

Capturing and Valuing the Views and Experiences of Family Members Accessing Cork/Kerry Mental Health Services



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The project was managed and supported by Anne O' Connor (Head Occupational Therapist), Kerry Mental Health Management Team.

Principal Researcher: Aoife Farrell

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Introduction

The purpose of this document is to present the findings of an Action Research Study into the views and experiences of family members of those accessing HSE Mental Health Services in Cork and Kerry. The research was carried out by Aoife Farrell (Principal Researcher) on behalf of HSE Cork Kerry Community Healthcare Mental Health Services as part of their continued engagement with the Advancing Recovery in Ireland (ARI) Project. The project was funded specifically through Service Reform Fund Phase 1 funding.

Background

According to the HSE Mental Health Division Operational Plan 2017, a major goal in terms of service transformation is to move towards more recovery-oriented ways of working. A key objective in terms of achieving this is to become more centrally informed by the views and experiences of service users and family members.

Under the auspices of the Advancing Recovery in Ireland (ARI) Project, Cork and Kerry Mental Health Services have secured funding through the Service Reform Fund (Recovery Stream) in order to formulate a robust plan to transform services locally. The purpose is to build capacity within and outside of the services, the ultimate aim being to develop and expand upon recovery-oriented services.

Family members/carers/supporters of people who use the service are a group which has been poorly represented to date. Therefore, the focus of this Action Research Project is to hear their views on issues deemed important to them and attempt to respond accordingly in a comprehensive recovery-focused manner.

Aims and Objectives

The primary objective of this Action Research Study is to garner the views and experiences of family members/friends/supporters of those who access the mental health services in Cork and Kerry. It is hoped that, as a result of this process of engagement, the resulting evidence may be used to;

- further understand the subjective lived experiences of family members in Cork and Kerry
- highlight and build upon existing good practice and innovative work with family members in the region
- identify opportunities for further engagement with and support of family members within HSE Mental Health Services
- develop an evidence base for partnership work with family members
- identify opportunities for capacity-building work with family members across the region
- support the inclusion of family members in future development of services

Methodology

Drawing from key principles of the ARI Project and in line with the Operational Plan of the Mental Health Division, this Action Research Study was informed by values of recovery, inclusion and partnership. The methodology comprises both primary and secondary research in order to develop a full understanding of the views and experiences of family members as well as best practice as it pertains to engaging with and supporting this group of stakeholders.

Primary Research

In terms of primary research, the methodology was qualitative by design. A qualitative approach is deemed most appropriate in this instance since it allows for the subjective experiences of family members to be explored. Data collection was carried out by means of a series of focus groups with family members across the region. It is hoped that, through engagement at local level, family members would be facilitated in becoming involved and some of the barriers in terms of access could be lessened. Further rationale for the focus group approach came from the fact that geographical representation would be ensured, essential when covering a large geographical area which comprises various different Community Mental Health Teams across the Cork Kerry Community Healthcare Services.

Secondary Research

In order to contextualise the findings from the primary research outlined above, a review of the relevant literature was also carried out. This secondary research was conducted by means of a literature review examining national and international research around family members experiences. In addition, the secondary research comprised reviewing policy and best practice as it relates to engagement, recovery and capacity building work with family members.

Sampling

The findings presented here are based on a series of focus groups, individual interviews and written submissions collated by the Principal Researcher from May – Sep 2017. Recruitment for focus groups took place through contacts within HSE Mental Health Teams and the sampling was as follows:

Date	Venue	Number of Participants
15.05.17	Kenmare	5
18.05.17	Cork City	12
25.05.17	Tralee	7
31.05.17	Listowel	5
12.07.17	Killarney	7
16.08.17	Dingle	4
31.08.17	Caherciveen	3
14.09.17	Killorglin	4

As is shown in the above table, 46 family members took part in focus groups. Focus groups were semi-structured by means of design in order to facilitate contributions and open discussion from the participants. The schedule was devised in advance by the Principal Researcher. In addition to these focus groups, 6 written submissions from family members were analysed as well as one 1:1 interview.

Findings and Analysis

The focus group and interview data were recorded digitally and transcribed by the Principal Researcher. Subsequently, the views and opinions garnered were collated by the Principal Researcher and arranged thematically for the sake of brevity. The findings and analysis are presented here with reference to relevant secondary research as it pertains to the experiences of family members.

A summary of the key recommendations is given below with a detailed account of the findings and analysis on which they are based presented in the subsequent chapters.

Summary of Key Recommendations

Chapter 1 – The Lived Experiences of Family Members	
1.1	The impacts on family members of supporting someone with mental health difficulties are varied, complex and far-reaching. Services must acknowledge this and respond accordingly with holistic assessments and tailored supports for family members’ health and wellbeing.
1.2	There should be explicit recognition by Mental Health Services of the crucial role that family members play in supporting service users’ recovery journeys.

Chapter 2 – First Contact with Mental Health Services and Basic Information Provision	
2.1	Basic information on service delivery and supports should be provided to family members at first contact with the services and a structured and standardised approach should be taken.
2.2	A designated point of contact should be made available for family members who are supporting an individual using the services.

Chapter 3 – Meaningful Involvement of Family Members in Service Delivery	
3.1	Active partnership and involvement of family members should be promoted, where appropriate.
3.2	Clarity needs to be given to family members and service users regarding information-sharing and confidentiality and the limits therein.
3.3	The benefits of partnership with family members should be promoted and, when consent is given, they should be actively involved in a meaningful way in the service user’s care.
3.4	An information-sharing protocol needs to be established in order to learn from the good practice currently taking place. Distinct options should be made available for service users surrounding consent and information-sharing.

