSW, Lobban et al. (2020) conducted a randomised controlled trial of a novel approach, titled REACT. This consists of online, self-led psychoeducation, combined with a resource directory, peer support forum, and direct messaging with FPSWrs. They compared people who availed of REACT with those who received their usual supports combined with the resource directory. While both groups experienced statistically significant improvements in their general health, there was no significant difference between the two groups, indicating that REACT did not carry any additional, unique benefits.

Lastly, while not an evaluation, Mental Health Reform (2019) investigated the needs and experiences of family members of people experiencing MHDs in Ireland. Their study evidenced the demand for FPSW. Almost one-fifth of the 786 participants reported attending family peer support groups, making them the second most popular form of support. Many participants stated that there is a need for more such groups, feeling that simply being able to discuss their experiences with people who understand them first-hand would reduce feelings of isolation and generally benefit them.

5.2.2 Qualitative findings

A number of research studies qualitatively explored the value of FPSW for clients. Participants of these studies reported a range of benefits to availing of FPSW. These are outlined below, alongside some example quotes to illustrate the impact of the supports on participants.

Among the most common benefits of FPSW discussed by participants were information and skill-building (Grennan et al., 2022; Brown et al., 2022; Higgins, 2012). Many of the

FPSW supports explored within research were psychoeducational. In some cases, they even involved guest clinician speakers, such as psychiatrists. This was valued by participants, who appreciated the opportunity to ask the speaker for clarification on issues that had not been sufficiently addressed by their relative's clinicians (Higgins, 2012). The information gained through FPSW could then be passed on to others in the participants' network, spreading the lessons learned even further (Higgins, 2012).

knowledge were also reported by participants who availed non-psychoeducational FPSW (e.g. Levasseur et al., 2018; Visa & Harvey, 2017). For example, participants who attended group supports gained knowledge through the sharing of information and resources by other family members (Grennan et al., 2022). They reported becoming more knowledgeable about their relative's MHDs, treatment, and the mental healthcare system. This allowed them to better understand their relative, separate their difficulties from the person, and gain better insight into the services and supports that are available to them (Levasseur et al., 2018; Visa & Harvey, 2017; Brown et al., 2022; Higgins, 2012). They learned about the need for self-care and how to practise it, as well as different coping strategies, enhancing their own wellbeing (Levasseur et al., 2018; Reynolds et al., 2022; Grennan et al., 2022; Hopkins et al., 2021). They developed their communication skills and learned how to appropriately respond to crises, which contributed to a decrease in tensions within their family and improved their relationship with their relative (Levasseur et al., 2018; Reynolds et al., 2022; Grennan et al., 2022). In this way, family peer support benefited not only those who availed of it, but also their family members (Visa & Harvey, 2017; Grennan et al., 2022). Through gaining knowledge within these areas, participants reported feeling less blame for their relative's difficulties and less guilt around not being able to resolve them (Levasseur et al., 2018; Grennan et al., 2022). At the same time, for some, this increased understanding led to enhanced self-awareness, including the various ways in which participants may have been contributing to their family member's MHDs (Reynolds et al., 2022). One participant in Levasseur et al. (2018) stated:

"Within months of attending the [support group], I was able to educate myself and to have knowledge on why my son was behaving the way he was and felt the way he did." (p. 338)

In addition to their enhanced knowledge, many participants spoke of the value of the emotional support they received through FPSW. This included simply being listened to and having a safe space to air their difficulties and discuss their experiences (Levasseur et al., 2018; Visa & Harvey, 2017; Grennan et al., 2022; Brown et al., 2022; Hopkins et al., 2021; Higgins, 2012). Some mentioned feeling validated in their experiences and emotions, including their anger and grief (Reynolds et al., 2022; Grennan et al., 2022; Higgins, 2012). The compassion and understanding offered to participants by their peers was seen as crucial (Levasseur et al., 2018; Visa & Harvey, 2017; Grennan et al., 2022; Higgins, 2012). In fact, by far the most commonly mentioned helpful aspect of family peer support was the peer element - receiving support from someone who genuinely understood what participants were experiencing as they too had experienced it (Levasseur et al., 2018; Visa & Harvey, 2017; Reynolds et al., 2022; Grennan et al., 2022;

Brown et al., 2022; Hopkins et al., 2021; Higgins, 2012; Lobban et al., 2020). This helped participants feel more accepted and less alone, isolated, and judged. Through this, they felt more comfortable in opening up about their experiences (Visa & Harvey, 2017). In addition, hearing others' stories, including the FPSWrs' story, inspired hope in participants (Levasseur et al., 2018; Visa & Harvey, 2017; Reynolds et al., 2022; Grennan et al., 2022; Hopkins et al., 2021; Higgins, 2012). There was a general sentiment among participants that support offered by other family members is different to the support of clinicians or extended family and friends, who may have the best intentions but do not have the same first-hand experience and knowledge. Example quotes from participants demonstrate these various impacts:

"She told us that she had a child with [a] similar illness; he healed, so we were given the support that [our son] would be healed too. ... The hope that was provided was the best thing." (Visa & Harvey, 2017, pp. 5-6)

"The loneliness of it is gone ... the isolation that you feel." (Reynolds et al., 2022, p. 742)

Some participants reported receiving valuable practical support from their FPSWrs (Visa & Harvey, 2017; Hopkins et al., 2021). This included referrals to other services; being accompanied by the FPSWr to appointments; and FPSWrs liaising with clinicians on their behalf. In some cases, FPSWrs provided financial assistance, which had a material impact on participants' lives. In some studies, participants reported appreciating the independence of FPSWrs, as they were seen as separate from other mental health service staff (Visa & Harvey, 2017). This was particularly important to people who felt intimidated by clinicians or had negative experiences with mental health services.

Overall, existing research indicates that FPSW enhances participants' recovery and greatly improves their lives (Levasseur et al., 2018). As a result of FPSW, participants reported feeling calmer and more able to cope with the challenges they were facing (Visa & Harvey, 2017; Reynolds et al., 2022). They found their strength and grew more self-confident and resilient. For some, the importance of family peer support was even greater as it was the only form of support available to them (Grennan et al., 2022). In some cases, this was due to stigma leading participants to fear discussing their experiences with others, again highlighting the importance of receiving support from peers (Higgins, 2012). In addition, some participants who availed of group-based support enjoyed being able to help the other attendees and felt more equipped to help others outside the group as a result (Grennan et al., 2022). Participants described FPSW as "invaluable ... the best thing [they] could have done" (Reynolds et al., 2022, p. 741) and "a lifeline" (Grennan et al., 2022, p. 5). One person stated:

"If I didn't have [the FPSWr] ... I would be in the Psych Unit myself. ... There are no words to sort of describe how supportive they've been, not just for me, but for my mum, and the whole family." (Hopkins et al., 2021, p. 9)

Some of the benefits raised within the qualitative studies were specific to an intervention and do not apply to all forms of FPSW, though they offer valuable learnings for

implementing FPSW more broadly. For example, in Lobban et al. (2020), participants appreciated that the online peer support forum was anonymous. This was contrasted with family peer support groups, which may not be a viable option for individuals for whom anonymity is crucial - for example, because they live in a small community, or because they work in mental healthcare and are concerned about running into their clients' family members in such groups. Being able to access the forum whenever they needed, rather than having to make and attend appointments to receive support, was also valued.

5.2.3 Case Study 1: National Alliance on Mental Illness "Family-to-Family"

The effectiveness of the Family-to-Family programme was investigated in three quantitative studies included in this review: Lucksted et al. (2013), Mercado et al. (2016), and Schiffman et al. (2015). Results of these studies demonstrate that participating in the programme carries a range of statistically significantly positive impacts. These include feeling less burdened by challenging aspects of being a family member of someone with MHDs; feeling less impacted by concerns about needing to always be available, dependency issues, and a sense of loss; experiencing less anxiety; and experiencing more positive personal experiences and good aspects of participants' relationships with their relative (Schiffman et al., 2015). Other documented benefits include improvements in positive coping skills, psychological distress, family empowerment, family functioning, self-care, and self-perceived mental health knowledge (Lucksted et al., 2013; Mercado et al., 2016). Importantly, Lucksted et al. (2013) demonstrated that these effects are maintained nine months after the programme. In fact, they found that after finishing the programme, participants experienced further improvements, for example, in their levels of worry. This suggests that learnings gained from the programme continue to have a growing positive impact on participants' lives even after they stop attending. Given the effectiveness of the programme and its adaptability to a range of cultural contexts, there may be value in exploring the possibility of delivering Family-to-Family in Ireland.

5.2.4 Case Study 2: Family Navigation Project

To explore the impact of adding a Parent Advocate to the Family Navigation Project, Markoulakis et al. (2022) asked 14 of their clients to rate their agreement with a number of statements about the Advocates. Responses were overwhelmingly positive. All 14 participants strongly agreed that the Advocate is a good listener. Thirteen strongly agreed and one participant agreed with all of the following statements: "I am comfortable sharing [my] own personal experiences and concerns with [the Advocate]", "The [Advocate] can put themselves 'in my shoes'", and "I feel understood by the [Advocate]" (p. 743). All 14 participants reported being satisfied with the Advocate and 13 stated that they would be extremely likely to recommend the Advocates to a friend or family member. Participants were least satisfied with the availability of and frequency of contact with the Advocate, rather than with the service itself. In addition, Markoulakis et al. (2022) compared outcomes among these 14 clients to 12 clients who had only accessed the clinician navigator. A significant improvement in caregiver experience after

accessing the service was noted among both, but this effect was stronger among those who saw the Advocate alongside the clinician navigator.

5.2.5 Case Study 3: Bealach Nua

Garavan (2016) evaluated the first year of the functioning of the Bealach Nua service on the basis of interviews with seven family members and the two FPSWrs employed in the service, as well as questionnaires from 14 clients completed before and after engaging with the service. Qualitative data from the evaluation demonstrated the value of the service for families. Participants appreciated simply having a space where they could talk about their experiences and be met with empathy and understanding. The lived experiences shared by the FPSWrs and their clients facilitated this empathic understanding. Participants valued being met with "a common sense ear, not a medical ear" and connecting with their FPSWr "on a human level, not just a professional level" (Garavan, 2016, p. 16), again highlighting the value of the peer-led nature of the service. In addition, participants benefited from receiving information and advice on engaging with mental health services, available supports outside of mental health services, and coping skills. Garavan (2016) states that these accounts are supported by "significant" improvements in quantitative measures of wellbeing, such as participants' belief in their ability to cope and confidence in caring for their relative. However, claims of significance are not supported by relevant statistical tests.

Burke et al. (n.d.) conducted a further, quantitative evaluation of the service a number of years later, providing further insight into the findings first documented by Garavan (2016). They found a statistically significant increase in the general wellbeing of the 19 family members who were included in the evaluation. Participants' wellbeing improved significantly across areas such as their relationships with their relative with MHDs, family, and friends; physical health; finances; and emotional wellbeing. Participants' need for support also decreased significantly as they availed of the Bealach Nua FPSW servuce, while their level of support increased significantly. Taken together, the findings of these two evaluations indicate that family members who avail of the Bealach Nua service find the supports positive and helpful, and this is reflected in quantitative measures of their wellbeing.

5.3 Barriers and Challenges

Though existing research on FPSW is largely focused on its benefits and value to family members, some barriers and challenges to availing of and delivering FPSW were also noted.

Practical challenges to availing of FPSW included work and transport, as some participants found that the support clashed with their work hours or was located far from their home (Levasseur et al., 2018). This was closely tied to financial barriers, as some participants could not afford the transport costs, as well as poor or unavailable public transport options for rural participants (Cottrill, 2011). For some, their caregiving responsibilities towards their family member with MHDs were in themselves a barrier to seeking support (Levasseur et al., 2018; Visa & Harvey, 2019). For example, some

participants could not leave their relative home alone and did not have anyone who could accompany them while they were at a support group or appointment.

Many studies noted the need for greater access to and provision of FPSW. The limited availability of the FPSWrs in some programmes was also raised, as some participants felt that they needed more time with the FPSWr and called for greater funding for FPSWrs (Cottrill, 2011; Hopkins et al., 2021; Visa & Harvey, 2019). In Bealach Nua, contact with FPSWrs was limited to approximately ten sessions per family. Garavan (2016) cites avoidance of dependency and "mobilisation of the family's own resources" (p. 25) as reasons for this. However, this limit contradicts the person-centred nature of FPSW, attempting to apply a "one size fits all" approach to a service that should be based upon each clients' individual needs. In studies of group-based FPSW, participants often felt that more groups are needed (Levasseur et al., 2018; Grennan et al., 2022). Some noted that the groups were too short to allow for sufficient depth of discussion (Higgins, 2012).

Though participants in some studies appreciated having guest clinician speakers (e.g. Higgins, 2012), others felt that introducing healthcare professionals into their support group made the dynamics of the group more hierarchical (Grennan et al., 2022). Some participants reported leaving these guest talks feeling hopeless about the future, for example, feeling that their family member will never be able to stop taking medication (Higgins, 2012). One participant was told by a clinician facilitator that they will never have a real relationship with their partner because of the partner's difficulties. These messages of hopelessness counteracted the hope gained from hearing their peers' success stories.

Other challenges raised included fear of stigma and being judged as a barrier to participation for some family members, especially those living in small communities (Cottrill, 2011; Visa & Harvey, 2019). Visa & Harvey (2019) note that within their study, concerns around stigma were particularly prevalent among those from diverse and non-English-speaking backgrounds. The distribution of questionnaires to evaluate the impact of the intervention was also problematic for some participants, who felt that this disrupted the programme, had literacy issues, or simply did not like completing questionnaires (Higgins, 2012). In Visa & Harvey (2019), some participants noted that the benefits of seeing a FPSWr were short-lived, as their circumstances remained the same.

With regards to the specific content of psychoeducation interventions, participants in Higgins (2012) felt that the programme was idealistic. For example, being told about the importance of self-care and taking time to look after themselves was a source of frustration for family members who could not do that due to lack of respite services. In addition, some participants felt that the content was inaccessible as it was too text-heavy and did not use plain English (Higgins, 2012).

For participants who availed of group-based supports, though hearing others' stories carried many benefits, some negative effects were also noted (Grennan et al., 2022; Lobban et al., 2020). For example, some participants compared their difficulties to those of others and felt that they did not deserve the support, as they saw their challenges as less severe. Some participants worried about discussing their successes so as not to seem boastful. Accordingly, others reported envying participants who had experienced

these successes. Some felt overwhelmed by the degree of difficult emotions and experiences discussed in the group. Another challenge specific to group supports stemmed from personality clashes between members. Some participants felt that certain attendees of their groups dominated the discussions, which diminished their ability to benefit from the support (Higgins, 2012). Among those who availed of one-to-one supports, some participants wished for the opportunity to meet other family members (Visa & Harvey, 2019).

Participants' suggestions for improving FPSW included the provision of digital peer support (e.g. online forums) and specific crisis support (Levasseur et al., 2018). Some called for more practical supports for family members, such as respite and financial aid (Visa & Harvey, 2019). In Grennan et al. (2022), one participant felt that it would be helpful to have culturally-specific group facilitators. In Garavan's (2016) evaluation of Bealach Nua, some participants wished for FPSWrs to be available as advocates or companions in their appointments with clinicians. Some also felt that FPSWrs should be embedded into the multidisciplinary team to enable better communication with clinicians. At the same time, others felt that their functioning outside of the multidisciplinary team is beneficial and changing this might compromise their independence and non-biomedical approach.

5.4 Clinicians' and Family Peer Support Workers' Perspectives

While many of the research studies included in this review focused on the perspectives of family members, some involved the FPSWrs and, in rarer cases, clinicians. This provided insight into the experiences of being a FPSWrs and the perceptions of FPSW among clinicians.

In terms of the value of their role, the perspectives of FPSWrs were closely aligned with the benefits reported by clients. FPSWrs felt that they promote hope and optimism by being a living example of recovery (Health Workforce Australia, 2014; Hopkins et al., 2021; Butterfly Foundation for Eating Disorders, 2022). They reported providing emotional support, both directly and indirectly, for example, by validating their clients' experiences through sharing their own, similar stories (Hopkins et al., 2021; Davis et al., 2011). Giving family members a safe space to talk and responding with empathy were seen as crucial aspects of their role (Hopkins et al., 2021; Davis et al., 2011), particularly for clients who do not have anyone in their social network who has faced similar challenges (Butterfly Foundation for Eating Disorders, 2022). Encouraging and supporting self-care was also mentioned (Hopkins et al., 2021), as well as connecting family members with other services and supports (Butterfly Foundation for Eating Disorders, 2022). Parent peer advocates in particular felt that their clients are empowered through their work (Davis et al., 2011).

Further benefits were noted for the family member experiencing MHDs, who may feel less guilt around the impact of their difficulties on their family if the family is receiving support (Hopkins et al., 2021). Additional benefits were also discussed in the case of caregivers of young people with eating disorders, as clinical treatment in this context typically involves family-based therapy, which can be challenging. FPSWrs can

empathise with and reassure the caregivers, as they too have been through it (Butterfly Foundation for Eating Disorders, 2022). This, in turn, increases the likelihood of the therapy being successful. Finally, improvements within the organisation have been recorded too. In Hopkins et al. (2021), 28 of the 29 participating clinicians agreed that the presence of FPSWrs created a more family-centred culture within their organisation.