Chapter 4 – Experiences of Overall Service Delivery	
4.1	Good practice currently underway in Acute Units should be recognised and opportunities to standardise support and engagement with family members in this setting explored.
4.2	While staff in acute settings are to be commended for their dedication and support of family members, attention needs to be given to making the buildings/visiting rooms more suitable for visiting family members, especially children.
4.3	A partnership approach to discharge planning must be taken and the importance of communication with family members with regard to discharge is to be emphasised.
4.4	Attention needs to be given to family members’ experiences of involuntary admissions and information and supports should be made available.

4.5	Crisis services and out-of-hours support should be made available for family members and details of how to access these services be shared.
4.6	The difficulties for family members in supporting a service user transitioning from CAMHS must be acknowledged and appropriate supports put in place for the transition period.

Chapter 5 – Family Members’ Unique Support Needs

5.1	Information and Training should be given to family members to build their capacities in terms of supporting service users and understanding their experiences.
5.2	Recovery education and training for family members should be promoted by Mental Health Services and opportunities should be provided for all family members to take part.

Chapter 6 – Community Resources and Family Member Peer Support

6.1	Where supports and services within the community are available, this information should be signposted to family members in order to provide addition pathways for accessing support.
6.2	Stigma is a barrier for family members in terms of accessing supports in the community. Family members as a group should be facilitated in coming together to share experiences in a recovery-focused manner.
6.3	Peer support as a recovery initiative for family members should be embraced and nurtured by Mental Health Services and made more widely available to family members seeking support.

Chapter 7 – Planning Future Engagement

7.1	In terms of planning future engagement with family members, services must be cognisant of the barriers which are experienced, especially the (perceived or otherwise) impact of stigma and the lack of flexibility of services.
7.2	A culture change within the organisation is required in order for family members to be involved in a meaningful way and it is fundamental that management within the HSE are supportive to that end.

Chapter 1 – The Lived Experiences of Family Members

At the outset of this report, it is necessary to contextualise the findings in the unique lived experiences of family members who support/care for individuals experiencing mental health difficulties. Therefore, Chapter 1 will explore the impact of the supportive role on the lives of family members.

Research has shown the crucial role that family members play in supporting a loved one with mental health difficulties (Kartlova-O'Doherty *et al.*, 2006). However, it has been recognised that this role is not always fully recognised or valued by Mental Health Services (Royal College of Psychiatrists, 2013). It is therefore essential that the lived experiences of family members are understood by services in order to respond effectively in supporting this group.

1.1 The impact of supporting someone with mental health difficulties

Supporting a loved one through mental health difficulties can be a rich and rewarding experience and love, compassion and commitment to their family members' wellbeing were expressed by participants throughout the series of focus groups. However, mental health difficulties affect the whole family; relationships, work, finances, one's sense of personal freedom, recreational life and the mental and physical health of the family unit (Baronet, 1999). Many of these negative impacts were highlighted throughout the focus groups and are described by participants below. Emotional difficulties were the most discussed in terms of impacts, with primary experiences being stress, anxiety and fear.

- *'stress, a lot of stress. At one point I got sick...I ended up in hospital because of the stress levels of it'*
- *'I felt awful. I felt like I was two people. That took so much energy, it was unreal like'*
- *'I don't think we ever felt worse in our lives and helpless, absolutely helpless'*
- *'exhausting, frustrating and it's extremely isolating, you're very alone'*
- *'I find fear the biggest thing, you can never switch off the fear'*
- *'it's very difficult, it's overpowering. It's emotional, physical, financial, mental. Well, I could maybe get over the financial if I could have some kind of peace'*

- *'I mean it's changed everything. The worry. The not knowing, not knowing what the future holds. Tough times. None of us ever anticipated this'*
- *'I said to the doctor last week 'at the rate things are going here now, you'll have me as a patient!' I get depressed.*
- *'our family, we've had a lot of problems but out of all of it, I think out of all the things we've had this is the hardest. Your helpless. You're lost. My mother sees it, my sister sees it, my children see it. We're all mad about [family member] but the transformation in him is heart-breaking'*

Studies have shown that there are negative health implications for family members as a result of their supporting role. Research has found that family members in the UK are three times more likely to report ill-health, including mental health difficulties, than the rest of the population (Singleton *et al.*, 2002; Princess Royal Trust for Carers, 2011). From the selected quotes above, it can be seen that there is a considerable impact on family members, especially in terms of their emotional and mental wellbeing. It is imperative that the increased risks are acknowledged and fully understood in terms of responding appropriately with support.

1.2 Feelings of being depended upon

In addition to the impacts on health and wellbeing, the data from the research also show that many family members felt that their loved one was completely dependent upon them, which resulted in a loss of self for many participants;

- *'it's life changing because you don't have your own life anymore. You just don't have your own life. You're a carer, basically a carer to another adult person'*
- *'it's a constant worry, it's always there'*
- *'It's like still having a child because you still have that high dependency whereas they are adults now and intelligent and competent people but they still need somebody there with them all the time making sure that they are okay'*
- *'you don't sleep, you don't eat. It's just that you can't cope yourself...I felt I was doing everything wrong'*
- *'it's all-consuming really. It's a full-time job for the last couple of years. That's it. What more can I say? There seems to be no support'*

Specifically, many family members pointed to the lack of public transport as a factor, especially in rural areas, which added to the feeling of being depended upon for driving the service user to appointments and other activities.

Furthermore, concerns were raised by family members over what would happen to their relative if and when they themselves were no longer able to support them;

- *'what's going to happen to himself when myself and [spouse's name] disappear? That's a huge worry'*
- *'if I'm not there, if his father is not there – who is going to look after him? And that's heart-breaking and I suppose we shouldn't be thinking that far ahead but...you do as a parent'*
- *'you'd be saying to yourself – 'what's going to happen when we're away for a weeks holidays?' It's in the back of your head all the time when you are on holidays'*

In a 2008 study, Care Alliance Ireland found that family members/carers presented 'a considerably less positive picture of life compared to the general population' (2008; 4), with experiences of stress, anxiety and depression common amongst respondents. Certainly, many participants in this study presented a less positive picture of life for themselves and, as detailed below, the impacts of this spread to the wider family unit.

1.3 Impact on the whole family

Furthermore, the impact on the wider family was identified, oftentimes resulting in negative effects for other family members and challenging family dynamics.

- *'you see it's a family situation, it's not one person at all'*
- *'oh wrecking. My husband is wrecked from it. We're all wrecked from it. His siblings are wrecked from it. We're all heartbroken like, you know'*
- *'[other family member] got a stroke out of it...it's the stress they can't deal with'*

The impact on the overall dynamic of the family was also highlighted, with particular reference to siblings and children within the family;

- *'her siblings are younger so I guess they're not as aware. They feel that she is sucking up a lot of my attention and it's very difficult for them, it's not fair. You're always going to help the one that needs the help most'*
- *'very difficult in the house, it puts a lot of pressure on the family. It's hard to deal with. It's like the elephant in the room'*
- *'it upsets them [other children], they find it very hard to handle. I'm trying to keep the bright side out on the phone and they think that [family member] is better she is and then when they come home they realise she is not. It's very difficult for us'*
- *'It changes the family dynamic, it takes up a lot of my time as well. I have other children. You can't help blaming yourself, blaming things that might have happened, you always try and find something to blame'*
- *'And I've two daughters and it affects them too. They'll say 'you'll travel 20 miles to sort that problem [for service user] and I'll come next'*

Lack of support for siblings was a theme which emerged throughout the focus groups and an issue that was particularly concerning for parents. Conflict within the family as a result of the aforementioned stress and feelings of being depended upon was also named as a challenge. Participants suggested a need for training in this area to equip them with knowledge and skills. This will be discussed further in Chapter 5.

1.4 Isolation and the lack of social supports

Throughout the series of focus groups, attention was also drawn to the stigma (perceived or otherwise) which was experienced by family members. This, oftentimes, resulted in difficulty drawing on informal family or community supports which exacerbated feelings of isolation and loneliness.

- *'you can't be burdening your friends with it too, day and night. You want to keep your friends too and not make them sour'*
- *'and then you feel sometimes that you don't want to be talking to them all the time either because they'd say 'Christ would she ever stop going on and on and on...'*
- *'Me looking for support personally? I felt like this is his life and I can't talk to you about his problem...I didn't feel like it was my place...I didn't feel I could give his problem to my sister or my best friend, I didn't know what to do'*

- *'my neighbours are burnt out from listening to me over the years. We were very very upset over the years and I used to be emotional with them but you can't be emotional all the time. They'd say 'oh, here she comes again!'. So now when they as I say 'thank you , I'm okay'*

There is a need for Mental Health Services to recognise the considerable and far-reaching impacts on family members as a result of supporting their loved ones. As can be seen from the sections outlined above, family members feel a considerable impact on their own lives as a result of supporting someone who uses the services. The findings would suggest that there is a need for recognition of and support around difficulties such as;

- Stress, fatigue and emotional strain
- Personal health and wellbeing
- Social isolation, stigma and a lack of supports

Recommendation 1.1: The impacts on family members of supporting someone with mental health difficulties are varied, complex and far-reaching. Services must acknowledge this and respond accordingly with holistic assessments and tailored supports for family members' health and wellbeing.

1.5 Lack of recognition for the role

Family members can be a rich source of knowledge and expertise in terms of supporting the service user's unique recovery journey. It has been recommended that there is an 'explicit recognition of the crucial role of carers' needed from Mental Health Services (Royal College of Psychiatrists, 2013; 4). These sentiments were echoed throughout the Research Study, for example;

- *'what's not recognised I think is that the consistency of care is sitting at this table. That's where the consistency of care is. You're attending meetings. You're there every day. It's that consistency of care that's not recognised by the system'*
- *'the fact that families walk that journey. We all walk that journey so recognition of that [is needed]'*
- *'Another thing is taking the family for granted. We were basically told 'ah well, we know that she has good family support at home, that's why we haven't been doing as*

much' We were told that in this very building and at what cost to us? But they don't care'

- *'it's vital that they [services] do listen because we know them best. How do they know? 10, 15minutes talk to someone – how can you assess them? Now I know that they're very good at noticing whether they are psychotic or whatever; they're this, they're that and the other but like...they are not listening to us [as family members]'*
- *'seems like the more you do, the more they...I hate to say take advantage but it feels like that...they take advantage of the situation and then you feel like you should do less so the trained professionals will do more. But then, are you doing a disservice to the patient?'*
- *'they need to come out into the community and see what life is like on the front line'*

In 2012, research was carried out in West Cork into the experiences of family members supporting someone who experiences mental health difficulties. As has been found here, isolation and a lack of recognition for the role were highlighted as major concerns for participants (West Cork Carers Support Group, 2010). In order for Mental Health Services to engage meaningful with family members, there needs to be a recognition of the role they play in supporting the service user's recovery and general wellbeing.

Recommendation 1.2: There should be explicit recognition by Mental Health Services of the crucial role that family members play in supporting service users' recovery journeys.

Chapter 2 – First Contact with Mental Health Services and Basic Information Provision

The onset of mental health difficulties within a family can be a time of fear, confusion and distress. Therefore, first contact with mental health services is seen as a crucial time for family members in terms of accessing support. This chapter will present the findings from the Research Study with regard to first contact with the Mental Health Services and the experiences of general communication with Mental Health Teams. Following on from this, Chapter 3 will discuss more specific engagement/structured involvement of family members in relation to the service users' support and treatment.