At the same time, challenges in the FPSWrs' work were also noted. In an Australian study of the mental health peer workforce (Health Workforce Australia, 2014), carer PSWrs felt that more clarity around their roles and responsibilities was needed. This was echoed in other studies, where FPSWrs noted that some family members have inaccurate perceptions and expectations of their work (Cottrill, 2011) and struggle to differentiate their roles from clinical roles (Hopkins et al., 2021). In Davis et al. (2010), participating peer advocates cited lack of clarity over their role as the main reason why some family members decline their services. For some FPSWrs, this lack of clarity led to difficulties in staying within the boundaries of their role, as well as being asked by clinicians to work beyond their boundaries, since those boundaries are unclear (Hopkins et al., 2021).

Separately, Health Workforce Australia (2014) reported a demand for greater professional networks among PSWrs. They note that the isolation often experienced by family members is exacerbated when they are also isolated in their roles as FPSWrs. Additionally, some FPSWrs highlighted the lack of respect from others for their role. They felt that they are seen as less knowledgeable due to not having "those credentials behind [their] name" (Cottrill, 2011, p. 16), such as Masters degrees and PhDs. Similarly, in Health Workforce Australia (2014), participants called for greater training for clinicians to combat stigmatising and negative perceptions of FPSWrs. Among the FPSWrs who participated in their study, over one-fifth felt that their expertise and knowledge is not valued by their organisation. Hopkins et al. (2021) noted the importance of having leadership that is truly committed to FPSW in facilitating and supporting FPSWrs. Similarly, for FPSWrs in Bealach Nua, a key concern was clinicians' recognition and valuing of their profession (Garavan, 2016). Though they did not wish to be part of the multidisciplinary team, they expressed a need for greater recognition of their work by the team. Relatedly, they also expressed a desire for professional standards concerning their competencies alongside ongoing training to enhance these.

Higgins (2012) provides some further insight, as their intervention involved direct collaboration between FPSWrs and clinicians in facilitating groups. This came with benefits and challenges. Both FPSWrs and clinicians felt that the collaboration allowed them to understand one another more and connect at a human - rather than professional - level. FPSWrs gained insight into the workload faced by clinicians. Through this, they came to understand that the shortcomings of mental health services are not always the clinicians' fault. On the other hand, one FPSWr felt that the presence of a clinician introduced a hierarchical structure, as they worked at the service which the participating family members were linked to and used non-person-centred language (e.g. "patients").

Some additional, important points were raised in Vaswani-Bye et al. (2024). Within their study, participants discussed the inherent complexity of being a FPSWr, as the needs and wellbeing of their relative may change over time and impact their ability to conduct their

work. They emphasised that flexibility in their role is crucial for this reason. They also noted that their role can lead to burnout, as connecting with other family members is in itself an emotional experience, and especially when combined with supporting their own relative experiencing MHDs. Some participants also struggled with the fact that they had access to clinicians to support them in their role as FPSWrs, but could not access clinicians to support their family member:

"It's like if you are dying of thirst and you're in a room and there's a well and there's a sign on it that says, 'This well is not for your personal use' ... It's to be in a meeting with [the clinicians] and what you want to say is, 'Please help my son.' And you can't. It's a difficult thing." (Vaswani-Bye et al., 2024, p. 238)

5.5 Training Family Peer Support Workers

A brief discussion of research into the training of FPSWrs is warranted, as this was attended to in some of the included literature. Brennan (2015) explored the training of "relatives peer supporters" as part of an Irish project. Training for the role involved a seven-week course on recovery (e.g. values, ethics, the recovery model), peer support (e.g. principles, communication skills, boundaries), and other available supports (e.g. for the peer supporters). Six of the 22 family members who completed the training participated in a focus group on their experiences of the course.

Though the end goal of the course was to equip family members with the skills to support others, it also carried personal benefits for themselves and their recovery journey. Participants reported gaining self-awareness and insight into their experiences through the course. Their understanding of their own family dynamics was enhanced and, through this, they could improve these dynamics. They learned about the importance of self-care and their own personal recovery, distinct from that of their family member. As a result, some family members began to spend more time focusing on themselves. Additional benefits were discussed in relation to the group-based nature of the course, which resembled the reported benefits of family peer support groups. In particular, through hearing the stories of others who had similar experiences to their own, participants felt understood, comforted, supported, hopeful, and less alone. These findings were echoed in another study into a US training programme, in which participants reported improved family dynamics, greater hope, and a sense of community as a result of the training (Vaswani-Bye et al., 2024). Following the course, participants were invited to an overnight, weekend "wellness break", inclusive of talks, workshops, group activities, food, transport, and accommodation, at no expense to the participant. This was appreciated by participants, who valued the respite and enjoyed seeing the other participants again.

Participants also offered some feedback for improvements that could be made to the course. One person suggested pairing up the course participants, so that they could support one another. Another person stated that it would have been helpful to have physical resources, such as a workbook of some kind, to revisit after the course ended. This could be inclusive of a glossary, to make the course more accessible. Role-playing

was also suggested as a more practical method of learning the skills taught on the course. In fact, the provision of role-playing as an element of their training was valued by participants in Vaswani-Bye et al. (2024). They also reported finding it helpful to have recordings of their training sessions which they could revisit as needed.

5.6 Gaps in Existing Research

Though the research identified through this review provided very valuable insights into FPSW, a number of gaps were noted. In general, there is a need for more research on FPSW. During the literature search, it became clear that PSW for people with MHDs has been researched to a much greater degree than FPSW. In order to advance the field of FPSW, ensure that FPSW follows best practice, and secure funding for and commitment to FPSW from services and the government, it is crucial that more research into FPSW is funded and conducted.

In addition, we identified some areas where research on FPSW was particularly lacking. Firstly, much of the research found through our search investigates family peer support groups, rather than one-to-one support. While these groups are evidently valuable, they cannot attend to all of the needs of family members, nor are they acceptable or appropriate for all families. More research into one-to-one FPSW is needed.

Secondly, more research is needed into PSW targeting family members of adults with MHDs. At present, the emphasis is on supports for caregivers of young people experiencing MHDs. This is not entirely surprising, as one-third of the literature included in this review was based in the US where FPSW is largely limited to youth services. Nonetheless, this represents a major gap in the research, as the impact of MHDs on the family does not end when the affected person reaches adulthood.

Thirdly, more research into specialist forms of FPSW would be valuable, such as FPSW in the context of eating disorders or FPSWrs who come from and provide support to specific marginalised populations. Finally, there is a need for more high-quality randomised controlled trials of FPSW. Of the 59 research sources identified through the literature search, only four were randomised controlled trials, and three of these were eliminated due to low evaluation scores. One additional mixed methods study included a randomised controlled trial as one of the methods. While other types of research are also valuable, randomised controlled trials - when conducted well - provide high-quality evidence on the effectiveness of supports. They are an important method of assessing the impact of services and would be greatly informative in FPSW.

As discussed in <u>Section 3.2.2</u>, existing research on FPSW falls extremely short in the area of co-production. This is a substantial limitation and flaw of these research studies. In their systematic review of 66 studies into the impact of co-production on health and social care research, Brett et al. (2012) noted benefits for every stage of the research process, which greatly enhance the overall appropriateness and quality of the research. From an ethical standpoint, it is crucial that those who are most affected by research are involved in its design and delivery, regardless of any added benefits for the research process. In the context of FPSW, failing to include the voice of family members in

research on FPSW goes against its very nature. The core reasoning underlying FPSW is that family members carry valuable expertise and insight, which is distinct from the expertise of clinicians and, crucially, can only be gained through lived experience. This expertise is missed when the research team does not feature the family member voice. In addition, as noted in Section 1.2, PSW originated in the psychiatric consumer/survivor/ex-patient movement, which is rooted in a philosophy of "nothing about us, without us". Neglecting to integrate the voice and expertise of family members into the research process is fundamentally at odds with this underlying philosophy.

6. Family Peer Support in the Context of Addiction

This section details literature concerning FPSW in the context of addiction. While the focus of the present review is on mental health services, the Working Group felt that the common co-occurrence of substance abuse with MHDs - known as "dual diagnosis" - warrants the inclusion of both topics within the review. In addition, exploring the provision of FPSW in addiction services may offer valuable insights for the development of these supports within mental health services.

In searching for sources on FPSW in the context of substance abuse, we found that much of the international literature is dominated by Al-Anon. Five of the six identified research studies on FPSW in the context of addiction concerned Al-Anon. As such, we organise this section by approach, beginning with literature on Al-Anon and Nar-Anon and later discussing other approaches.

6.1 International: Al-Anon and Nar-Anon

6.1.1 History

On an international scale, Al-Anon and Nar-Anon are among the most well-known, widely available, and longest running forms of structured family peer support. Al-Anon and Nar-Anon are the sister organisations of Alcoholics Anonymous (commonly known as AA) and Narcotics Anonymous (NA) respectively. AA is the oldest of these organisations, founded in the US in 1935 by William Wilson and Bob Smith, who found recovery from alcoholism in sharing their stories with others.

AA was initially open to both those affected by alcoholism and their family members, but soon afterwards members began to feel that separate groups were necessary. Informal family groups began to be established around the country. In 1951, these were formalised under the name of Al-Anon Family Groups by Anne B. and Lois W. - William Wilson's wife. Following the proliferation of AA, NA was established in 1953, followed by Nar-Anon Family Groups in 1971. Separate groups have since been set up for young family members, known as Alateen and Narateen (Al-Anon Family Groups, 2020). AA, NA, Al-Anon, and Nar-Anon groups are now available globally, and new groups can be established wherever a need is identified (Al-Anon Family Groups UK & Éire, 2014).

The focus of the following discussion is on Al-Anon, as literature on Nar-Anon is very limited. In fact, we were unable to find any research sources on Nar-Anon which met the criteria for inclusion. However, the Al-Anon and Nar-Anon approaches are very similar, with NA and Nar-Anon being modelled on AA and Al-Anon. As such, literature on Al-Anon provides insight into Nar-Anon also.

6.1.2 Approach

Though officially named "Family Groups", Al-Anon groups are open to anyone affected by another person's alcoholism, even if the person is no longer in active addiction. Each group is self-led, functioning largely autonomously of the umbrella organisation, with members contributing to the running of their group. Al-Anon is founded upon the premise that alcoholism is a family illness, where family members too develop a preoccupation with alcohol as they attempt to control and influence their relative's drinking (Al-Anon Family Groups, 2023). Members are encouraged to redirect their focus from the relative to themselves, focusing on their own recovery and ways of coping with the person's addiction (Timko et al., 2012). It is believed that through these changes in their attitude towards the relative and their alcoholism, the family member can achieve recovery. In Al-Anon meetings, members come together to support one another in this refocusing by sharing their stories and reading Al-Anon literature (Al-Anon Family Groups UK & Éire, 2014).

Although Al-Anon attendees are referred to as "members", they do not formally sign up to the programme or organisation (Hiatt, 2017). This is key to upholding the members' anonymity, which, as suggested by the name, is a fundamental principle of Al-Anon. However, this also makes it impossible to establish how many people attend Al-Anon groups. There are no fees, though donations from members are welcome (for example, to cover the cost of renting a meeting space), especially as outside contributions are not accepted (Al-Anon Family Groups, 2023). Members can attend as many different groups and meetings as they wish. Each group is led by a Group Representative, elected by members for a set term (Al-Anon Family Groups UK & Éire, 2014).

What unites all Al-Anon groups are their 12 Steps, Traditions, and Concepts (Al-Anon Family Groups, 2023; 2022). The Steps, Traditions, and Concepts form Al-Anon's three legacies: "recovery through the steps; unity through the traditions; service through the concepts" (Al-Anon Family Groups, 2023, p. 13). It is believed that recovery for people affected by another person's alcoholism is achieved through accepting and practising the 12 Steps. The Traditions guide the structure and attitudes of the groups and the Concepts describe the functioning of the wider organisation.

A full discussion of the 12 Steps, Traditions, and Concepts is beyond the scope of this review. Instead, we briefly summarise the 12 Steps, as these are believed to be the key to family members' recovery. The first Step opens with admitting the profound impact of alcoholism and one's powerlessness over it. Through accepting their inability to influence their relative, the Al-Anon member becomes empowered to enact change within their own lives (Timko et al., 2012). Thereafter, the Steps focus on placing trust in a Higher Power to "restore [members] to sanity" (Al-Anon Family Groups, 2023, p. 13). Members are encouraged to form a "searching and fearless moral inventory" of their wrongdoings and "shortcomings"; admit these to God, themselves, and others; ask and trust God to remove these; and make amends to those who they have wronged. The final step asserts that members will experience a "spiritual awakening" as a result of following these Steps, and commits members to carrying the message of the Steps on to others.

As evidenced by these Steps, the underlying philosophy of Al-Anon is one of spirituality. Belief in a Higher Power is considered imperative to recovery. Within the Traditions, there is a similar emphasis on God as the only authority to Al-Anon and its members. However, Al-Anon is not explicitly allied with any specific religion and maintains that the 12 Steps can be a way of life "to all people of goodwill, of any religious faith or of none" (Al-Anon Family Groups, 2023, p. 13). Discussions of religion within meetings are discouraged.

6.1.3 Sponsorship

One element of the Al-Anon approach which sets it apart from other peer support groups is that of Sponsorship. After some time in Al-Anon, newer members are encouraged to choose a more experienced member to be their Sponsor (Al-Anon Family Groups, 2023; Timko et al., 2012). Every Sponsorship relationship is different, but their general purpose is to guide the Sponsee through the programme, provide one-to-one support, and offer them a space to open up more deeply (Hiatt, 2017). Sponsees are encouraged to contact their Sponsors in times of crisis. In A.A., this means contacting the Sponsor before they decide to drink; in Al-Anon, this is jokingly phrased as "pick[ing] up the phone before they pick up the gun" (Hiatt, 2017, p. 42). Thus, every member receives group peer support through Al-Anon meetings and one-to-one support through their Sponsor.

Hiatt (2017) explored the Sponsorship relationship by interviewing long-term Al-Anon members who had both had a Sponsor and been a Sponsor. Although some participants had some negative experiences with Sponsorship, all spoke of it overwhelmingly positively and saw it as crucial to their recovery. The Sponsor was seen as someone the Sponsee could trust and open up to, who would guide them, encourage them, and lead by example. Some Sponsors reported advising their Sponsees to initially call them everyday, to form a habit of reaching out. These phone calls - both daily and in moments of need - were crucial. Sponsees contacted their Sponsors to seek support through difficult life circumstances, such as grief and divorce. One Sponsor recalled a phone call during which their Sponsee admitted to developing a drug addiction; as a result of their conversation, they entered rehab. For some, Sponsorship enhanced their other relationships by modelling a healthy, supportive relationship and teaching Sponsees how to be vulnerable, trust others, express their needs, and set boundaries. Over time, the Sponsorship relationships often evolved into friendships where the support became reciprocated.

6.1.4 Uptake and Effectiveness

As of 2012, there were 28,000 Al-Anon groups and 24,000 Alateen groups in existence across 115 countries (Timko et al., 2012). In the US, Al-Anon is the most widely used form of support for people affected by another person's alcoholism (Timko et al., 2012). According to Al-Anon Family Groups UK & Éire, there are over 700 Al-Anon groups across Ireland and the UK. Specific groups can be found through a map on their website. Online and hybrid groups are also available.

Much of the research on the effectiveness of Al-Anon was conducted prior to 2010 and therefore fell outside of the scope of this review. However, some recent research was identified. For example, Corrigan (2016) qualitatively explored the influence of Al-Anon on members' resilience. Accounts from ten members showed that Al-Anon attendance increases resilience through personal growth, enhanced functioning, and cognitive reframing. Personal growth included increased self-awareness, self-esteem, and confidence. Spirituality was seen as a vehicle for this growth. The Al-Anon focus on yielding control over to a Higher Power led participants to trust that their life will work out and that their difficulties are part of a greater plan. Regarding enhanced functioning, participants' internalisation of Al-Anon philosophy influenced their decision-making and problem-solving, helping them to navigate difficult situations and lead their lives more effectively. A key element of cognitive reframing was the first Al-Anon Step: acceptance of one's powerlessness over their relative's alcoholism and shifting of focus onto what is controllable. In addition, consistently with Hiatt (2017), participants spoke of their Sponsors as key sources of support and noted the value of having role models who have worked the programme in enhancing their hope in their own recovery.

Timko et al. (2015) additionally sought to investigate the effectiveness of Al-Anon in terms of social processes. These "social processes" consisted of bonding, such as feeling that one belongs within their group; goal direction, or the encouragement of personal growth by the group; structure; provision of role models; and involvement in rewarding activities. They found that attendance at Al-Anon meetings significantly improved members' quality of life, with this effect being greater the more meetings they attended. Importantly, these various social processes were found to mediate this effect. In other words, attending Al-Anon led to an improvement in quality of life due to group factors such as bonding, encouragement of personal growth, and role models.