2.1 First contact with services and basic information provision

Research has shown that family members' first contact with mental health services can be a time of 'shock, devastation, uncertainty and vagueness with regard to what was happening to their relative' (Kartlova-O'Doherty *et al.*, 2006; 185). The fundamental need for basic information, especially when mental health difficulties first emerge, was highlighted by participants in the focus groups;

- *'from my perspective, they need to explain immediately in layman's terms to the family everything we don't know; the likely outcome and everything we have to try. At least then you've got buy in from the beginning'*
- *'[on lack of available information] only thank goodness for Google and the internet, that's the only way I can stay informed. I am very much isolated...'*
- *'We just feel clueless I suppose because we don't have the medical experience'*
- *'What I have a little quibble with the HSE around is there's not a whole lot of information or pamphlets out there...we'd no information. We'd no leaflet to tell us what to look out for, we'd nothing to tell us what the signs were...there was no one to talk to, there was no one to go to for preventative advice, there's nothing'*
- *'a frank discussion [is needed] at the beginning of an illness as to expectations of an outcome'*
- *'you're trying to find out information and you go back over it again and you say, 'I did so many things wrong' and if I had done it right would I have caught it more in time.... I didn't understand'*

- *'I'm fully convinced if we had a better input 10 years ago...if we had input in the very beginning, if we hadn't let him shrink his whole world...so information very early on [is what's needed]'*
- *'I wouldn't even have known that this service [day hospital] was available and I live in the town'*
- *'sure, if I don't know it's there, I can't use it, simple as that. And then you hear it's there and you wonder...It's not like I go around with my eyes closed'*

These findings have shown a lack of knowledge and understanding by family members in terms of both the experience of mental health difficulties and how the Mental Health Service operates. Clearly this adds to the stress and confusion at what is a difficult time. However, in the cases where support and information were received by family members during first contact with the services, the responses were extremely positive;

- *'I think the team did a lot in the beginning to really encourage us and to give us a guide. It was about acceptance and that we have a right to be upset too'*
- *'we've met Occupational Therapists, we've met psychologists – you could name them all! Every type of 'ologist' has been involved in providing insight into my [family member's] care and it's a phenomenal experience to come up here [service] or to get a phone call'*
- *'advise from the professional staff on the patient's wellbeing [has helped]. What is going on for them within the unit of the hospital and advise on what we can do at home to help'*

The experiences above highlight the shortcomings and inconsistency of the services with regard to providing basic information to family members. Information around mental health difficulties, how the service operates and what supports may be available should be provided to family members as standard upon first contact with mental health services.

Recommendation 2.1: Basic information on service delivery and supports should be provided to family members at first contact with the services and a structured and standardised approach should be taken.

2.2 Communication with Service Providers

Following first contact with Mental Health Services, family members will usually attempt to engage with service providers to access further support and information. Research has found that that open and trusting communication with service providers was highly valued by family members (Kartlova-O'Doherty & Tedstone Doherty, 2006).

Throughout the Research Study, evidence was found of many positive engagements for family members with HSE Mental Health Services. Moreover, many participants spoke with high regard for many individuals with whom they have contact, especially in the case whereby there is a designated person whom they can call for support and information;

- *'[service provider] she's very on the ball, she's level, she can ring saying 'this is what happened today, isn't it great that this happened'. She provides a great service'*
- *'the [community service provider] was amazing. When I was away I could ring her and see how he was. There was nothing formal, she was just super, super, super at her job. And you do meet individuals who are just amazing'*
- *'[community nurse] was a great support in many ways. You could ring him, you could discuss everything with him. He was very caring for his patients but he's retired and that's not happening anymore'*
- *'[nurse's name] would have gone beyond the role to be as supportive...was doing more than what I think the HSE would define the job as'*
- *'[nurse's name] is a saint. You know the way we are just sitting here talking, you can talk away to him. I suppose they are very encouraging. When things are going good they really praise [service user] and they even say to myself that I am doing great and whatever. The encouragement is great'*
- *'[nurse] comes with his tablets and I'd know her locally. She would ask if there was any trouble and I'd be able to tell her'*
- *'the fact that you can pick up the phone and discuss your fears, concerns and success with the patient's carer [service provider] is invaluable'*

The findings here would suggest that, at an informal, individual level, family members value contact with trusted individuals on Mental Health Teams. However, as acknowledged by participants, there seem to be little by the way of formalised/structured routes of engagement. This challenge was recognised by some participants;

- *'what I think is lacking, something that we need is not something exceptional or temporary. I think it's something more permanent and maybe more often'*
- *'I'm trying to care for my [family member] so I'd like to think that there was somebody there to help me when I can't approach him or whatever'*
- *'one worker that you know that you can trust and say 'look I've a bit of a problem here' and they could say 'I'll be there'*
- *'well if I knew who to communicate with! [service provider] has retired. She used to ring every now and again and we could meet but I haven't heard anything now in two years'*
- *'there's no one you can turn to really'*
- *'to be fair the staff are very nice. It's the protocol that's the problem'*

In terms of guiding policy, a key recommendation in *A Vision for Change* is that 'a member of the multi-disciplinary team to act as a keyworker/designated point of contact [for family members] with the team' (2006). There is a strong case therefore, for standardising the examples of good practice outlined above which are currently taking place. In accordance with policy and best practice, and as noted in family members' reflections, a designated contact person would be seen as an extremely useful support for family members.

Recommendation 2.2: A designated point of contact should be made available for family members who are supporting an individual using the services.

Chapter 3. Meaningful Involvement of Family Members in Service Delivery

As the previous chapter has shown, contact with the Mental Health Services, especially having a designated contact person within the service, is seen to be an extremely beneficial support for family members. This chapter will move on from that to discuss more structured and meaningful involvement of family members as active partners supporting recovery.

3.1 The benefits of involving family members

As outlined in the previous chapter, family members who have contact with mental health services consider it to be valuable in terms of accessing support and information. Moreover, involvement of family members has shown to have positive outcomes for service users and reductions in hospital admission rates (Pharoh *et al.*, 2006; Fadden, 1998). In addition to general contact and information-seeking, however, participants spoke of the importance to themselves of being involved in a more structured and meaningful manner with service providers;

- *'all the family [should be] involved. If you just look at the patient, you're not having the whole picture and I think the family should work together'*
- *'I think it would have been very valuable for us all to sit down so that we were all on the same page but that didn't happen at all'*
- *'inclusion, inclusion, inclusion – we're not asking for much, we're just asking to be included. They want us to drop them at the door, they want us to pick them up, they want us to collect the medicine, they want us to do the dry cleaning but they don't want to include us'*
- *'It would be nice to have more consultation and involvement. Not necessarily every appointment or anything like that but if there was a review or something...it would be good to have family members' input. It would just help me to support [family member]'*

As noted by participants in the Research Study, involvement with the services may support and encourage family members in being active partners in their relative's recovery. If family members are made feel part of an individual support system, they can

be empowered as an active partner in the individual's recovery and encouraged to continue giving practical and emotional supports outside of the services. Furthermore, meaningful involvement of family members, where appropriate could be beneficial in terms of their own wellbeing; lessening the fear and confusion and promoting positive strategies for supporting their loved one.

Recommendation 3.1: Active partnership and involvement of family members should be promoted, where appropriate.

3.2 Confidentiality and Information-Sharing

In terms of moving towards more meaningful involvement and partnership with family members, issues surrounding confidentiality and information-sharing need to be addressed. Participants in this Action Research Study, for the most part, recognised the importance of confidentiality between service users and their Mental Health Teams;

- *'[communication] in an open situation. Not in a 'I'm going to tell tales to the psychiatric services!' [laughs]. In a much more open sort of a way where we are all there to support each other'*
- *'I'm not going to have my speak in a meeting unless my [family member] says nothing. The meeting is between his doctor and him but I am very keen to get involved in anything that would help him at home'*

However, some data garnered from the focus groups would suggest that there is a lack of clarity surrounding confidentiality, resulting in frustration and confusion for family members;

- *'the confidentiality thing is tricky but I think its rooted in medical confidentiality and I'm not sure how appropriate that is for mental illness...the other thing is the veto by the patient. The patient can say no I don't want this person to know and that's the issue closed. But very often the patient is not in a position to make a helpful judgement'*
- *'the last time he was in hospital there and he wanted me to stay with him when the doctor came in and they said no. The doctor was coming in and [family member] goes 'can my mam stay in?' and they said 'no, we'd prefer if she waited outside'*

- *'I feel like standing up on a box sometimes and shouting to the world 'what is this thing of confidentiality?'*
- *'we're very happy with the psychiatrist except for the fact that he hasn't enough confidence in us to speak with us'*

Service providers are bound by law and professional codes of ethics to a duty of confidentiality to service users. It is imperative that this duty is upheld. However, from some of the responses given above, it is unclear as to whether there is a full understanding and clarity for family members around this issue. It is essential, therefore, that confidentiality and consent are understood fully by all stakeholders; service providers, family members and service users. Clarity needs to be given to families around the importance of confidentiality and the right to privacy and autonomy for service users.

Recommendation 3.2: Clarity needs to be given to family members and service users regarding information-sharing and confidentiality and the limits therein.

3.3 Meaningful Involvement and Partnership with Family Members

Through involvement with the Mental Health Team, family members can provide information and insights which could greatly assist in supporting the service user's recovery. In the instances where service users have given consent for their family member(s) to be involved, participants found the opportunity to engage with the Mental Health Team as extremely beneficial;

- *'straight away I think the most important thing is communication. We're very fortunate in that [family member] has allowed us to be part of his care. When you meet any service provider, he allows us to hear his progress and what has been happening with him and this is a massive support for us'*
- *'it would be horrendous for us if he didn't give consent. We would be in a dark hole...you have to do battle, it's not an easy ride'*
- *'we found the team to be very open and approachable, we're very involved, it's helpful'*
- *'we have the benefit of meeting with the Mental Health Team and our daughter and ourselves. We found that helpful...before that we felt excluded and remote...Once communication was set up, we felt a lot better about things. Now it didn't solve all the*

problems but it certainly helped to feel that there was some connection there and feeling not quite so lost'

It is clear from the quotes above that participants in the Research Study were extremely enthusiastic and appreciative when given the opportunity to become involved. Moreover, proactive moves on the part of the team were recognised and valued by family members;

- *'the team got us involved. They would have said it to [family member] who said it to us to come back so it was definitely the team. They want to get us involved and obviously we would do whatever it would take'*
- *'they do seem enthusiastic about meeting the family...they do seem to want to get the family involved and that's very important because obviously these are the people who have to care for the person, live with the person'*
- *Here I must say with the group and the team and everything he has, they really do involve the family...I can sit in on the meetings, they will ask [service user] how things are going for him, they will ask me how things are going. They'll continuously inform me of what changes are made to the medicine, what they are going to do next and they are continuously talking'*
- *'well I suppose there now with [nurse's name] and the team, [doctor's name] and everything – they way they communicate with us and they tell us straight. Right up front, it's amazing and I'm right in the centre. I must say thanks be to god and hopefully it'll keep going that way'*

It is clear that good practice is being carried out by teams in terms of centrally involving family members in the delivery of services. Since a vast swathe of research shows that outcomes are improved when family members are involved, the benefits of involving family members should be discussed and promoted with service users, where appropriate.