6.1.5 Who Does Al-Anon Work For?

As discussed by Short et al. (2015), the majority of Al-Anon members are women. While it has been suggested that this may be due to the gender disparity in addiction - where men are more likely to experience addiction, so (heterosexual) women are more likely to have a partner who is experiencing addiction - Short et al. (2015) sought out to explore this further by comparing men and women who attend Al-Anon meetings, across demographic characteristics, reasons for attending Al-Anon, health status, personal functioning, and the "drinker's" characteristics.

Demographically, Short et al. (2015) found that male and female Al-Anon members were mostly similar. In terms of reasons for attendance, women were more likely to attend Al-Anon due to concerns over their own quality of life, stress, anxiety, hopelessness, and physical health problems. Accordingly, women reported higher levels of anxiety, depression, and hopelessness. Men also showed more positive attitudes towards themselves than female members. As such, Short et al. (2015) suggest that men might be less likely to attend Al-Anon as having a relative who is experiencing addiction may have a lesser impact on their mental health - they may need Al-Anon less. On the other hand, men were more likely to attend as they wanted to help the person experiencing addiction. Short et al. (2015) propose that this motivation may be a barrier to men's

attendance at Al-Anon. The focus within Al-Anon is on shifting focus away from trying to help and influence the person experiencing addiction and is therefore incompatible with this goal.

Separately to the gender imbalance, Timko et al. (2014) investigated the prevalence and predictors of dropout in Al-Anon by comparing those who remain active to those who drop out. Overall, over half of Al-Anon newcomers ceased attendance within six months. Those who dropped out were less likely to attend Al-Anon due to problems with the person experiencing addiction or their own partner, and more likely to cite problems with other relatives as their reasons for attending. They were more likely to have been signposted to Al-Anon by other Al-Anon members, rather than a healthcare provider. Regarding health status, people who dropped out showed lower rates of diagnosed medical conditions and recent physical abuse, and had a greater sense of control over their lives. They were more satisfied with their finances, wellbeing, quality of life, and relationship with their relative. They also showed less concern about the relative's alcohol use.

Taken together, Timko et al. (2014) interpret these findings as suggesting that people who drop out of Al-Anon may downplay the severity of their problems and therefore see less need to attend. However, there is an alternative interpretation. Similarly to the male participants in Short et al. (2015), those who drop out of Al-Anon may have less need to attend, as they report higher satisfaction with various aspects of their lives, lower prevalence of diagnosed medical conditions, and lower rates of physical abuse. They may not be downplaying their difficulties, but simply experiencing these difficulties to a lesser extent. The Al-Anon philosophy may also be less relevant to them, as the 12 Steps focus on addressing members' efforts to control their relative and empowering them to exert control over their own lives instead. Those who are not as concerned about the person experiencing addiction and already feel a sense of control over their lives may not find this process helpful. The disparity in the source of signposting to Al-Anon is also interesting. Perhaps a recommendation from a healthcare professional is seen as more legitimate, causing attendees to have greater faith in Al-Anon and therefore commit to it for longer.

Expanding on the topic of drop-out, Timko et al. (2022) conducted a randomised controlled trial of an "intensive referral" programme to Al-Anon. The programme sought to facilitate participation in Al-Anon through four sessions with an "Al-Anon coach" who addresses barriers to engagement, such as misconceptions about Al-Anon. The sessions begin with an explanation of Al-Anon and what is involved in meetings. They then evolve into encouraging the client to attend meetings and participate in the various aspects of the programme, as well as problem-solving any emerging barriers. The Al-Anon coach does not necessarily have lived or family experience of addiction. Timko et al. (2022) found no evidence that participating in the programme increases Al-Anon attendance, demonstrating that it is not an effective method of enhancing participation.

6.2 Ireland: Family Support Groups

6.2.1 South East Regional Family Support Network

In Ireland, one of the main organisations providing FPSW in the context of addiction is the <u>South East Regional Family Support Network</u> (2013). Established in 2004, the Network represents the needs of family members of people experiencing addiction and supports family peer support groups in Kilkenny, Wexford, Carlow, Waterford, and Tipperary. As in Al-Anon, the Network encourages family members to recognise that they cannot control their relative's addiction. Among the supports offered to peer support groups is the development of <u>Good Practice Guidelines</u> (South East Family Support Network, 2010). The following discussion focuses on the Guidelines which may be most informative for the establishment of family peer support groups in mental health services.

6.2.2 Establishing and Running a Group

In establishing a new group, the Guidelines recommend exploring the rationale, logistics, ethos, and scope of the group. It is important to consider, for example, the needs of the local community, resources needed to run the group, support the group will offer, and its target audience. Assessing existing supports in the area and available resources for running the group is advised, to prevent duplication of efforts and ensure sustainability. Promoting the group may involve engagement with relevant local stakeholders, use of posters and leaflets (e.g. at GP clinics, family resource centres), and advertising through local media. Information days in the community may also be helpful. A code of ethics, including values and principles, should be established at the outset and revisited over time.

In terms of the running of the group, the guidelines recommend that each meeting opens with reference to this code of ethics, emphasising confidentiality. The use of a reflection, quote, or relaxation exercise may help to ground members in the group. During the meeting, ideally, each member should be given the opportunity to speak, but those who are going through an especially hard time should be given priority. Each meeting should close on a positive and supportive note, such as recounting a recent positive experience. If a member is particularly struggling, it is advised that another member stays in touch with them until the next meeting. At the end, there should be time made for members to chat and get to know one another in a less formal environment.

The Guidelines outline a number of other features important to the successful running of a family peer support group. These include confidentiality; trust and respect; being non-judgmental; sharing stories; emotional support; practising hope; seeking solutions; being resourceful; identifying members' needs; referral; and ongoing support. Confidentiality includes data protection, considering whether personal information about members needs to be recorded and stored at all. If data is recorded, the guidelines advise that members' ethnicity is noted also. Being resourceful can involve inviting external speakers to the group or accessing training (e.g. in suicide awareness or crisis intervention). Referral involves directing members to other supports outside of the group.

Ongoing support means providing care and support to members between meetings. This can take a range of forms, from engaging with a clinical professional to organising a "buddy" system within the group.

6.2.3 Facilitation

Skilled facilitation is central to the effective running of the group. The facilitator, who is also a group member, should carry a number of attributes, including commitment to the values and principles of PSW, self-awareness, self-confidence, organisational skills, and active listening skills. They should be able to manage the group, including any challenges, by ensuring that all members have the opportunity to share and recognising when certain members may need to be encouraged to speak. They should have a set of techniques and tools which they can use in the group and be sufficiently in tune with members to know when someone may need additional support. Recognising and enforcing boundaries is also important. The facilitator should be mindful of the difference between facilitation and counselling, taking control, directing the group, and friendship. These skills are learned through experience and may be developed further through training.

6.3 United States: Family Peer Specialists

The SAMHSA (2023a) report on <u>Incorporating Peer Support Into Substance Use Disorder Treatment Services</u> details the practice of PSW within addiction services in the US, including FPSW.

6.3.1 Role of Family Peer Specialists

FPSWrs in US addiction services are known as Family Peer Specialists (SAMHSA, 2023a). SAMHSA (2023a) highlights the importance of attending to the needs of the family as part of addiction treatment. They note that since substance abuse affects the entire family, treatment programmes which do not address the family's needs are likely to be less effective. The Family Peer Specialists' approach is individualised, respectful, culturally responsive, solution-focused, and skill- and knowledge-based. The Specialists support families in engaging with any services that are available to them, rather than just helping them access these services. They advocate for the family and assist them in developing their own self-advocacy skills. They seek to enhance the family members' understanding of substance abuse and support them on their own path to recovery.

SAMHSA (2023a) notes that many family members may be unaware of FPSW and too focused on seeking care for their relative to ask for support for themselves. As such, staff in addiction services should be proactive about informing family members of Family Peer Specialists. The qualities and benefits of FPSW should be explained to the family, drawing attention to the lived experience of the Specialist, noting that Peer Specialists are trained, and discussing the various forms of help and support that the Specialist can offer. Alongside explaining what Family Peer Specialists do, what they don't do should also be discussed, such as delivering treatment, offering medical or legal advice, or sharing confidential information about the person experiencing addiction.

6.3.2 Qualifications and Supervision

Family Peer Specialists must be sufficiently qualified, through the provision of training, supervision, and certification. Training should prepare Specialists to carry out their work in a manner that is trauma-informed and culturally responsive. However, training and certification for Family Peer Specialists is limited in the US. Though some states offer general PSWr training that is available to FPSWrs, only six states offer family-specific PSWr training (SAMHSA, 2023a).

Certification programmes (which do not involve training, but validate and confirm existing skills) typically require that Family Peer Specialists are supervised. Many states also require supervision when the Specialist is certified and practising. Supervision is carried out by another licensed professional, such as a psychologist or social worker. Supervision serves two primary functions. Firstly, it fosters the development of the Specialists' skills, improving the quality of their services. Secondly, it offers protection and support to the Family Peer Specialist, for example, if they are asked to provide help that extends beyond their training, abilities, or knowledge.

6.4 United Kingdom: Family Recovery Champions

6.4.1 Whole Family Recovery Project

Adfam is a UK charity aiming to improve the lives of families affected by addiction. In 2018, Adfam released a <u>report</u> on its Whole Family Recovery Project (Adfam, 2018), conducted in Greenwich to support the recovery of families in the area. The project trained family members to become Family Recovery Champions, who would in turn support and inspire other family members in their recovery. Adfam (2018) note that while Recovery Champions (who are in recovery from addiction) are in place in many addiction services in the UK and internationally, Family Recovery Champions were not in existence in any other service at the point at which Adfam developed their project.

The Whole Family Recovery Project was based upon the experience and expertise of Adfam, which indicated that family support should entail one-to-one practitioner support, information provision, and PSW. Their key characteristics of family support are threefold. Firstly, FPSW should recognise the need to support families in their own right, rather than solely for the benefit of the person experiencing addiction. Secondly, FPSW should be built upon a supportive, person-centred ethos. Thirdly, family members should be closely involved in service design. The Project sought to meet four outcomes: enhance family members' knowledge of addiction, including treatment options and their own rights; offer FPSW, combating feelings of isolation; supporting family members in developing, running, and managing their own services; and enhancing the chances of recovery among people experiencing addiction. These outcomes were achieved through the work of the Family Recovery Champions. Adfam's (2018) report is summarised in the following section.

6.4.2 Training for Family Recovery Champions

Family Recovery Champions were trained in offering information and support to family members through initial, introductory training and bimonthly forums featuring top-up training and information updates. The forum allowed the Champions to access additional training, improve their services, and learn from other Champions. Adfam (2018) reports that this forum was established in accordance with the needs of the Champions and was crucial to the development of the project.

6.4.3 Provision of Services

The support provided by Champions involved a number of elements. Firstly, group peer support was offered through a programme called Family Steps. Secondly, six-session family information programmes were offered on a rolling basis. These were run by Family Recovery Champions and family members could also avail of one-to-one support from the Champions through these.

Thirdly, one-to-one peer support was also made available through a pilot service at a local drop-in addiction treatment centre. This was done in recognition of the fact that people experiencing addiction may be accompanied to drop-in centres by a family member, thus making the centre another avenue of reaching out to families. Additionally, attending a drop-in centre can be frightening, so family members may benefit from peer support in the process. Family Recovery Champions were available at the reception area of the centres; reception staff would offer their services to family members. Adfam (2018) report that the demand for this service was so high that the frequency of provision was increased from weekly to three times a week.

To further their information-sharing and awareness-raising work, the Champions produced leaflets and newsletters about the project and substance abuse more broadly. These were distributed to professionals and family members, raising awareness of the Project and reaching out to those who may not be able to attend the services. The Champions also spoke at local, regional, and national events to provide insight into the needs of families and advocate for investment in family services.

Finally, Family Recovery Champions recognised that some populations may be harder to reach and less likely to seek support. To connect with these populations, two Champions from ethnic minority backgrounds used their existing networks to reach out to their communities. They were supported by other Champions in doing so, who recognised that reaching out to marginalised populations should not be solely the responsibility of marginalised Champions. This included, among others, establishing a stall at the local Asian Festival, which attracted "hundreds of individuals" (p. 12).

6.4.4 Lessons Learned

The Adfam (2018) report concludes with a number of lessons learned from the Project. While some of these echoed other literature on PSW, such as the capacity of the Family Recovery Champions to understand the family member's perspective, others were more

unique and warrant highlighting. Perhaps one of the most impactful findings of the Project was that the peer support service engaged with family members in a manner that other services cannot. In particular, many family members who met the Champions through drop-in centres reported that they would be unwilling to access other formal family support services. The flexibility of the Champions also sets them apart from other professionals. As a result, the demand for their services greatly exceeded expectations. Adfam (2018) emphasises that Champion training and supervision was crucial in ensuring the success of the Project and supporting them in managing this demand, as was acknowledgment of their work through celebratory events. This is perhaps additionally important in the context of PSWrs who are volunteers, as in the case of the Champions. Crucially, Adfam (2018) highlights that PSW should not seek to replace existing services but rather work alongside them, adding "enormous value" (p. 16) to the services. Finally, funding is raised as a major challenge. Despite its success, funding for the Project ceased in 2018. Beyond the report, no other information about the Project continuing or expanding to other areas was found, suggesting that it likely ended with the ceasing of funding in 2018.

6.5 Australia: Circles of Support

"Circles of Support" is a co-designed, peer-led recovery and empowerment programme for family members of people experiencing addiction in the Northern Territory of Australia (Tari-Keresztes et al., 2022; 2023). The programme was designed by a local lived experience Network with funding from the Government. It was delivered by skilled peer facilitators, across seven modules.

Module 1 ("Settling in") provided an overview of the programme, agreed upon shared values for the group, and allowed participants to get to know one another and the facilitators. Module 2 ("The unique experience of informal carers") explored the experience of family members, aiming to validate participants' experiences and support them in separating the relative's behaviours and difficulties from who they are as a person. Module 3 ("Understanding recovery") educated participants on recovery through a biopsychosocial-spiritual model. Module 4 ("Effective communication") addressed communication and conflict styles, needs, boundaries, effective communication, and safety. Little information is provided about Module 5 ("Responding to stigma"), but this likely attended to the high rates of stigma faced by people experiencing addiction and their families. Module 6 ("Navigating the system") provided participants with information on and tools for navigating services and supporting their relative's recovery. Module 7 ("Celebrating our journey together") involved reviewing the programme as well as celebration, gratitude, and "visualising a hopeful future" (Tari-Keresztes et al., 2022, p. 18). Self-care strategies were addressed within most modules. The programme was delivered across three groups, in nine weekly, three-hour sessions, with a total of 19 participants. The sessions were strengths-based and involved personal stories, as well as reflection and feedback. Participants were recruited with help from local community groups and service providers, and through public education and community literacy sessions.

The impact and value of the programme were evaluated through a co-produced mixed methods approach, involving interviews and surveys with programme participants and facilitators. The pre-programme survey was completed by 16 people (including two facilitators), while 10 completed the post-programme survey. Seven participants and four facilitators were interviewed.

Qualitative findings demonstrated that participants greatly valued the programme. For many, this was the first time they participated in a peer support programme, or any kind of support focused on their own wellbeing. The peer approach was seen as very valuable. Some participants specifically joined the programme to meet others who share their experiences and, indeed, many were "amazed" by the power of the peer approach (Tari-Keresztes et al., 2023, p. 6). One participant described peer support and connection as "the most important" (p. 6) aspect of the programme. Participants reported feeling connected, accepted, and understood (Tari-Keresztes et al., 2022).

In addition to the peer-led nature of the programme, participants spoke highly of the content of the modules. In particular, they reported benefiting from learning about post-traumatic growth and the stages of change for families, as these enhanced their insight, self-awareness, and hope. The circles of control model, which reminded participants of their lack of control over their relative's addiction and encouraged them to shift their focus onto what they can control, was also praised. Other areas of the modules highlighted by participants as particularly helpful involved self-care, communication, boundary-setting, crisis response skills, and advocacy. Some participants expressed wishing that they had this knowledge earlier in their recovery journey (Tari-Keresztes et al., 2022).

Quantitative data concerning the impact of the programme on participants is less clear about its benefits (Tari-Keresztes et al., 2022). Participants experienced significant reductions in stress levels after completing the programme, compared to their stress levels before participating. They also showed improvement on measures of "social recovery", concerning connecting with others and feelings of belonging. However, there was no significant change in participants' self-perceived health, the frequency of specific indicators of stress, and other aspects of recovery.

7. Discussion and Recommendations

This final section of the report summarises the findings outlined in <u>Sections 4</u>, <u>5</u>, and <u>6</u>, highlighting key points, similarities, differences, and discords across the international practice literature and research sources. The aim is to extend international knowledge and research findings to the Irish context, arriving at a set of recommendations concerning FPSW in Irish mental health services.