Recommendation 3.3: The benefits of partnership with family members should be promoted and, when consent is given, they should be actively involved in a meaningful way in the service user's care.

3.4 Consent and sharing information

As mentioned above, issues around confidentiality and information-sharing are often seen as a problem area when it comes to the inclusion of family members. The findings from the Research Study show that, when a service user chooses not to give consent, this can be an extremely difficult experience for family members;

- *'that's what we found very difficult at the beginning; the psychiatrist saying 'he's an adult and what goes on here is confidential'*
- *'I've been shut out totally'*
- *'the care plan was written by them. We had no comeback. We were railroaded and whatever we said wasn't listened to'*
- *'we went to the doctor recently and asked him could we meet him, just him and he said no way, we couldn't'*
- *'we don't have contact. The only thing is every six months [family member] has a review and she doesn't want us to attend the review. The psychiatrist when you ask him says 'your daughter is an adult, you don't need to be there'. They seem to be overusing the confidentiality clause, I think it's being overused in this day and age...we feel we could support her better if we could discuss her case with her team and that's not allowed'*

While the right of service users to privacy and confidentiality is fundamental, it has been argued that the confidentiality clause has been 'abused' by service providers to avoid (inevitably time-consuming) communication with family members (Royal College of Psychiatrists, 2013). However, in negotiating this tricky situation, innovative and supportive practice was identified by participants in the Research Study;

- *'I went in [to family member's GP] and he said to me he couldn't discuss [family member] with me but he listened to me for an hour of me telling him what I thought. Now he couldn't exactly tell me what to do but he listened'*
- *'the nurse is great, you can communicate. I called her the last day and I told her such and such a thing and she said; 'you can tell me whatever you want but I can't talk to you' which is fair enough. I understand that she has to have some privacy'*
- *'we don't want to know the deep, dark secrets, they [service providers] can be dealing with that. I'd rather not know. But in general terms and overall safety is what we're looking at...I just want to know that she's okay'*

As is evident above, opportunities have been taken by service providers to support and listen to family members, even in the instance when consent has been refused by the service user. This was found to be very beneficial to family members.

Recommendation 3.4: An information-sharing protocol needs to be established in order to learn from the good practice currently taking place. Distinct options should be made available for service users surrounding consent and information-sharing.

Chapter 4 – Experiences of Overall Service Delivery

Following on from family members' communication and engagement with the Mental Health Services, Chapter 4 will present a summary of participants' experiences of overall service delivery. The most predominant themes emerging from the Research Study in this regard were around Acute Inpatient Services, Admission and Discharge Planning, Crisis Services, and transfer from CAMHS to Adult Services. The findings and analysis are presented below.

4.1 Positive Experiences of Acute Inpatient Services

In general, this Research Study found that the experiences of Acute Inpatient services as reported by participants were overwhelmingly positive. High regard was especially given to hospital staff with family members noting their interactions with service providers in acute settings as extremely supportive;

- *'in that hospital, which I'd never have wanted the child to go, it's the best thing that's ever happened for him and for me'*
- *'[hospital] is very good now in fairness. It's a depressing place; god help us avoid it if you can! It's a very depressing place but I must say the staff there were very very good. Absolutely A1. I will say that for them. They are more than what you would call nurses. It's a dedication'*
- *I could not get over how kind they were in the unit, the new part. All young staff and they were so professional and so kind. Kind. Kind went a long way for me and respectful towards the person. The dignity of the person I felt was maintained'*

Participants put specific emphasis on the interactions with staff and how open communication and a willingness to engage with them as family members were seen as very supportive at that time;

- *'the way he was being treated [worked well] sure I didn't know how to treat him! Over there everything felt more normal and he was looked after so well with his medication and the nurses and doctors there and they all had time to speak to me. They all spoke openly to me over there in the hospital. It was the best thing that ever happened'*

- *'the security of the hospital and how he was treated there. He wasn't molly-coddled and he was challenged. And the support of the team there and that I could actually see them at any time'*
- *[[family member] spent a lot of time in hospital – 8 months last year. They've never refused to meet us. They would meet with [[family member] first and then they would meet with me. They have met me on my own, they have met my family. Now we've asked for those...'*

Recommendation 4.1: Good practice currently underway in Acute Units should be recognised and opportunities to standardise support and engagement with family members in this setting explored.

4.2 Areas for Improvement

Notwithstanding the examples of good practice in hospital settings which were highlighted by family members and outlined above, some areas for improvement were also recognised by participants in the focus groups. The predominant focus in terms of possible improvements to acute settings was around the appearance and upkeep of buildings and making the setting more 'family friendly'. Examples of responses are as follows;

- *'it's just the building, the paint work and everything...above in [private hospital] they put the papers in every day the way that people can go in and read the papers. Small things like that, simple things; a few paintings'*
- *'would drag a normal person down never mind a person with problems. It should be bright and colourful'*
- *'honestly the staff makes up for it, that's the only consolation. No point in having a beautiful building if...but it is a pity you can't have both'*

Furthermore, attention was drawn to the unsuitability of the setting for children who may be visiting family members in hospital.

- *'inside in the hospital and I'm thinking of the children. They are seeing very sick people when they need to see their mother or father or whoever is there belonging to them. Give them a little place because they are seeing very unwell people...i think children and teenagers should be protected from it'*

- *'just a little space over there for children. A couple of toys or whatever, a colouring book'*
- *'it's not family friendly. It's cramped. If you had a young family, avoid it. Which is terrible because if you are the patient, you need to see your family and have contact with them'*
- *'the communal area was very dreary and very kind of... open...there's no little spaces that you could just go and sit in a room maybe. And the nature of the illness, people can be loud, clients can be loud'*
- *'when you come out of the psychiatric ward having visited the patient, you need somewhere to go and have the biggest cry of your life. It's horrendous'*

Recommendation 4.2: While staff in acute settings are to be commended for their dedication and support of family members, attention needs to be given to making the buildings/visiting rooms more suitable for visiting family members, especially children.