A number of the following recommendations involve standardising the field of FPSW in Ireland. This carries a range of benefits. Firstly, standardisation enhances the quality and consistency of FPSW across the country, benefiting clients. Secondly, standardisation supports FPSWrs, by establishing structures for employers to follow. This protects their role, ensures that the essence and ethos of FPSW are maintained across services, and holds employers accountable. Thirdly, as per the Mental Health Commission of Canada (2021), establishing standards of practice for PSW "will enhance the credibility of peer support as an essential component of a transformed mental health system" (p. 8). Setting universal guidelines and standards validates FPSW as a legitimate and essential field, and FPSWrs as important, qualified professionals with unique skills, knowledge, and contributions.

The following recommendations were written to support the development of the FPSWrs' Toolkit. At the same time, some may fall beyond its scope or aim, depending on the Working Group's vision for the Toolkit. However, they may still provide valuable insight for the development of the Toolkit or may inform other, future developments in FPSW in Ireland. It is up to the Working Group to decide which of the below recommendations they wish to apply to their Toolkit.

7.1 Co-Production

The extent of co-production varied greatly across the literature included in this review. As discussed in Section 3.2.2, research sources performed very poorly on the co-production criterion of the evaluation framework. With regards to practice documents, those written by NGOs were often co-produced as the authoring organisations were often peer-led. On the other hand, documents written by government departments or statutory organisations ranged from showing no indicators of co-production to demonstrating a strong lived experience voice throughout. A major criticism leveraged against the UK Competence Framework for Mental Health PSWrs (NHS Health Education England, 2020a; 2020b; 2020c) concerned the lack of co-production in its writing. Though an Expert Reference Group involving people with lived experience was engaged in the process, the core team did not have any stated lived experience. They were commissioned due to their expertise in writing competency frameworks. In addition,

engagement with the Expert Reference Group was described as tokenistic and motivated by optics, with their feedback often ignored. The Framework was also criticised for abandoning and not understanding the essence of PSW; perhaps greater engagement with PSW experts and experts by experience would have avoided this. Indeed, the CEO of the National Survivor User Network <u>states</u> that the Framework "is a product of deeply flawed processes and, as such, a lot of its content is problematic". She highlights the insufficiency of inviting people with lived experience to "be involved in areas which [they] should lead".

The above criticisms of the Framework focus on involvement of people with lived experience of MHDs, as the Framework concerns PSW more generally, inclusive of but not limited to FPSW. Accordingly, any work done within the field of FPSW should be led by family members and FPSWrs. A major strength of the FPSWr Toolkit Working Group is that it consists of FPSWrs (and, by extension, family members). This will serve as a major strength of the Toolkit also and should be carried through to other work done within FPSW in Ireland, at national, regional, and organisational levels. Within the Toolkit in particular, the importance of co-production in establishing FPSW in mental health services should be highlighted. In addition to working with families and FPSWrs directly, partnering with existing family-led CVS organisations may also enhance FPSW due to their experience and expertise in working with and supporting family members, as well as the trust and connections they have built with families.

The positioning of co-production as the first recommendation is deliberate. Co-production should lie at the heart of all work done within mental health services, and especially within (family) peer support. This is emphasised by the HSE Mental Health Engagement and Recovery Office (2023). Similarly, the US organisation FREDLA (2016) notes that co-producing family peer support services with family members is important to their effective provision. As such, family members and FPSWrs should guide the implementation of every recommendation that follows. Rather than stating this within each section, we specify at the outset that this is a universal requirement.



Recommendation 1: Place FPSWrs and family members at the lead of all future developments in FPSW in Ireland.

- Partner with existing FPSWrs and family members in writing FPSWr role descriptions, requirements, and other organisational documentation.
- Partner with FPSWrs and family members in producing any national and regional documentation and guidance on FPSW, such as frameworks, core competencies, and best practice guidelines.
- Partner with FPSWrs and family members in designing and delivering initial and continuing training for FPSWrs.
- Partner with FPSWrs and family members in designing any novel approaches to and methods of providing family peer support, to ensure that they are accessible and acceptable to family members and aligned with their needs.

 Support and fund research into FPSW that is co-produced with and led by family members.

7.2 Values and Principles

The values and principles of PSW were discussed within the UK <u>Competence Framework for Mental Health PSWrs</u> (NHS Health Education England, 2020a; 2020b; 2020c), Canadian <u>Guidelines for the Practice and Training of Peer Support</u> (Mental Health Commission of Canada, 2021), Australian <u>National Lived Experience (Peer) Workforce Development Guidelines</u> (Byrne et al., 2021a; 2021b), and <u>Western Australian Lived Experience (Peer) Workforces Framework</u> (Government of Western Australia Mental Health Commission, 2022). All of these documents concerned PSW in general, inclusive of FPSW. As such, they are applicable but not specific to FPSW.

The Mental Health Commission of Canada (2021) highlights the importance of defining the values of PSW in ensuring that the essence of the field is not lost in the process of its professionalisation. In other words, these core values create a foundation for future developments in the field, such as the creation of guidelines, training, certifications, and other documents and standardisation mechanisms. They should capture the most central pillars and fundamental beliefs of peer support. All those involved in the provision or development of PSW, whether as PSWrs, managerial staff, policy makers, or funders, should work in accordance with these values. In turn, principles should explain how these values are applied in the context of PSWrs' role. An alternative to defining principles is to provide examples of the application of these values in practice, similarly to the Western Australian Framework (Government of Western Australia Mental Health Commission, 2022).

Though there exists variation within the values and principles defined in the above documents, some common themes arise. Firstly, reference to the voluntary, person-centred, choice-based nature of peer support is common. Clients availing of PSW should only do so by choice and must never be required to engage. The support offered by PSWrs is guided by the clients' wishes and preferences; they are supported in their "self-defined personal recovery" (NHS Health Education England, 2020a, p. 12). Within this, some frameworks also include a rejection of coercive or restrictive practice by PSWrs; they state that PSWrs should never be asked to engage in coercive or restrictive practice, and should encourage their workplace to move away from such practices.

Secondly, values and principles highlighting the relational basis of PSW are common. The relationship between the PSWr and the client forms the basis of the support. This relationship is equal, mutual, and reciprocal. The PSWr is not seen as an expert, but rather a companion with shared experiences. Both the PSWr and the client learn and grow through the relationship.

Thirdly, values concerning hope and a strengths-based approach were present across a number of documents. The PSWr has fundamental faith in their clients' recovery. They attend to the clients' existing strengths and resources. PSWrs' approach is

person-centred, rather than illness-centred. Other common values included empathy, diversity, social inclusion, human rights, and authenticity. Less common were references to the trauma-informed approach of peer support, lifelong learning and development of the PSWr, valuing lived experience expertise, and respect.



Recommendation 2: Co-produce a set of core values for FPSWrs

These values:

- Must be specific to FPSWrs, rather than applying to PSWrs more generally, though there may be overlap between the two. While defining shared values is a common approach, the resulting values must be relevant to peer support for both people with MHDs and their families. As such, values that are unique to the specific type of peer support, and not applicable to both, are lost.
- Will guide organisations employing FPSWrs in defining job descriptions, tasks, requirements, career progression opportunities, and other similar structures.
- Will guide any future developments in the field of FPSW in Ireland, such as the writing of guidelines, training, competency frameworks, and other mechanisms of professionalisation.
- Should be reviewed annually to ensure that they remain relevant and applicable, making revisions and changes as necessary as the field of FPSW develops and evolves.
- Should be complemented by a set of core principles or examples of how these values translate to the practice of FPSW.

7.3 Aims and Scope

In order to ensure clarity around the role of FPSWrs, it is important that the scope and aims of their work are clearly defined. Many international documents note that lack of clarity around PSWrs' roles poses challenges to their work, including the embedding of FPSWrs into existing services and teams, and family members' understanding of the support that FPSWrs can offer (e.g. NHS Health Education England, 2020a). Research findings echo the lack of clarity around FPSWrs (Health Workforce Australia, 2014; Cottrill, 2011), including the distinction between their role and that of clinicians (Hopkins et al., 2021). Consequences of this include difficulties staying within the boundaries of their role; being asked to work beyond those boundaries; conflict; and stress (Hopkins et al., 2021; Western Australian Association for Mental Health, 2014; Tandem, 2015; National Mental Health Consumer & Carer Forum, 2010). In one study, FPSWrs felt that misunderstanding of their work is the primary reason why families decline their services (Davis et al., 2010). As such, the Toolkit should set clear definitions for the role of FPSWrs, including the aims and scope of their work, highlighting their unique contributions.

The framing of the purpose of offering FPSW varies across international literature. In the US, family peer support is provided in recognition of the importance of engaging with the

family in supporting the person experiencing MHDs (Schober & Baxter, 2021; FREDLA, 2016; Olin et al., 2016; New York State Office of Mental Health, 2024). The focus is not on the family members' own wellbeing and recovery, but rather enhancing the recovery of the person affected by MHDs. This is evidenced in research. In reviewing existing research on FPSW, Acri et al. (2017) found that many studies do not assess family-level outcomes, instead looking only at the impact of supporting the family member on the person experiencing MHDs. In contrast, outside of the US, FPSW typically aims to support the family members' recovery. Their wellbeing is recognised as important in its own right, independently of the impact of supporting the family member on the person with MHDs (Australian Health Ministers' Advisory Council, 2013; GRAMHS, 2022; Mental Health Commission of Canada, 2021). The potential positive impact on the person experiencing MHDs is recognised, but this is not the primary aim. Some research studies documented that even when FPSW is provided specifically for the benefit of family members, positive outcomes for the person experiencing MHDs are also noted, for example, through resulting improvements in the relationship between the person experiencing MHDs and their family member (Visa & Harvey, 2017; Grennan et al., 2022).

Aside from the above distinction, there exists a lot of overlap in how different organisations and countries conceptualise the aims of PSW. However, as previously mentioned, many international practice documents included within this review covered FPSW but were not specific to it - they addressed PSW more broadly. As such, these documents defined the general aims of PSW. Commonly mentioned aims involve supporting clients' wellbeing, support in navigating services, advocacy, information provision, skill building, fostering hope, assisting the client in building community connections, and being a living example of the real possibility of recovery (Nikkel et al., 2021; NHS Health Education England, 2020a, 2020b; Mental Health Commission of Canada, 2021). Many documents also frame the PSWr as an agent of change within their team, who inspires and encourages their workplace to move towards more recovery-oriented, person-centred, trauma-informed practice. However, the PSWr should not be the sole person responsible for this reform. The responsibility for improving the culture of the organisation falls on all of its staff. This is discussed in greater detail in Section 7.10. In general, care should be taken if including this as an element of PSWrs' role. The core function of the FPSWr role is to support family members. Any additional tasks concerning cultural reform should be at the discretion of the FPSWr, such that the support offered to their clients isn't compromised, and that they do not experience burnout.

Though it is worth noting some of these similarities and overlaps in literature on PSW more broadly, the aims of FPSW should be defined separately. This is particularly crucial considering the aforementioned lack of clarity surrounding the role of FPSWrs. Examples of aims mentioned in literature that are specific to FPSW (in the context of MHDs and addiction) include supporting the wellbeing of family members; assisting them in communicating and working with the mental health service attended by their family member; signposting; supporting them in communicating with and improving their relationship with their family member; enhancing their understanding of their family member's difficulties; and building their hope in both their own recovery and that of their

family member (GRAMHS, 2022; Mental Health Commission of Canada, 2021; SAMHSA, 2023a). Research into FPSW provides further insight into the aspects of FPSW that family members find particularly beneficial (see Section 5.2.2). These include: information provision, for example, concerning MHDs, treatment, and available supports; skill-building, for example, communication skills, coping skills, and crisis management; encouragement of and information on self-care; emotional support, including being listened to and met with compassion; validation of their emotions; inspiring hope in participants, for example, through sharing their own stories; celebrating clients' and their family members' successes; and practical supports, such as referrals to other services, financial support, accompaniment to appointments, and liaison with clinicians on the clients' behalf. In Garavan's (2016) evaluation of Bealach Nua, participants wished for FPSWrs to be available as advocates and, similarly to international research, companions during appointments with clinicians. The role of FPSWrs in crisis services should also be considered. In some international services, FPSWrs are included within crisis supports, but only during operating hours and not out-of-hours services (New York State Office for Mental Health, 2024). In Levasseur et al. (2018), participants called for the development of specific FPSWrs crisis supports.

In alignment with the values of peer support, the work of FPSWrs should always be individualised and based upon the clients' vision for their recovery. As such, defining the aims of FPSWrs must strike a balance between being specific enough to provide clarity around their role, but flexible enough that they can be adapted to each individual client.



Recommendation 3: Clearly define the aims of the work conducted by FPSWrs in Irish mental health services.

These aims:

- Must be specific to FPSWrs, rather than addressing PSW more generally.
- Will guide the development of job descriptions and role responsibilities of FPSWrs employed within mental health services.
- Must be aligned with the values and principles of FPSW.
- Should emphasise the unique contributions of FPSWrs and clearly distinguish between their role and that of other, clinical staff.
- Should balance providing enough specificity to clarify the role of FPSWrs with offering enough flexibility to not compromise the person-centred, client-led nature of FPSW.
- Should focus on the responsibilities of FPSWrs with respect to clients, defining, for example, the kinds of support that they provide. The core aim of FPSW is to support family members. Caution should be taken when including additional,

other elements within the aims of their role, such as enacting cultural change within their organisation.

7.4 Enhancing Access to Family Peer Support

When defining the specifications and scope of the FPSWr role, accessibility must be at the forefront. This can be looked at from two angles. Firstly, setting eligibility criteria for availing of FPSW will inherently restrict its access. For clarity, it is important to define who can and cannot receive the support of a FPSWr. However, care must be taken when doing so, as restricting the availability of FPSWrs may inadvertently exclude some of the most vulnerable individuals from being able to avail of support. Secondly, the manner in which support is provided may restrict - or enhance - its accessibility, depending, for example, on the clients' financial status, home circumstances, or health or disability status. Both of these areas are considered below.

The availability and accessibility of FPSW varies across international literature. With regards to eligibility criteria, one variation concerns the specific family members that FPSW is available to. In the US, the emphasis is on services for parents and primary caregivers. This may be partly due to the fact that FPSW in the US is available mostly within youth services (e.g. Schober & Baxter, 2021). Addiction services are an exception to this, where FPSW is also offered to family members of adults experiencing addiction. As a result, the range of family members who can avail of FPSW is also broader (SAMHSA, 2023a). Within other countries, there are often no stated restrictions on the relation of the family member (or other loved one) to the person with MHDs. Al-Anon and Nar-Anon go a step beyond this, as their family groups are available to all people who are or have been affected by another person's addiction - even if that person is no longer in active addiction, and even if they have died (see Al-Anon Family Groups UK & Éire website for further information).

Eligibility requirements regarding engagement with mental health services also vary. For example, the Royal Commission into Victoria's Mental Health Services (2021b) recommends that supports for family members of people with MHDs are available regardless of the person's engagement with mental health services. In contrast, in Irish public services, FPSWrs are only available to family members of people who are engaging with the local mental health service (GRAMHS, 2022; Garavan, 2016). GRAMHS recognise that this can cause challenges, particularly when the client is not on good terms with their family. Since only family members of GRAMHS clients can avail of GRAMHS FPSWrs, offering FPSW to a family member is equivalent to confirming that their relative is a client of GRAMHS. This is a violation of confidentiality, unless the clients' consent is obtained. If the client does not consent, the family member is left without support. Aside from this challenge, family members of people with MHDs may need support regardless of their relative's engagement with services. In fact, families that are not engaged with mental health services may need support even more than those who do. Within the Bealach Nua evaluation, Garavan (2016) states that families of people who do not consent to their involvement in their care experience extreme levels of frustration, isolation, and powerlessness - but these families may not be able to access support if their relative does not consent to them being informed about their engagement with mental health services. In addition, some people experiencing MHDs may be accessing private care, and these private services may not offer FPSW - leaving their families without support also. This is a particularly important consideration within the Irish context, where waitlists for public mental health services can be very long and clients may have no other option but to seek out private care.

To avoid difficulties concerning confidentiality and expand the reach of FPSWrs, FPSW should be made available to all relatives of people experiencing MHDs. Whether the person with MHDs is engaged with mental health services should not impact their family members' eligibility for support. Of course, this would require significant investment into FPSW, to allow for the recruitment of sufficient FPSWrs to meet potential demand. Partnering with NGOs and CVS organisations which already offer family peer support may help to facilitate this, until sufficient funding is made available to recruit enough FPSWrs within public services. CVS organisations may also assist with raising awareness of FPSW among families of people who are not clients of mental health services.

With regards to the second point, that is, enhancing access to FPSW by considering how it is provided, a number of suggestions were noted in international practice and research literature. For example, the Mental Health Commission of Canada (2021) recommends that PSW is provided in a range of settings to ensure access for all. On this note, one creative model of enhancing the accessibility of FPSW is that of Adfam (2018). As part of their service, FPSWrs were stationed at addiction drop-in centres, to reach out to families accompanying their relatives to the centre. Some family members who availed of this service stated that without this, they would not have accessed formal supports. Adapting this model to Irish services may be valuable in reaching families who may not engage with supports otherwise.

Further suggestions for improving the accessibility of FPSW were identified through research. One consideration concerns fear of stigma among (potential) clients. In Cottrill (2011) and Visa & Harvey (2019), participants identified concerns around stigma and being judged as a barrier to availing of FPSW. This was particularly relevant for those living in small communities - a factor very relevant to Ireland, as much of the Irish population lives in rural areas. Participants from diverse and non-English-speaking backgrounds also expressed particular concerns around stigma. Accounting for this may be important in ensuring that FPSW is accessible to family members from minority backgrounds. In Lobban et al. (2020), where peer support was provided through an online forum, participants appreciated the anonymity of this medium. This was contrasted with family peer support groups, which were considered particularly inaccessible to family members who work in mental healthcare and thus had concerns around running into families of their clients.

These findings suggest a number of solutions. Firstly, establishing anonymous, online support forums may be helpful in extending FPSW to those whose concerns about anonymity prevent them from accessing in-person supports. These forums could be moderated by trained FPSWrs and would allow family members to seek support both from the FPSWrs and one another. While Lobban et al. (2020) did not find any quantitative evidence to support the effectiveness of this type of support, further research in this area

is needed, and qualitative feedback indicates that family members did find this helpful. Secondly, increasing the availability of one-to-one FPSW would alleviate concerns relating specifically to peer support groups. Thirdly, considering the physical location of FPSW is vital. Ideally, FPSWrs and support groups should be located in neutral venues, rather than mental health facilities. Family members who are concerned about anonymity may hesitate to avail of supports that are based in mental health services, out of fear that they will be seen entering the venue. Providing support in neutral venues, such as community centres, or even offering at-home visits, may help to alleviate these supports. Fourthly, and similarly, offering one-to-one support over the phone or video call may be a suitable option, especially if a neutral venue is not available.

Other barriers to access concerned more structural, systemic factors. Family members reported being unable to avail of FPSW due to their work, location, and caregiving responsibilities (Levasseur et al., 2018; Visa & Harvey, 2019; Cottrill, 2011). Financial challenges exacerbated some of these, for example, for clients who could not afford transport to their appointments (Levasseur et al., 2018). Availability of social support and access to professional care was also closely tied to these barriers, as some family members did not have any friends, family, or professional support or care workers who could stay at home with their relative while they attended appointments. Others simply felt too overwhelmed by their caregiving responsibilities to be able to engage with FPSW.

These challenges underscore a critical point: while FPSW is of immense value and comes with a wide range of benefits, it cannot, on its own, address the myriad of structural, systemic, and societal challenges faced by people with MHDs and their relatives. No amount of investment into FPSWrs will help families who cannot avail of their services, as they cannot afford to take time off work, access respite services, or pay staff to support their relative while they seek support. This was evident in the studies discussed in this review. In Visa & Harvey (2019), some participants noted that the effects of the support they received were short-lived, as their day-to-day circumstances remained unchanged. Though their FPSWrs offered them a great deal of support, the difficulties they faced were too great to be alleviated through using coping skills or talking with the FPSWr. In Higgins (2012), some participants considered the session content to be idealistic and not reflective of the reality of the mental health system. Importantly, this was an Irish study, demonstrating that these problems affect Irish families too. A quote from one participant exemplifies this frustration:

"Sometimes you felt it was just an exercise ... [The facilitators] kept saying, 'You need your own space,' and, 'You need to have time for yourself,' and, 'You need this.' How are you supposed to get that? Who is giving us the support? There is no respite." (p. 25)

While these are not challenges that can be addressed by a FPSWr, it is important to highlight them when discussing the needs of family members. Additionally, there are some steps that can be taken to attempt to alleviate the barriers to accessing FPSW caused by these systemic factors. Provision of at-home or online appointments may be of help to family members who cannot afford transport or whose caregiving

responsibilities prohibit them from attending in-person appointments. These adaptations may also be helpful to people with disabilities, who may have difficulties travelling to or entering certain locations due to their health status. An online support forum may also be more accessible to family members who face these challenges. In Lobban et al. (2020), participants appreciated being able to access the forum as needed, without having to schedule and attend an appointment. Providing family members with practical support, for example, help with applying for financial aid, could also have a material, positive impact on family members' circumstances.

Other challenges identified in research concerned materials distributed by FPSWrs and in support groups, as some were considered too text-heavy and technical. Providing resources in simple English and through a range of media would alleviate these difficulties. Finally, participants across a number of studies mentioned the availability of FPSWrs as a problem. They wished for more appointments and time with the FPSWr, greater funding for FPSWrs, more family peer support groups, and longer group sessions (e.g. Markoulakis et al., 2022; Cottril, 2011; Visa & Harvey, 2019, Higgins, 2012). In Bealach Nua, the availability of the FPSWr was deliberately restricted to approximately 10 sessions per family member, contradicting the person-centred philosophy of FPSW which stipulates that support should be individualised to the needs of each client.



Recommendation 4: Enhance the accessibility of FPSW.

- Avoid restricting the availability of FPSWrs to specific relatives. Any family member, friend, or supporter who is affected by another person's MHDs should have access to FPSW.
- Provide FPSW through a range of settings and modes, including face-to-face within and outside of mental health services, over the phone, online, and at the client's home.
- Explore the possibility of providing drop-in family peer support sessions at settings such as community mental health services, primary care centres, day hospitals, and GP clinics, to engage with family members who may be accompanying their relatives to appointments.
- Expand FPSW services to all family members of people experiencing MHDs, not
 just family members of people who are engaging with mental health services.
 This will require substantial financial investment. In the interim, explore the
 possibility of partnering with peer-led CVS organisations to expand the scope and
 availability of FPSW.
- Explore the possibility of establishing an anonymous, online, peer-moderated support forum for family members, including the demand for such a forum.
- Provide both one-to-one and group-based family peer support, to avail of the benefits of both and maximise access to supports.

- Ensure that any psychoeducational material provided to clients is written in plain language and available in a range of formats (e.g. printed, online text files, video, audio) and languages.
- Establish an online, openly accessible directory of resources for family members of people with MHDs, including resources in various formats and languages.

7.5 Skills and Competencies

Core competencies and skills for PSWrs were outlined within international literature, including the UK Competence Framework for Mental Health PSWrs (NHS Health Education England, 2020a; 2020b), US Core Competencies for Peer Workers in Behavioral Health Services (SAMHSA, 2015), US Core Competencies of Parent PSWrs (Purdy, 2010), Canadian Guidelines for the Practice and Training of Peer Support (Mental Health Commission of Canada, 2021), and Australian Queensland Health Lived Experience (Peer) Workforce Framework (Queensland Health, 2023). With the exception of Purdy (2010), these documents concern PSW more broadly, rather than being specific to FPSW. In fact, SAMHSA (2015) recognised the potential need to draft a separate set of competencies for FPSWrs, noting that their framework can serve as a foundation for this. In Garavan's evaluation of Bealach Nua (2016), FPSWrs employed at the service wished for the establishment of professional standards concerning their competencies.

There exists substantial overlap across the core competencies outlined within these documents. Firstly, reference to relational and interpersonal skills is found in every document, including areas such as communication, relationship-building, and active listening. The ability to share one's lived experience also falls within this area, including knowing when personal disclosure is appropriate and how to do so in a manner that inspires hope and facilitates connection.

Secondly, the inclusion of some kind of knowledge base is common across the documents. For example, the PSWr should understand the values and principles of peer support, including areas such as recovery, person-centred practice, and trauma-informed practice. They should have knowledge of MHDs, self-harm, and suicide prevention. They should also understand the distinction between the role of a PSWr and that of other, clinical staff. Some competency frameworks mention that PSWrs should be aware of local laws, regulations, and structures that may be relevant to their practice. In an Irish context, this could involve the Children First Act 2015, Mental Health Act 2001, and Act 2015, as well as any local and national services that a family member may be linked in with for further or more specific support.

Thirdly, competencies concerning the provision of support are common, including specific tools, skills that convey hope and empathy, personalising the support to the clients' needs, supporting recovery planning, crisis management skills, and advocacy. The ability to support clients in engaging with activities that are meaningful to them, building community connections, and developing coping skills, may also be included within this. Finally, some frameworks state that the PSWr should show an ability and willingness to educate their colleagues around recovery and encourage cultural change

within their organisation. This is discussed in detail in <u>Section 7.7</u>. Other common themes include self-care, ethics (including confidentiality), teamwork, and self-reflection (for example, the ability to reflect on how the person's own values and attitudes may impact the support they provide).

Notably, the inclusion of psychological approaches within the UK <u>Competence Framework for Mental Health PSWrs</u> (NHS Health Education England, 2020a, 2020b) attracted criticism from the psychiatric consumer/survivor/ex-patient movement. Peer support is, by definition, not clinical, and PSWrs should not be expected to work from a clinical approach or complete tasks typically assigned to clinical staff, such as psychologists. Critics of the Framework argued that including this as a core competency demonstrates lack of understanding of the nature of PSW and blurs the line between peer support and clinical care. For comparison, the US <u>Core Competencies of Parent PSWrs</u> (Purdy, 2010) similarly include having an understanding of clinical, mental health treatment and prevention as a competency. However, the framing of this is different. The purpose of this understanding is not to apply this clinical approach within the Parent PSWrs' practice. Rather, the Parent PSWr can use this knowledge to assist the family in understanding their child's care.

From the perspective of family members, research shows that the skills they desire from FPSWrs are aligned with those outlined in international frameworks. For example, in Markoulakis et al. (2017), participants stated that empathy, listening, validating the client, boundaries, and knowing when personal disclosure is appropriate were important skills for the FPSWr to possess. Across research, there was a clear sentiment among clients that support provided by other family members is unique and different to the support offered by clinicians, as they possess expertise that can only be gained through first-hand experience. The unique qualities and contributions of FPSWrs should be emphasised in the development of an Irish core competency framework for FPSWrs.

Producing a set of nationwide core competencies for FPSWrs in Ireland would enhance the consistency and quality of FPSW in Irish mental health services. It would serve to clarify the role of FPSWrs to a range of stakeholders, from other mental health staff to policy makers, by defining what does and does not fall within their remit and skillset. It may also contribute to the legitimisation and professionalisation of the field by documenting the tangible, unique skills of FPSWrs. A competency framework creates a standard upon which future developments in the field can be built, such as designing training for FPSWrs to enhance their skills within the outlined areas.



Recommendation 5: Co-produce a Core Competency Framework for FPSWrs in Irish mental health services.

This Framework:

- Must be specific to FPSWrs, rather than applying to all PSWrs.
- Will form a foundation for future developments in FPSW in Ireland, such as the development of specific training, qualifications, certification, or recruitment materials for FPSWrs.
- Should reflect the values and principles of FPSW and stay true to its nature and philosophy.
- Should be reviewed annually to ensure that it remains relevant and applicable, making revisions and changes as necessary as the field of FPSW develops and evolves.
- Must exercise caution with regards to the inclusion of psychological or clinical approaches. If this is included as a competency, it is important to be clear about its purpose and how it applies to the role of FPSWrs, such that their non-clinical, person-centred ethos is not compromised.

7.6 Recruitment

Recruitment processes were discussed within a number of documents included in this review. These addressed a range of areas, from interviewing, to setting and assessing the requirements of the role, to accessibility and reasonable accommodations. In general, as much as possible, recruitment should be standardised nationwide, with minor adjustments to suit the needs of the local community or organisation. This will ensure consistency in the quality and type of support offered across services.

Regarding the recruitment process, several guidelines recommend that existing PSWrs are involved in recruitment, including on the interview panel (e.g. Byrne et al., 2021a; 2021b; Queensland Health, 2023; Peer Work Hub, 2016b). Since applicants will likely discuss their lived experience during the interview, emotional support should be made available in the aftermath.

With regards to setting role requirements, most practice documents specify that alongside having relevant lived experience, PSWrs must meet some form of requirement concerning being in recovery. The Mental Health Commission of Canada (2021) phrases this as being "in a positive state of recovery" (p. 5). This can be assessed through a number of approaches. For example, recruiters may enquire about and assess the applicants' ability to articulate their personal definition of recovery, the lessons they have learned through their journey, the strategies they use to cope with challenges, and how

they can apply these various elements to support others (National Federation of Families for Children's Mental Health, 2011; Queensland Health, 2023; SAMHSA, 2023b). In the US, this requirement is sometimes framed in terms of a minimum length of time that the person has been in recovery, or length of time since diagnosis. However, this is at odds with the individualised nature of recovery. It assumes that a minimum amount of time is a requirement to be considered to be in recovery, even though each person's recovery is specific to them and not determined by the duration of their journey. Accordingly, the Canadian <u>Guidelines for the Practice and Training of Peer Support</u> (Mental Health Commission of Canada, 2021) specify that assessing the recovery requirement should not be based upon (length of time since) diagnosis, but rather the person's ability to recognise when they are in need of a "health break" (p. 21).

Across fields and roles, even if there is no requirement for specific qualifications, it is common for employers to require candidates to have a minimum level of education, such as a Junior or Leaving Certificate. This may be used as a proxy to assess literacy and numeracy. It is assumed that if a candidate has this minimum level of education, then they have adequate literacy and numeracy for the role. However, SAMHSA (2023b) advises against this. Their Technical Expert Group, consisting of stakeholders including PSWrs, state that this has "limited positive impact on the peer workforce" (p. 17) and makes the role less accessible. Family members of people with MHDs may face barriers to completing education. For example, children of parents with MHDs may have had caring responsibilities when they were at school age, limiting their ability to perform well in school. Even without a Junior or Leaving Certificate, candidates may have the skills required to carry out the role; if this is the case, they should not be excluded solely because of their formal education. Notably, in Markoulakis et al. (2017), participants echo this by stating that FPSWrs' single most important qualification is their lived experience - not formal education.



Recommendation 6: Co-produce standardised guidelines for the recruitment of FPSWrs in Irish mental health services.

Within these, recommend that services:

- Co-produce all recruitment materials, including the role requirements, with FPSWrs and family members.
- Clearly define the role requirements and responsibilities of FPSWrs, to ensure clarity surrounding their role for applicants, FPSWrs, clinicians, and family members.
- Ensure that existing FPSWrs are involved in recruitment, including on the interview panel.

- Include a requirement for prospective FPSWrs to have lived experience of recovery, in addition to having a family member with MHDs. As recovery is unique to each person, the assessment of this should be individualised, rather than, for example, based upon the length of time since the family member was diagnosed.
- Provide applicants with emotional support following the interview, as discussing their personal experiences of being a family member may trigger difficult feelings or distress. Whether the applicant avails of this support should not be made known to the recruiters, to avoid bias.
- Avoid requiring that prospective FPSWrs have a minimum level of education (e.g. Junior/Leaving Certificate). Assess literacy and numeracy directly, instead of using education as a proxy.

7.7 Training and Certification

The topic of initial and ongoing training for FPSWrs was discussed in depth in practice literature and briefly addressed in research. FPSWrs should have access to FPSWr-specific training, rather than, or in addition to, general PSW training (Tandem, 2020; National Mental Health Consumer & Carer Forum, 2021). The design and delivery of any such training should be led by family members and existing FPSWrs. The proposed content of training for FPSWrs suggested in the literature is closely aligned with the core competencies, as per Section 7.5. The purpose of offering training to FPSWrs is to enhance their abilities within these areas and equip them with the skills needed to use their lived experience expertise to support other family members, in a manner that is trauma-informed and culturally appropriate. However, as mentioned in Section 7.6, requiring that FPSWrs have certain qualifications at the point of entry into the field is generally not recommended. FPSWrs' lived experience is their most fundamental and valuable "qualification". If a prospective FPSWr can demonstrate that they have the skills necessary to carry out the role, they should not be excluded due to lack of a certain level of education. The purpose of offering training to FPSWrs should be to enhance their skills within these areas, contributing to continuous professional development, and/or to provide them with skills needed for more senior or leadership-based FPSWr roles (e.g. peer supervisor or peer management roles). Specific training may be designed and made available for family members who wish to become FPSWrs but feel that they do not currently have the required skills, but this should be optional. In addition to enhancing FPSWrs' core competencies, the Mental Health Commission of Canada (2021) recommends that the historical and social context of PSW is explored within training (including within FPSW-specific training), noting that "[a]n awareness of the historical context of mental illness serves as a foundation for understanding the legacy of oppression and discrimination out of which current trends in peer support developed" (p. 34). The Australian Peer Workforce Development Guidelines (Byrne et al., 2021a; 2021b) similarly **PSWrs** should be of state that aware the psychiatric survivor/consumer/ex-patient movement.