4.3 Discharge Planning

As noted above, family members' experiences of hospital settings were mostly positive, due in no small part to the commitment of staff. However, some challenges were identified by family members in terms of navigating inpatient settings. One of the areas which proved most problematic for family members was discharge planning.

Throughout the series of focus groups, participants identified discharge from acute services as particularly challenging from their experiences. From a policy perspective, recommendation 7.8 in *A Vision for Change* states that; 'protocols and policies should be agreed locally...particularly around discharge planning' (2006; 66). The extent to which protocols have been agreed upon locally is unclear and family members' involvement (or lack thereof) in discharge planning was identified as a key concern for participants;

- *'I would have huge issues around it [lack of discharge planning] because my [family member] was involuntarily admitted for years and then he's just left out with no communication with me whatsoever. He'd walk home or take a taxi. No one cares about his situation at all - who's there or anything like that. Happened umpteen times'*
- *'[upon discharge] we realised that our family member wasn't fit or proper to be sent out the way they were and basically, we had no choice...it was unfair on her, it was*

unfair on us...they came out on a Friday and they were back in on the Sunday. They shouldn't have been let out of the hospital in the state they were in... we couldn't advocate for the patient...we as family members could do nothing. We had no say'

- *'no contact [following discharge]. My [family member] came out after 9 weeks inside in hospital. No health nurse, no community nurse, nothing. I'm the only one. I've no family. I'm the only one. I kept telling them that but there was nobody contacted me for a solid two or three months'*
- *they were like 'there you go now, take her home'. I said 'can you explain to me, can you give me details?' and they said 'sorry, it's confidential'...what am I supposed to do? I am her main carer'*

The Mental Health Commission (2009) recommends the development of an information sharing and discharge protocol around discharge from hospital which would include discharge planning at the earliest opportunity following admission. Discharge from hospital is identified as a time when service users are 'at risk' in terms of their recovery (Crawford, 2004) and a time when supports within their families and communities play a crucial role. Therefore, the importance of comprehensive and inclusive discharge planning cannot be overstated. Family members often play a crucial role in supporting the service user following discharge and appropriate communication with them in a tripartite approach would optimise recovery outcomes for service users as well as supporting the family member.

RECOMMENDATION 4.3: A partnership approach to discharge planning must be taken and the importance of communication with family members with regard to discharge is to be emphasised.

4.4 Involuntary Admissions

The experience of involuntary admission can be a very distressing time for families and an area where sensitivity and support for family members must be prioritised by Mental Health Services.

- *'I find with involuntary admissions it's all the paperwork. The person was let out again after two weeks and he had to be readmitted and I had to go through the whole rigmarole again of the paperwork. It's there, it's in the system! It's time-consuming and you repeat the same thing over and over and over. It's like being Garda vetted over and over again'*
- *'afterwards that [involuntary admission] can come back – 'you signed me in like!'*

Most participants in focus groups were unclear about the procedures surrounding involuntary admissions, the role of Authorised Officers and the use of emergency services. While a thorough examination of these procedures is beyond the scope of this report, suffice to say that support and information systems for family members with regard to involuntary admission need to be improved.

Recommendation 4.4: Attention needs to be given to family members' experiences of involuntary admissions and information and supports should be made available.

4.5 Crisis Supports

For obvious reasons, times of crisis can be particularly distressing for family members and an instance when they might need specific support from Mental Health Services. The need for crisis supports was identified by participants in the Action Research Study;

- *'you'd want a name and a number to call somebody. You can't be calling someone that you'd only be annoying. There has to be someone there who would answer the phone and tell you what to do'*
- *'there was one time he got a fit at home and I rang up one of the social workers that I used to have because I didn't have any other number. He was in the fit and I didn't know what to do so I rang her up and she was at some meeting in Cork and she was giving out to me for ringing her up. I thought he was dying like!'*
- *'an out of hours service would be very good. We have to ring South Doc and call out all these medications over the phone...if we had someone – a dedicated mental health crisis person that would be able to deal. Every other service has it, GPs have southdoc. Every other service seems to have back up'*

No clear picture has emerged from the focus groups as to the breadth and availability of crisis supports for family members, with some participants expressing confusion and a lack of understanding around what might be available to support them;

- *'I wasn't aware there was such a thing as a crisis nurse'*
- *'we'd call to GP I suppose, that's what you'd do I suppose. That's what we did when [family member] was suicidal, we called the GP and he said 'come over straight away'*

In terms of interactions with crisis-specific supports, experiences from family members' points of view were as follows;

- *'So the crisis team came out...they said there's no real need for us to be here so we're going to head. Didn't give me a leaflet, nothing, just left me. I said I actually do need help because I think this is bigger than just me and they said 'if there's any issues just go back to A & E'*
- *'I rang the crisis nurse, no answer on the phone. There wasn't even 'if in emergency, contact GP, contact hospital whatever...' there was nothing, absolutely nothing. There was no one covering for an entire weekend...I needed help here. There was no one, absolutely no one listening to me. I felt like crisis nurse? I don't know what that means because there was no help for me'*

Family members' experiences here are echoed in research reports which have highlighted the need for crisis supports for family members (Kartlova-O'Doherty *et al.*, 2006; Mental Health Commission, 2005). It would seem that there is a lack of consistency in terms of designated crisis supports for family members who participated.

Recommendation 4.5: Crisis services and out-of-hours support should be made available for family members and details of how to access these services be shared.