Aside from the content and purpose, international literature provides some useful information on training delivery and provision. Firstly, accessibility must be considered

when designing and offering training. Entry requirements should be limited to those that are absolutely necessary, keeping in mind the aforementioned challenges and barriers that may prevent some family members from being able to finish school or complete their Junior/Leaving Certificate. The cost of availing of the training should be kept to a minimum, with scholarships and grants available to those who cannot afford to cover these costs (Norton et al., 2023; Hodges et al., 2022). The training should be accredited to maximise its value to trainees and further contribute to the legitimisation of the field of FPSW. The modes of delivery of the training must also be made as accessible as possible, including hybrid learning options (Hodges et al., 2022) and the provision of materials in various formats, including physical handouts and textbooks that can be revisited as needed (Brennan, 2015). Finally, research provides some insight into teaching and training methods that FPSWrs have found particularly effective. Group-based teaching seems to carry benefits not just in terms of the effectiveness of the training, but also trainees' wellbeing, as group training and courses appear to have a similar positive impact on participants as family peer support groups (Vaswani-Bye et al., 2024; Brennan, 2015). Role-playing and pairing up participants to mentor and support one another were also valued and recommended for inclusion in future training. In Vaswani-Bye et al. (2024), where the training was delivered virtually, participants appreciated that the sessions were recorded, allowing them to revisit them as needed. Further information on the training of PSWrs and FPSWrs internationally can be found in Sections 4.4.4, 4.5.9, 5.5, and 6.4.2.

Alternatively, or in addition to providing training, some international literature discussed certification for FPSWrs. Certification is available in some countries, for example, through Peer Support Canada. Crucially, this is not the same as training and does not necessarily involve training. The process of certification requires that PSWrs demonstrate that they possess the skills necessary to carry out the role, for example, through verbal and written assessments, interviews, and a review of the candidate's work and volunteer experience. PSWrs do not need to have undergone training to be certified, as long as they have the required skills and competencies. Certification offers FPSWrs the option of receiving formal recognition of their abilities, without the additional barriers of training and courses. In addition to the personal value for the FPSWr, certification benefits the field of FPSW as a whole by validating it as a valuable, skillful, unique profession, and enhances the consistency of FPSW nationwide. As in the case of training, certification processes and requirements should be led by family members and existing FPSWrs, and the assessed skills should be aligned with the core competencies (Section 7.5). Any costs associated with certification should also be kept to a minimum, with scholarships and subsidies available for those who need them. Further information on certification is available in Sections 4.3.5 and 4.4.5.



Recommendation 7: Develop accessible training programmes and certification mechanisms for FPSWrs in Ireland, led by family members and existing FPSWrs.

- Develop accredited, introductory and ongoing training for FPSWrs, aligned with the Core Competency Framework recommended in Section 7.5.
- Develop opportunities for ongoing training for experienced FSPWrs, to support the further development of their skills and enhance career progression opportunities.
- Develop certification mechanisms to provide FPSWrs with a pathway to receiving formal recognition of their skills without necessarily needing to complete a course or degree.
- Align all training and certification programmes with the Core Competency Framework, as per Recommendation 5.
- Minimise the costs of training and certification programmes for FPSWrs, providing scholarships, grants, and subsidies to those who cannot cover the costs.
- Ensure that any training and certification programmes are as accessible as possible, for example, through limiting entry requirements, offering hybrid learning options, providing reasonable accommodations, developing materials in a range of formats, and accommodating various styles and modes of learning. The delivery of certain short-term courses through HSELand may be a viable option.

7.8 Specialist Family Peer Support Workers

The concept of specialist/specialised PSWrs is discussed in international literature (e.g. Byrne et al., 2021a; 2021b; Mental Health Families and Friends Tasmania, 2023; Australian Government Department of Health, 2019). Such workers, in addition to their lived experience, are part of a specific population or have a specific type of lived experience. These additional criteria may be chosen to target populations that are particularly likely to need PSW, or whose specific experiences may make it more difficult for them to connect with PSWrs who don't share those experiences. Though research on specialised FPSWrs is lacking, such FPSWrs may be better able to connect with certain vulnerable groups and support them in their recovery. For example, in Adfam's (2018) Whole Family Recovery Project, Family Recovery Champions from ethnic minority backgrounds used their existing networks to reach out to their communities.

There are a number of populations that may benefit from this specialised approach in the context of FPSW in Irish services. For example, the Traveller community faces very high rates of MHDs (McGorrian et al., 2013; All Ireland Traveller Health Study Team, 2010; Department of Health, 2022). At the same time, their experiences with the healthcare system are often negative due to stigma and discrimination, which can lead to reluctance

among the community to seek care (All Ireland Traveller Health Study Team, 2012). Poor cultural competency among healthcare workers can also cause challenges. The recruitment of specialised Traveller FPSWrs may help to address some of these barriers, as potential Traveller clients may be more willing to engage with a FPSWr who is from their community and understands their culture⁴. Other vulnerable groups which may similarly benefit from a specialised FPSWr from within their community include immigrants and refugees, people with disabilities, other ethnic minorities, and LGBTQIA+ people. In accordance with the Australian Government Department of Health (2019), if such roles are established, it is important that additional supports are offered to these FPSWrs, due to their added vulnerability to discrimination. Anti-discrimination policies should also be put in place and a general, inclusive workplace culture should be fostered, where staff from all backgrounds and communities can feel safe, welcome, and supported.

In addition to specialised FPSWrs targeting certain populations, there may be value in establishing FPSW roles for family members of people with specific MHDs. In particular, the Butterfly Foundation for Eating Disorders (2022) highlights the additional, unique challenges faced by caregivers of young people with eating disorders. The standard model of clinical intervention in these cases is Family-Based Therapy, which involves parents "refeeding" the young person by taking control over their eating. This can be a very challenging experience for the entire family, as it contradicts the typical trajectory of a young person's development, where the parents grant them increasing levels of independence and choice as they grow up. It can feel counterintuitive and lead to arguments and tensions within the family. Importantly, these challenges are very specific to Family-Based Therapy for eating disorders. Families engaging in this therapy model may therefore benefit from seeing a FPSWr who has also parented a young person with an eating disorder.



Recommendation 8: Explore the possibility of recruiting specialised FPSWrs, with specific lived experience or from specific backgrounds or communities.

- Engage with family members, existing FPSWrs, and marginalised communities to establish whether there exists a need for such services, and if so, for what populations.
- Consider existing knowledge on groups facing higher risk of MHDs and greater barriers to accessing care, to establish who may benefit from these specialised roles.
- Consider the varying needs of family members of people with different MHDs and consult with family members to assess the need for specialised FPSWrs with experience of specific MHDs.

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⁴ A specialist <u>Traveller PSWr</u> was hired by the HSE in 2022, but to date, this has not been extended to FPSW.

- Ensure that the potential recruitment of specialised FPSWrs is culturally appropriate and led by members of the relevant community.
- Ensure that existing staff at mental health services are prepared to invite specialised FPSWrs onto their teams, such that these new staff members are brought into an environment that is safe, welcoming, and non-discriminatory. This can be achieved, in part, through the provision of training on diversity, inclusion, stigma, anti-racism, discrimination, and cultural humility, designed and delivered by individuals from the relevant community.
- Support specialised FPSWrs in conducting outreach with their communities, particularly those that are hard to reach or may otherwise be reluctant to engage with formal supports.
- Provide additional supports to specialised FPSWrs, including emotional supports as well as supports in reporting instances of discrimination within the workplace.
- Work with relevant communities and member-led organisations to create further guidelines and structures for the recruitment and employment of specialised FPSWrs.

7.9 Supervision

The provision of supervision to FPSWrs is recognised as crucial across international literature, both in the context of MHDs and addiction and particularly within the US and Australia. The need for peer and line management supervision for PSWrs and FPSWrs was also highlighted as an important consideration for the development of PSW in Irish services by Norton et al. (2023). Supervision is a key part of ongoing professional development, enhancing the quality of support provided by PSWrs and reducing the risk of burnout. For example, in the US, SAMHSA (2023b) names peer supervision as one of the twelve national model standards for the certification of PSWrs, while the National Federation of Families for Children's Mental Health (2011) highlights the importance of supervision in enhancing and supporting the work of FPSWrs. SAMHSA (2023a) additionally highlights the value of supervision for FPSWrs in addiction services, noting that it enhances their skills and services and protects and supports their wellbeing. In Australia, supervision for peer workers is recognised as crucial within national (Byrne et al., 2021a; 2021b) and state-based documentation (Queensland Health, 2023; Peer Work Hub, 2016b), and among NGOs (Tandem, 2015). Hodges et al. (2022) recommend that supervision is embedded into practice standards for PSWrs, to enhance funding.

There exists a range of approaches to supervision for FPSWrs. Two key factors to consider are, firstly, who delivers the supervision, and secondly, whether it is delivered in a group setting or one-to-one. Group and one-to-one supervision both carry benefits and disadvantages. Group supervision facilitates the formation of FPSWr networks and may enable better problem-solving and knowledge-sharing (Mental Health Coalition of South Australia, 2022). On the other hand, one-to-one supervision allows for greater depth of discussion, as each FPSWr has their own sessions during which they can focus on their

specific experiences, challenges, concerns, and queries. It also eliminates concerns surrounding confidentiality that may arise in a group context.

With regards to the supervisor, international guidelines strongly advocate that supervision for FPSWrs is provided by other, more experienced FPSWrs, rather than by clinical staff (Byrne et al., 2021a; Peer Work Hub, 2016b; Butterfly Foundation for Eating Disorders, 2024; Mental Health Coalition of South Australia, 2022). This is known as "peer-to-peer supervision". Where this is not possible (for example, because there are no other FPSWrs employed at the service), the service should partner with an external organisation to provide peer-to-peer supervision - for example, a peer-led organisation that represents family members of people with MHDs, or an NGO that itself employs FPSWrs. Supervision delivered by clinical staff (known as "clinician-to-peer supervision") is considered insufficient as the role of FPSWrs is not clinical in nature. The guidance provided by clinicians may not be aligned with the ethos of PSW, instead following the aims of traditional clinical supervision, for example, discussion of diagnoses and treatment plans. A clinical supervisor also cannot provide first-hand insight into the dilemmas, challenges, and methods of using one's lived experience in one's work (National Federation of Families for Children's Mental Health, 2011). In contrast, the shared personal and professional experience of the supervisor and supervisee in peer-to-peer supervision enhances the value and relevance of the supervision. Research has also shown that PSWrs have a preference for lived experience leadership, management, and supervision (e.g. Te Hiringa Mahara: Mental Health and Wellbeing Commission, 2023). Though the National Federation of Families for Children's Mental Health (2011) notes that clinician-to-peer may offer the clinician an opportunity to learn about the value of PSW. the primary purpose of supervision is to support the supervisee. Decisions regarding supervision should be made to maximise its value to the supervised FPSWr, not the supervisor. Australian literature additionally recommends that, if possible, managers of FPSWrs are also FPSWrs (Byrne et al., 2021a; Peer Work Hub, 2016b).

In addition to the above considerations, international guidelines recommend that supervision is provided on a regular basis as well as an "as needed" basis. In other words, attending regular supervision sessions should be a requirement for FPSWrs and employers should ensure that FPSWrs have the time to do so. However, if additional supervision is needed outside of these regular sessions, this should also be made available. The supervisors should also receive ongoing training and support (e.g. Mental Health Coalition of South Australia, 2022).



Recommendation 9: Provide FPSWrs with access to regular, appropriate supervision.

• Employ experienced FPSWrs to supervise other FPSWrs. If this can't be done internally, external supervision arrangements can be made through building

partnerships with organisations with a strong track record of employing and/or supporting FPSWrs.

- Provide regular supervision sessions to FPSWrs, ensuring that they are given "protected time" to attend these sessions.
- Provide additional supervision sessions to FPSWrs on an "as needed" basis.
- Ensure adequate supervision, training, and support for supervisors, to enhance their wellbeing and the quality of their supervision.
- Where possible, employ experienced FPSWrs as managers for newer FPSWrs. Where this is not immediately possible, the organisation should work towards this as a long-term goal.

7.10 Integrating Family Peer Support Workers into Mental Health Teams

PSWrs' and FPSWrs' approach to supporting people with MHDs and their families differs considerably from traditional approaches to mental healthcare provision. Though work has been done in recent years to shift Irish mental health services towards more person-centred, recovery-oriented practice, cultural change within organisations and fields is a slow process and much remains to be done. The valuing of lived experience and family member expertise in services is also in its infancy. Historically, the empowerment of the client was not a priority within mental health services, with clients having little choice and say over their care and treatment (Johnstone, 2000; Western Health Board, 2002). With regards to family involvement, clinicians can be reluctant to engage with families, partly due to inaccurate historical perceptions of the family as the universal origin and cause of MHDs (Kuipers & Bebbington, 1990; Nicholls & Pernice, 2009).

FPSWrs and their approach to supporting families challenge these traditional perceptions and attitudes. They go against the status quo in mental health services, which may lead to reluctance among clinicians to accept and welcome FPSWrs into services and teams. Clinicians who hold more traditional views of clients and their families may also not recognise the value of family members' expertise (Tandem, 2015). This is documented within international research and literature. In Cottrill (2011), FPSWrs felt that they are not respected or seen as knowledgeable by other staff as they do not have "those credentials [behind] their name" (p. 16). In Health Workforce Australia (2014), over one-fifth of participating PSWrs and FPSWrs felt that their expertise and knowledge is not valued by their organisation. Garavan (2016) similarly found that clinicians' recognition and valuing of the FPSW profession was a key concern among the FPSWrs working in Bealach Nua.

Some solutions to this challenge have been suggested, with the most common being the provision of co-produced training on FPSW and its value to clinicians and staff at every level of the organisation (Health Workforce Australia, 2014; NHS Health Education England, 2020a; Byrne et al. 2021a; 2021b; Hodges et al. 2022). As per Norton et al. (2023), there may be a need to make this training mandatory for some - if not all - mental health

service staff. Clarity over the role of FPSWrs and ongoing communication, including actively addressing any questions and concerns, is also crucial. To enhance the continuity of this knowledge, the Australian organisation Orygen provides orientation and newsletters on FPSW to all new clinical staff (Leggatt & Woodhead, 2016).

Ensuring that staff in leadership positions are truly committed to FPSW is crucial, as they can then encourage broader cultural change across the organisation and support the FPSWrs (Cottrill, 2011). The HSE Mental Health Engagement and Recovery Office (2023) recognises organisational commitment as fundamental to the provision of PSW and FPSW in mental health services. An overall organisational culture of reflective practice and openness to change will also support the integration of FPSWrs into mental health teams (NHS Health Education England, 2020a). The organisation must value expertise by experience and recognise PSWrs and FPSWrs as a critical part of mental health service provision, rather than an optional add-on or a way to save money or time (Nikkel et al., 2021; National Mental Health Consumer & Carer Forum, 2021; Byrne et al., 2021a; 2021b). Byrne et al. (2021a; 2021b) identified two additional factors as central to supporting a thriving lived experience workforce: co-production across all stages of service planning and delivery, including the sharing of power between lived experience and clinician expertise; and reducing coercive and restrictive practice. Section 4.5.5 and Table 3 provides more guidance on actions that can be taken by organisations to support the development of peer workforces, including FPSWrs.

An additional, interesting suggestion was put forward by Byrne et al. (2021a; 2021b), who proposed the appointment of allies to PSWrs (including FPSWrs) across the service or organisation. Allies are staff who are not themselves PSWrs, but who actively and vocally support and uplift the peer workforce. They advocate for and encourage cultural reform across the organisation and work to remove barriers to the implementation and effective functioning of PSWrs. Byrne et al (2021a; 2021b) provide examples of effective allyship, including actively opposing discriminatory language and practice, crediting and deferring to lived experience expertise where relevant, supporting lived experience leadership, and advocating for lived experience roles at every level. Allies should receive co-produced training on being an effective ally. Handover and continuity of knowledge is crucial.

In sum, organisational readiness is critical to successfully introducing FPSWrs into services. Substantial work must be put into reforming the culture of the organisation, addressing the attitudes of clinicians, and training existing staff on FPSW and its benefits, before FPSWrs are brought into the organisation. While the presence of FPSWrs may further advance these changes and reforms, this should not be the sole responsibility of the FPSWr (NHS Health Education England, 2020a). The organisation must be ready to accept and embrace FPSWrs before they are introduced, such that the FPSWr is not brought into a hostile and unaccepting environment.

Aside from organisational readiness and addressing the barriers to introducing FPSWrs into the organisation, an additional consideration is whether FPSWrs should be part of the multidisciplinary team. International literature doesn't provide clear guidance with regards to this. However, the documents identified through this review indicate that

outside of Ireland, it is commonplace to include FPSWrs on multidisciplinary teams, including in the UK (NHS Health Education England, 2020a; 2020b), in Australian public (Australian Government Department of Health, 2019) and community services (Leggatt & Woodhead, 2016), and in US youth services (New York State Office of Mental Health, 2024). This is in contrast with standard practice in Ireland (GRAMHS, 2022; Garavan, 2016). Within research literature, this is a contentious topic. In Visa & Harvey (2017), participants appreciated the independence of the FPSWrs, who were seen as separate to clinical staff. Clients who had faced negative experiences with clinicians particularly valued this. If FPSWrs formed part of the multidisciplinary team, they may no longer be perceived as independent. In Bealach Nua, some clients felt that FPSWrs should be embedded into multidisciplinary teams to facilitate better communication. Others appreciated their functioning outside of the team and felt that their independence and non-biomedical approach may be compromised if this were to change. The FPSWrs did not wish to be part of the multidisciplinary team at all. The authors of the report agreed that this separation is important (Garavan, 2016).

The risk of compromising FPSWrs' values, approach, and independence is a concern that warrants substantial consideration. However, this also raises an interesting question: should this risk be addressed by keeping FPSWrs out of multidisciplinary teams, or by challenging the organisational culture that creates these risks in the first place? An effective multidisciplinary team should be capable of navigating and respecting differences of opinion and approach. In fact, welcoming diversity of perspectives onto the team may result in better service delivery and enhance each individual team member's practice, by prompting them to reflect on their own perspectives and how they carry out their work. In addition, the presence of FPSWrs on multidisciplinary teams may actually encourage the remainder of the team to reconsider their biomedical stance, rather than harming the FPSWrs' non-biomedical stance. This, in turn, would support broader cultural change in the service, towards a more holistic, person-centred approach to MHDs and treatment. In Hopkins et al. (2021), 28 of the 29 participating clinicians agreed that the presence of FPSWrs led to cultural change within their organisation. The integration of FPSWrs into multidisciplinary teams may also enhance their legitimacy in the eyes of other staff, by placing them on the same level and inviting them to the same conversations as clinical staff. As mentioned, one critical element of supporting the development of the peer workforce is the recognition of PSWrs and FPSWrs as a crucial element of mental health services, rather than an optional add-on. Positioning FPSWrs outside of multidisciplinary teams may signal that they are not an integral part of the service. Separately to the impact on organisational culture and perceptions of the field of FPSW, integrating FPSWrs into multidisciplinary teams may facilitate a smoother transition in the current move from Community Health Organisations to HSE Health Regions.



Recommendation 10: Support the introduction and integration of FPSWrs into mental health services by actively creating an inclusive environment through addressing unhelpful attitudes and cultural factors.

- Provide co-produced training on FPSW, including its approach, unique contributions, and benefits, to all existing staff and clinicians in mental health services. Consider making this training mandatory for some, if not all, staff. Ideally, this training should be provided before FPSWrs are brought into the service.
- Continue and further support efforts to reform Irish mental health services towards a more person-centred, empowering, holistic, and family-friendly approach.
- Continue and further support efforts to meaningfully include the voice of people
 with lived experience and their family members into service design, planning,
 provision, and evaluation. Foster a culture where this is seen as essential rather
 than optional.
- Create roles for people with lived experience and their family members at every level of mental health services, including in leadership positions.
- Explore the possibility of introducing allies to PSWrs and FPSWrs into services. These allies should exist at every level of the service and receive adequate, co-produced training.
- Integrate training and information on FPSWrs into handover and onboarding materials. Any new staff joining the service should understand the role and importance of FPSWrs and be prepared to work alongside them.
- Explore the possibility of integrating FPSWrs into multidisciplinary teams, through consultations with existing FPSWrs, PSWrs, clinicians, family members, and clients of mental health services, considering all potential risks and benefits as well as international practice and research.

7.11 Data Collection and Measurement

Adequate and accurate data collection is a critical element of the development and delivery of any mental health service, support, or intervention. Collecting data on clients who avail of services allows for better understanding of the effectiveness of the service, including who it works for, when, why, and under what circumstances. This carries a range of benefits. The knowledge gained through this process supports continuous improvement of the service by highlighting areas that are working well, those that are not working as well, and where changes can and should be made. Information about clients' demographic characteristics and backgrounds provides insight into the needs of different communities and highlights groups not currently reached by the service. Services can then adapt their work accordingly and target communities which may be unaware of, or reluctant to avail of, their supports. Evidence regarding the impact of the service on

clients can help to secure funding for further service development and expansion. Additionally, if data collection is standardised across services, comparisons can be drawn between services. While these points apply to any form of mental health support, they are particularly important to consider in the context of relatively new, underresearched, and underfunded services and supports, such as FPSW. The importance of data in developing PSW is recognised internationally, for example, by the New Zealand Te Hiringa Mahara: Mental Health and Wellbeing Commission (2023) and the US organisation FREDLA (2016). The HSE Mental Health Engagement & Recovery Office (2023) also names data and evidence as an enabler to the development of PSWrs and FPSWr in mental health services.

Data collection within mental health services can broadly be divided into three categories, which can be extended to FPSW also. Firstly, FPSWrs may collect data on the number, type, and length of contacts they have with their clients. Secondly, demographic data on clients may be recorded, such as their age, gender, country of birth, ethnicity, health status, and others. Thirdly, FPSWrs may ask their clients to complete questionnaires to measure aspects of their wellbeing before, during, and/or after their engagement with the service. Changes in clients' scores on these questionnaires over time provide insight into the impact of the support on their wellbeing.

The first two of these are relatively straightforward and do not carry much additional burden for the clients. Demographic questions may be added to - and often already form part of - intake or registration forms, such that clients are not asked to complete more paperwork. The third aspect may be more challenging. For clients, completing questionnaires can be tiring, difficult, and uncomfortable. In Higgins (2012), participants expressed disliking questionnaires, feeling that they disrupt the flow of the programme and are particularly problematic for people with literacy issues. The very act of using standardised measurement tools in PSW may be seen as going against its nature. Peer support is individualised, based upon the clients' own goals and conceptualisation of their wellbeing, while these tools apply a "one size fits all" approach, where wellbeing is assumed to consist of the same elements for every client. In addition, for FPSWrs, all three of these elements involve additional work. While this work does carry benefits, FPSWrs' priority is supporting their clients, and introducing these additional responsibilities without consideration of their workload and time constraints may lead to burnout. In sum, this creates a challenging dilemma for FPSWrs and the field of PSW as a whole. Comprehensive data collection and measurement tools may harm FPSWrs' work and relationships with their clients, yet without data collection and measurement, services may struggle to secure funding, limiting their ability to continue their work at all.

If client data is collected, a number of considerations must be attended to. With regards to demographic information, ideally, this should be aligned with the Census, so that comparisons can be drawn between the client pool and the wider population. However, certain Census demographic categories have historically been exclusionary and missed certain details, for example, with regards to gender, sex, sexual orientation, and ethnicity (Kennedy & Griffith, 2023; Pavee Point, 2015). As such, services may wish to use an adapted version of the Census categorisation, where certain questions and responses

are expanded upon in accordance with relevant guidance and expertise, to ensure that all identities and backgrounds are represented.

With regards to using tools to quantify clients' wellbeing, the chosen tools must be high quality. They should show good reliability (i.e. consistency, such as whether different items on the questionnaire measure the same underlying concept or whether the questionnaire will return the same score on repeated administration) and validity (i.e. the extent to which the tool truly measures what it intends to measure). Bannigan & Watson (2009) and Bhattacherjee (2012) offer a more detailed discussion of validity and reliability. There exists a wide range of tools for measuring various indicators of wellbeing. It may be helpful to consider some established scales that have been used in other services or research on FPSW. A selection of the measures used in the studies included in this review are presented in Table 4 below.

Table 4. Selection of wellbeing measures used within the research studies discussed in this review

Name	Author	Used in	Description
Brief Symptoms Inventory	Derogatis et al., (1983)	Schiffman et al. (2015) Lucksted et al. (2013)	18-item measure of psychological distress, including anxiety, depression, and somatic (bodily) symptoms.
Experiences of Caregiving Inventory	Szmukler et al. (1996)	Schiffman et al. (2015)	50-item measure assessing family members' perceptions of demands stemming from their relative's MHDs. Both negative (e.g. stigma, difficult behaviours, dependency) and positive (e.g. good aspects of the relationship) experiences are included.
CES Depression	Radloff (1977)	Lucksted et al. (2013)	20-item scale assessing depressive symptoms, e.g. restless sleep, poor appetite, and loneliness.
Family Assessment Device	Epstein et al. (1983)	Lucksted et al. (2013) Mercado et al. (2016)	60-item questionnaire assessing family functioning and relations.
Family Problem-Solving Communication	McCubbin et al. (1996)	Lucksted et al. (2013) Brister et al. (2012)	10-item measure of negative (incendiary) and positive (affirming) family communication patterns.
Coping Orientation to Problems Experienced	Carver et al. (1989)	Lucksted et al. (2013) Mercado et al. (2016) Lobban et al. (2020)	28-item scale designed to assess effective and ineffective ways of coping.
Recovery Attitudes Questionnaire	Borkin et al. (2000)	Higgins (2012)	7-item measure assessing participants' feelings about the possibility of recovery.
Herth Hope Index	Herth (1992)	Higgins (2012)	12-item measure of participants' hopefulness about the future.
Warwick- Edinburgh Mental Wellbeing Scale	Tennant et al. (2007)	Chiocchi et al. (2019)	14-item measure of mental wellbeing. A shorter, 7-item version of this scale, called the Short Warwick-Edinburgh Mental Wellbeing Scale, is also in use.
General Health Questionnaire	Goldberg & Hillier (1979)	Higgins (2012) Lobban et al. (2012)	Extensively used measure of psychological wellbeing. A number of variations exist, containing 12, 28, 30, or 60 questions.
Kessler-10	Kessler et al. (2002)	Brown et al. (2022)	10-item measure of psychological distress, including anxiety and depressive symptoms.
Carer Wellbeing and Support Questionnaire		Lobban et al. (2012) Burke et al. (n.d.)	49-question measure assessing the experience of caring for someone with MHDs, including areas such as relationships, financial concerns, health, stigma, worries about safety, satisfaction with available information, and support from staff.

Source: TASC, 2024.

In addition to collecting data on clients, recording information on the workforce is also valuable. It provides insight into the populations represented and underrepresented within the field. Data on the workforce's needs and experiences may be collected, to inform developments in the services and provision of support to staff. Information on staff

satisfaction can inform initiatives seeking to enhance staff retention, wellbeing, and performance. This is already done in some countries. For example, Australia and New Zealand have conducted a number of nationwide surveys of their lived experience workforce, inclusive of PSWrs and FPSWrs and those working in the CVS (Health Workforce Australia, 2014; Te Hiringa Mahara: Mental Health and Wellbeing Commission, 2023).



Recommendation 11: Standardise data collection methods across all FPSW services nationwide.

- Record the number, type, and duration of FPSWrs' contacts with clients.
- Collect and record demographic data on clients, such as age, gender, ethnicity, country of birth, and disability status. Model these upon Census methods, adapting these to increase inclusivity where needed (e.g. expanding gender and ethnicity categories).
- Explore the possibility, feasibility, and acceptability of introducing quantitative measurement tools (questionnaires) into FPSW services, to monitor the impact of FPSW on clients.
- If such tools are introduced, ensure that the selected questionnaires are valid and reliable.
- If such tools are introduced, take care not to compromise the person-centred nature of FPSW. The goals of FPSW should still be based upon the clients' self-defined wishes, rather than shifting the focus onto improving clients' scores on these measures.
- To supplement the recorded quantitative data, systematically record qualitative information on client outcomes, including various aspects of their wellbeing, available supports, and day-to-day life and functioning. The same information should be recorded for all clients, as much as possible, to allow for comparisons and analysis of the data.
- Conduct regular nationwide surveys of the Family Peer Support Workforce in Ireland, collecting both quantitative and qualitative data on their demographic characteristics, experiences, and needs, and the challenges and positive aspects of their work. This may be expanded to include all PSWrs, including those working with people with MHDs and in CVS organisations.

7.12 Supporting the Support Workers

Considering the wellbeing of a workforce is important in any field, but particularly in the context of peer workforces. While people with MHDs and their family members may be present in any field, career, and organisation, PSWrs and FPSWrs are hired because of

their specific lived experience. With this lived experience come specific difficulties and, with that, specific needs. FPSW is provided in recognition of the unique stressors and challenges faced by family members; FPSWrs face these challenges too. The same barriers preventing family members from availing of FPSW may prevent them from entering FPSW. In Vaswani-Bye et al. (2024), FPSWrs spoke of the high risk of burnout in their role, as supporting families is an emotionally heavy task, especially as a fellow family member. Employers of PSWrs and FPSWrs have a responsibility to ensure that their workforce is adequately supported and that their existing difficulties are not exacerbated by their work. Supervision is one method of supporting FPSWrs, as per Section 7.9. However, this may not be sufficient.

One avenue of supporting FPSWrs involves the provision of adjustments and accommodations, to account for their specific circumstances and, if applicable, their responsibilities with regards to their relative (e.g. National Mental Health Consumer & Carer Forum, 2010). Under the Irish Employment Equality Acts, employers are required to provide reasonable accommodations to people with disabilities. Though this legal responsibility does not extend to family members of people with disabilities, FPSWrs may require similar accommodations to allow them to carry out their role effectively while still supporting their family member and looking after their own wellbeing. In general, employers should accommodate FPSWrs' needs with respect to their family members as much as possible and foster an organisational culture where employees feel safe coming forward with such needs, without fear of discrimination or repercussions. In addition to providing reasonable accommodations as needed and requested, there are certain structures and flexibilities that can be put in place for all FPSWrs, on the basis of the more common needs of family members.

Firstly, offering part-time, full-time, and flexitime contracts for FPSWrs will enhance the accessibility of the role and attract a more diverse workforce. This is recognised and recommended by Health Workforce Australia (2014) and the National Mental Health Consumer & Carer Forum (2010). Family members may have varying preferences and needs with regards to their work hours. Some FPSWrs may need part-time contracts in order to have time to support their relative. Other FPSWrs may need to work full-time for financial reasons, especially if they are financially supporting the person with MHDs. Others may have unpredictable, evolving needs and thus require a more flexible arrangement. Preferences may also vary with regards to specific work hours, with some FPSWrs wishing to work standard office hours and others preferring evening or weekend work. This may even suit clients better as some FPSWrs may then be able to offer out-of-hours appointments, hence increasing the accessibility of their support, as per Section 7.4.

Secondly, providing hybrid working arrangements may be helpful for FPSWrs, especially those who live with the person experiencing MHDs. Some FPSWrs may not be able to come into work in person everyday, particularly if they work full-time. On days when the FPSWrs does not have any in-person appointments with clients, they should have the option to work remotely, using this time to complete paperwork, respond to emails,

attend online appointments with clients, engage in continuous professional development, gather resources for their clients, or any other similar tasks.

Thirdly, in Vaswani-Bye et al. (2024), FPSWrs noted the need for flexibility in their role due to possible fluctuations in their relative's wellbeing and needs. Offering flexible work hours is one element of accommodating this, but another involves the provision of additional leave arrangements. Health Workforce Australia (2014) note that in some Australian PSW services, agreements are put in place between PSWrs and their employers, to plan for the possibility of their mental health deteriorating. They recommend that similar plans are implemented for FPSWrs, in the event that their relative's mental health deteriorates and the FPSWr needs to take time off work to support them. The National Mental Health Consumer & Carer Forum (2010) similarly recommends that additional leave arrangements are provided for PSWrs and FPSWrs, to account for their specific circumstances and their own and their family's needs. It is crucial that the FPSWr can trust that availing of this will not harm their work prospects and that they will be supported in their return to work when they are ready.

Aside from allowing for flexibility and offering accommodations, employers may provide emotional support to FPSWrs, to avail of as needed. The HSE offers an Employee Assistance Programme, which provides free, short-term counselling for all staff. While this is a valuable source of support, employees must ask their employers to refer them to the programme, which may deter staff from availing of the support. In addition, short-term counselling may not be adequate for meeting the needs of family members of people with enduring MHDs. Employers may expand on this service by providing more extensive psychological support, for example, through partnering with CVS organisations or contracting an external psychologist or psychotherapist. Employees should have the option to avail of these supports without needing to inform their employer.

Finally, as noted previously, FPSW is a relatively new field in Ireland that is still very much in development. The number of FPSWrs in Ireland is small and it is rare for services to hire more than one or two FPSWrs. This can lead to feelings of isolation, especially for FPSWrs working in services that are new to PSW and still work from a clinical, illness-centred, medicalised approach (e.g. Norton et al., 2023; NHS Health Education England, 2020a). Health Workforce Australia (2014) note that family members of people with MHDs often already feel isolated, and this is exacerbated when they are additionally isolated in their role as a FPSWr. Establishing a professional network to connect FPSWrs in Ireland may help to alleviate this. This network could be extended to FPSWrs based in CVS organisations. It could take various forms and involve in-person events, online meet-ups, sharing resources, organising educational talks, and even connecting with FPSWrs abroad to learn from and support one another. The network could also provide a collective bargaining voice in advocating for greater investment into FPSWr or other efforts to develop the field further. Offering group supervision could also help to connect FPSWrs with one another, though the challenges of group supervision must also be considered, as per Section 7.9.



Recommendation 12: Ensure that FPSWrs employed in Irish mental health services are adequately supported.

- Provide flexible working arrangements to FPSWrs, including part-time, full-time, and flexitime contracts and hybrid working options.
- Accommodate, as much as possible, any needs that FPSWrs may have regarding their work arrangements, fostering a workplace culture where FPSWrs feel safe disclosing such needs.
- Provide additional leave arrangements for FPSWrs, in the event that they need to take time off work to support their relative experiencing MHDs.
- In addition to any existing Employee Assistance Programme, offer FPSWrs confidential, one-to-one psychological and/or counselling support. Employees should be able to avail of this without needing to inform their employer.
- Establish a nationwide professional FPSWr network, to connect FPSWrs with each other and reduce feelings of isolation. The specific nature and scope of this network should be informed by the needs of FPSWrs and may follow similar international models.
- Regularly consult with FPSWrs to gauge their satisfaction with their role and available supports and gather information on any further structures or supports that may be valuable or needed.

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Appendices

Appendix 1 - Academic Databases Used in Literature Search

Table A1. Academic databases utilised in literature search and their scope

Database	Scope
Bielefeld Academic Search Engine (BASE)	multidisciplinary
Cochrane Library	Cochrane reviews & clinical trials
COnnecting REpositories (CORE)	multidisciplinary (open access only)
Directory of Open Access Journals (DOAJ)	multidisciplinary (open access only)
EBSCO Open Dissertations	Doctoral dissertations
Electronic Theses Online Service (EThOS)	Doctoral dissertations (UK only)
<u>EU Community Research and Development Information Service</u> (CORDIS)	EU-funded research
Google Scholar	multidisciplinary
ISRCTN registry	clinical trials
Open Access Theses and Dissertations	theses & dissertations
PLOS One	multidisciplinary
<u>PsycArticles</u>	psychology & mental health
<u>PubMed</u>	biomedical & life sciences
Science Direct	multidisciplinary
Social Science Research Network	humanities & social sciences

Source: TASC, 2024.

Appendix 2 - Keywords Used in Literature Search

Table A2. Keywords used in academic database searches, organised by theme

Family	Peer support	Mental health
Family OR relative*	Peer support*	Mental health AND (difficult* OR condition*)
Carer* OR caregiver*	Peer mentor*	Mental illness
Partner* OR spouse*	Peer-based	Mental ill-health
Parent* OR mother* OR father*	Peer-led	Mentally ill
Sibling* OR brother* OR sister*	Peer counsel*	Psychosocial disabilit*
Child* OR son* OR daughter*	Peer coach*	(Mental OR psych* OR emotional) disorder*
Cousin*	Peer assist*	Depression OR major depressive disorder OR MDD
Aunt* OR uncle*	Peer-driven	(Mood OR affective) disorder
Grand*	Peer advoca*	Bipolar disorder
	Peer	Eating disorder OR anorexia OR bulimia OR arfid OR binge eating disorder OR ednos
		Personality disorder*
		Anxiety disorder OR social anxiety OR generalised anxiety OR GAD
		Obsessive compulsive disorder OR OCD
		Self-harm OR self-injur*
		Suicidal (ideation OR intent) OR suicidality OR SI
		SMI
		Trauma OR post-traumatic stress disorder OR PTSD
		Addict* OR substance (abuse OR use) OR drug abuse
		Schizoaffective disorder
		Schizophrenia
		Psychosis OR psychotic (symptoms OR disorder)

Source: TASC, 2024.

<u>Note</u>: Asterisks (*) are used as a "wildcard". They substitute an unspecified character or set of characters, thus searching for a range of forms of the word simultaneously (e.g. plurals, conjugations). For example, "mentor*" searches for "mentor", "mentors", "mentorship", "mentoring". "AND" and "OR" are known as "Boolean operators" and, in combination with parentheses, also help in optimising the search. Detailed information on searching academic databases, including the use of wildcards, parentheses, and Boolean operators, can be found here.

Appendix 3 - Organisations and Websites Searched for Literature

Table A3. List of organisations and websites checked in literature search, organised by country and type

Туре	Australia	Canada	Ireland	New Zealand	United Kingdom	United States
	Carer Gateway	Health CAN	Department of Health	Government Inquiry into Mental Health & Addiction	Department of Health & Social Care	Healthy People 2030
	Department of Social Services			Ministry of Health	Health Publications	HHS - Office of the Surgeon General
	Government Department of Health & Aged Care				Office for Health Improvement & Disparities	Idaho Department of Health & Welfare
	Government of Western AU Department of Health				UK Parliament Health & Social Care Committee	Louisiana Department of Health
Government	NSW Health					Maryland Department of Health Behavioural Health Administration
	Queensland Health					Mississippi Department of Mental Health
	Royal Commission into Victoria's Mental Health Services					New York State Office for Mental Health
	South AU Health					North Dakota Health & Human Services
	Tasmanian Department of Health					Office of Disease Prevention & Health Promotion
	Victorian Government Department of Health					Texas Health & Human Services
Networks			South East Family Peer Support Network			Pennsylvania Peer Support Coalition

Туре	Australia Canada Ireland		Ireland	New Zealand	United Kingdom	United States
						Mental Health Technology Transfer Centre Network
	Arafmi	All IN Family	Aware	Able Minds	Action of Postpartum Psychosis	Active Minds
	Beyond Blue	Anxiety CAN	BodyWhys	Familial Trust	Adferiad	American Foundation for Suicide Prevention
	Black Dog Institute	British Columbia Schizophrenia Society	Family Carers Ireland	Family Drug Support	Beat	American Psychiatric Association Foundation
	Breakthrough Mental Health Research Foundation	CAN Alliance on Mental Illness & Mental Health	Grow	Mental Health Foundation of NZ	BipolarUK	Anxiety & Depression Association of America
	Butterfly	CAN Mental Health Association	Jigsaw	Mind & Body (under Emerge Aotearoa Trust)	Blackburn with Darwen	Black Mental Health Alliance
	Centre for Family Research & Evaluation	•		Mental Health & Wellbeing Support	Brighter Futures Together	Brain & Behavior Research Foundation
Non- governmental	Centre of Excellence in Peer Support	Eating Disorders Association of CAN	Mental Health Reform	Supporting Families in Mental Illness	Carers of West Lothian	Child Mind Institute
governmentat	Flourish AU	Family Association for Mental Health Everywhere	Peer Advocacy in Mental Health	Yellow Brick Road	Carers' Trust - Heart of England	Depression & Bipolar Support Alliance
	Grow	Family Smart	Shine		Centre for Mental Health	Families as Allies
	Helping Minds	Helping Other Parents Everywhere			Charlie Waller	Families Together in New York State
	Mental Health AU	Institute for Advancements in Mental Health			Eating Disorders Association NI	FAVOR
	Mental Health Carers AU	Mental Health Research CAN			Jewish Association for Mental Illness	FREDLA
	Mental Health Families & Friends Tasmania	Mood Disorders Society of CAN			McPin Foundation	GEAR Parent Network

Туре	Australia	Canada	Ireland	New Zealand	United Kingdom	United States
	Mental Illness Fellowship	National Network for Mental Health			Mental Health Foundation	Harbour Recovery Centre
	MIFWA	Pacific Post Partum Support Society			Mental Health Innovations	Healthy Minds Network
	Orygen	Parents' Lifeline of Eastern Ontario			Mental Health Matters	Hope for Depression Research Foundation
	SANE	Partners for Mental Health			Mental Health Research UK	Institute for Patient- & Family-Centred Care
	Tandem Carers	Pathways Serious Mental Illness Society			Mental Health UK	Intentional Peer Support
		Peer Connections Manitoba			Mind	International OCD Foundation
		Peer Support CAN			MQ Mental Health Research	Latino Behavioural Health Services
		PeerWorks			National Survivor User Network	Maryland Coalition of Families
		Psychiatric Survivors of Ottawa			North Tyneside Carers' Centre	Mental Health America
		Stella's Place			Props	Mental Health & Addiction Peer Support Services
		Strongest Families Institute			Recovery Cymru	Mental Health Foundation
		Youth Mental Health CAN			Rethink Mental Illness	Montana's Peer Network
					Rollercoaster Family Support	National Alliance on Mental Illness
					TEDS - Talking Eating Disorders`	National Council for Mental Wellbeing
					Together for Mental Wellbeing	National Eating Disorders Association

Туре	Australia	Canada	Ireland	New Zealand	United Kingdom	United States
					United for Global Mental Health	National Federation of Families
					VOCAL	Nevada PEP
					PeerHub	Project Return Peer Support Network
					Scottish Recovery Network	PRS
						The Jed Foundation
						The Kennedy Forum
						The National Child Traumatic Stress Network
						The Steve Fund
						The Trevor Project
						To Write Love on Her Arms
						Treatment Advocacy Center
						Wisconsin Family Ties
						Mad in America
	Carers AU	Family Care Centre	Health Research Board	Health Research Council of NZ	National Institute for Health & Care Excellence	Association for Behavioral Health & Wellness
Public body	Government of Western AU Mental Health Commission	Mental Health Commission of CAN		Mental Health & Wellbeing Commission		Ideas for Kids' Mental Health
	Mental Health Commission of NSW			Te Pou (national workforce centre for mental health, addiction & disability)		National Center for Adoption Competent Mental Health Services

Туре	Australia	Canada	Ireland	New Zealand	United Kingdom	United States
	Mental Health Council of Tasmania					National Institute of Mental Health
	Mental Health Victoria					Peer Support Services Technical Assistance Centre
	National Mental Health Commission					Substance Abuse & Mental Health Services Administration
	NSW Government Agency for Clinical Innovation					MCTAC / CTAC
	Queensland Alliance for Mental Health					National Association of State Mental Health Programme Directors
	Queensland Mental Health Commission					Curated Library about Opioid Use for Decision Makers
	Turning Point Victoria Mental Health & Wellbeing Commission					
	Victorian Agency for Health Information					
	Eastern Health	Fraser Health	HSE HSE Mental Health & Suicide Prevention	Health NZ Community & Public Health	NHS Southern Health Health & Social Care Northern Ireland	Medicaid
Public healthcare provider			HSE Mental Health Engagement & Recovery	Health NZ: Health Promotion	NHS	
					NHS England NHS Wales Public Health Scotland	

Туре	Australia	Canada	Ireland	New Zealand	United Kingdom	United States				
Recovery college			Arches Recovery College		Northumberland Recovery College					
	Dublin North & North-East Recovery College Recovery College South-East			Online Recovery College						
			-		Sussex Recovery College					
			Recovery College West		The Recovery College					
	World Health Organisation									
	Group Peer Support									
	Peers for Progress									
	Mental Health Europe	Mental Health Europe								
International	Al-Anon	Al-Anon								
	Nar-Anon									
	Praxis Care	Praxis Care								
	AU & NZ Mental Health A	ssociation								

Note: The following acronyms are used to refer to countries and regions: "AU" for "Australia(n)"; "NZ" for "New Zealand"; "CAN" for "Canada"/"Canadian"; "NSW" for "New South Wales"; "UK" for "United Kingdom".

Source: TASC, 2024.

Appendix 4 - Research Evaluation Framework

Table A4. Overview of the evaluation framework used to assess research literature sources

			Average scores (N)		
Category	No.	Criterion	54 evaluated studies	38 included studies	
	S1	Are there clear research questions (RQs)?	N/A	N/A	
Carooning	S2	Do the collected data allow to address the RQs?	N/A	N/A	
Screening questions (all research)	S ₃	Can the results of the research be applied in the context of Irish mental health services?	N/A	N/A	
	S4	Did the study receive ethical approval from an established institution? If not, is this justified?	N/A	N/A	
	1.1	Is the qualitative approach appropriate to answer the RQ?	3.78 (32)	3.79 (24)	
	1.2	Are the qualitative data collection methods adequate to address the RQ?	3.53 (32)	3.58 (24)	
	1.3	Are the findings adequately derived from the data?	3.89 (27)	3.93 (21)	
Qualitative	1.4	Is the interpretation of results sufficiently substantiated by data?	3.30 (32)	3.65 (24)	
	1.5	Is there coherence between qualitative data sources, collection, analysis and interpretation?	3.56 (32)	3.69 (24)	
	1.6	Is there consideration of reflexivity and the impact of the researcher on the research (and vice versa)?	1.34 (32)	1.46 (24)	
	2.1	Is randomization appropriately performed?	3.5 (3)	3.5 (2)	
Quantitative	2.2	Are the groups comparable at baseline?	3 (5)	3.5 (2)	
randomised	2.3	Are there complete outcome data?	2.5 (5)	3 (2)	
controlled	2.4	Are outcome assessors blinded to the intervention provided?	3.33 (3)	3.5 (2)	
trials	2.5	Did the participants adhere to the assigned intervention?	2 (5)	2 (2)	
	2.6	Is the application of statistical analyses appropriate?	3.1 (5)	3.5 (2)	
	3.1	Are the participants representative of the target population?	2.81 (8)	2.8 (5)	
	3.2	Are measurements appropriate regarding both the outcome and intervention (or exposure)?	3.94 (9)	4 (6)	
Quantitative	3.3	Are there complete outcome data?	3.14 (7)	3.5 (4)	
non- randomised	3.4	Are the confounders accounted for in the design and analysis?	2 (9)	2.33 (6)	
	3.5	During the study period, is the intervention administered (or exposure occurred) as intended?	4 (8)	4 (5)	
	3.6	Is the application of statistical analyses appropriate?	3.06 (9)	3.42 (6)	
	4.1	Is the sampling strategy relevant to address the RQ?	3.60 (21)	3.69 (16)	
	4.2	Is the sample representative of the target population?	2 (20)	2.2 (15)	
Quantitative	4.3	Are the measurements appropriate?	3.48 (23)	3.62 (17)	
descriptive	4.4	Is the risk of nonresponse bias low?	1.93 (21)	1.93 (15)	
	4.5	Is the statistical analysis appropriate to answer the RQ?	3.15 (23)	3.35 (17)	
	4.6	Is the application of statistical analyses appropriate?	3.22 (23)	3.56 (17)	

	5.1	Is there an adequate rationale for using a mixed methods design to address the RQ?	2.8 (15)	3.14 (11)
Mixed	5.2	Are the different components of the study effectively integrated to answer the RQ?	3.13 (15)	3.59 (11)
methods (qualitative &	5.3	Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	3.3 (15)	3.68 (11)
quantitative)	5.4	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	3.07 (15)	3.45 (11)
	5.5	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	3.03 (15)	3.09 (11)
Additional criteria (all	A1	Is the study co-produced with people with lived experience of MHDs or their family members?	1.42 (54)	1.57 (38)
criteria (all research)	A2	Is the research sufficiently inclusive of vulnerable populations?	1.54 (53)	1.50 (37)

Source: TASC, 2024. Adapted from Hong et al. (2018), with contributions from CASP (2018), JBI (2020), and Ofir & Schwandt (2014).

Note 1: The screening criteria were rated as "Yes" or "No". All other criteria were rated on a scale of 1 to 4, on the basis of whether the research addressed the criterion very well (4), sufficiently well (3), not well (2), or not at all (1). A "Can't tell" option was also provided for all criteria.

Note 2: The following items are not included in the original MMAT and instead were added to adapt the framework to the needs of this review: S3, S4, 1.6, 2.6, 3.6, 4.6, A1, and A2.

Note 3: For the screening criteria, an average score is not reported as these were judged as "Yes", "No", or "Can't tell", rather than receiving a score. For the other criteria, the number in parentheses after each average score shows the number of sources which were evaluated against this criterion, excluding those judged as "Can't tell". The maximum possible average score is 4, while the minimum is 1.

Appendix 5 - Sources Included in Review by Country and Difficulty

Table A5. Breakdown of sources included in literature review by type, country, and difficulty

Tong of differential	Practice documents & literature reviews						Total	
Type of difficulty	IE	UK	US	CA	AU	NZ	Int	Total
All mental health	3	4	14	2	24	-	-	47
Eating disorders	-	-	-	-	3	-	-	3
Schizophrenia	-	-	1	-	-	-	-	1
Addiction only	3	1	2	-	-	-	3	9
Total	6	5	17	2	27	0	3	60

Type of difficulty	Research literature							Total
	IE	UK	US	CA	AU	NZ	Int	Total
All mental health	6	1	9	2	4	2	-	25
Eating disorders	-	-	-	1	1	-	-	2
Borderline personality disorder	-	-	-	-	1	-	-	1
Psychosis	-	-	1	1	-	-	-	2
Psychosis and/or bipolar disorder	-	1	-	-	-	-	-	1
Addiction only	-	1	5	-	2	-	-	7
Total	6	3	15	4	8	2	0	38
GRAND TOTAL	12	8	32	6	35	2	3	98

Source: TASC, 2024.

Note: "IE" refers to Ireland, "CA" refers to Canada, "AU" refers to Australia, "NZ" refers to New Zealand, and "Int" stands for "International", i.e. concerning more than one country.

Table A6. Breakdown of research sources included in literature review by methodology and difficulty

Type of difficulty			Quantitati	Mixed		
	Qualitative	RCT	Non- randomised	Descriptive	methods	Total
All mental health	6	-	3	7	8	25
Eating disorders	2	=	-	-	-	2
Borderline personality disorder	-	=	-	-	1	1
Psychosis	2	=	-	-	-	2
Psychosis and/or bipolar disorder	-	-	-	-	1	1
Addiction only	3	1	3	-	1	7
GRAND TOTAL	13	1	6	7	11	38

Source: TASC, 2024.

Note: "RCT" stands for "randomised controlled trial".





HSE Mental Health Engagement & Recovery







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