4.6 Transfer from CAMHS to Adult Services

Many participants in the Action Research Study had the experience of supporting their family member to transition from Child and Adolescent Services (CAMHS) to Adult Mental Health Services. This experience was considered extremely difficult, especially for parents who frustrations included;

- *'it goes from 100 miles an hour to zero, overnight, on their birthday'*
- *'you feel you have the ear of professionals [in CAMHS] but then that stops and you are left wandering again and then you get into the adult service which for people who are only just 18 is a very difficult experience'*
- *'[family member] turned 18 recently and she was transferred from CAMHS to adult services. It went from me having to do everything for her; health wise, medicine wise, to not being involved, not even being consulted. And that happened overnight. There was no transition, none whatsoever...I understand that my [family member] is 18 but this didn't start when she was 18, this started when she was younger, when she was a child and I had to be involved...so the transition period was horrendous'*
- *'5 months previous I had to do everything for her [sobbing]. I had to log her medicine, I had to put the knives away, I had to do everything for her and now they're not telling me anything...[trails off crying]'*

According to research, a positive transition from CAMHS to Adult Services is rare (Paul *et al.*, 2013) and this certainly seems to be the case from the perspective of family members who took part. These difficulties must be acknowledged at policy level and during service delivery with appropriate supports put in place for family members.

Recommendation 4.6: The difficulties for family members in supporting a service user transitioning from CAMHS must be acknowledged and appropriate supports put in place for the transition period.

Chapter 5. Family Members' Unique Support Needs

In terms of moving forward and supporting family members in a meaningful and recovery-focused manner, it is imperative that their support needs are fully understood. Chapter 5, therefore, will present the findings from the Research Study regarding the unique recovery needs of family members.

Oftentimes the support of the service user can be the sole focus of interactions with the services and family members' considerations of their own recovery needs and wellbeing can be non-existent. For example,

'we know that initially a carer is likely to be far more interested in helping you [as the worker] to deliver a good service to the person that they care for/about rather than considering their own needs' (Avon & Wiltshire NHS, 2011; 2).

This phenomenon was observed throughout the series of focus groups with participants tending to focus on the service user's treatment within the service rather than their individual support needs;

- *'I could do with about a hundred years of counselling but I have to take solace in the fact that the user has great support'*

Notwithstanding this phenomenon, however, many participants in the focus groups identified the need for support for themselves;

- *'I don't expect the doctor to be able to fix him but I expect for me to be able to get help to be able to tolerate him'*
- *There was mindfulness with the nurse but that was focused on patients, not family members. So what about trying to reach family members as well?*

Counselling and the availability of respite services were also identified as potential supports for family members' own recovery needs. Furthermore, access to training and education was highlighted throughout.

- *'training would be brilliant'*
- *'that's what we need actually'*

Participants in the focus groups described the specifics of what might be useful to them as regards content for training and education. These fell into two broad categories;

- 1) understand the experiences of their family member and respond appropriately
- 2) develop their own coping strategies, interpersonal skills and build their resilience

The following sections discuss these needs in more detail.

5.1 Training around how best to support the service user

In terms of what they felt was needed from the services, many participants sought advice from professionals on how best to support their family member's recovery journey. For example;

- *'we want to know what we can do to help our family members...help us to help them manage their mental health'*
- *'all this work that you are getting at home from families is not being channelled appropriately. If families were educated up [it would be helpful]'*
- *'We're not trained to deal with someone who is in a psychotic episode. I'd be the first to admit that. I don't know what I'm doing. Am I doing the right thing? Am I doing the wrong thing? Is there a right thing, a wrong thing? Give us some bit of training. We came in here asking for training and we're being fobbed off'*
- *'we want training. We basically want training. We want to be taken, even if it's only for a day, where we will be trained to deal with their mental health'*

When asked to make some suggestions on the specific content of the training, family members put forward some of these learning needs;

- *'Understanding the diagnosis and everything like that. I think that could be done with more access to training and information. Shine puts on some good stuff on that sort of thing. That you are developing your own information and insight'*
- *'what I would like as well is to have meetings like this but to have a psychiatrist, psychologist, social worker and a nurse at the meetings'*

- *'we want to know what we can do to help our family members that is outside of a drug regime'*

There is a clear stated need for information and training for family members with regard to understanding mental health and responding appropriately with effective support.

Recommendation 5.1: Information and training should be given to family members to build their capacities in terms of supporting service users and understanding their experiences.

5.2 Recovery Education for Family Members

It must be noted, however, that in addition to concerns for the service user, there was a burgeoning awareness that family members themselves had unique recovery needs.

- *'the family has to be looked after. I mean the nucleus, the group has to be looked after. That's the actual most important thing to get them into a room like this with somebody kind'*
- *'It's very important because we are supporting the patients and if we are not well...we are having our struggle and we are having the struggle and the suffering and the pain of our family members as well'*
- *'something that would give us family members more tools in how to deal... It would give us more resources and maybe would make us feel more solid and would give us more strength'*

In terms of specifics of what might be useful for recovery education for family members, a lot of the suggestions were around understanding and managing their own emotional reactions.

- *how do you separate your own emotions from this? How do you take out your own emotions, plonk them in a chair and just go around and deal with this person as a patient...any bit of training they could give us at all over time'*

- *'the other feeling I have is guilt. I feel like 'what did I do wrong?' I thought I was the best mother that ever walked this earth. I can't figure at all...'*
- *'when I'm interacting with [service user] I think 'well I should have said something else'. All of this goes through my head a few hours afterwards; 'maybe I should have said something else, that set him off' or 'could I have done something else?' and that is a bit of guilt'*

In addition to understanding emotions, family members also felt that it would be beneficial to be trained in specific coping strategies, boundaries and supporting younger family members;

- *'Something that sounds so simple as techniques for managing stress. I live in permanent stress and I'm sick all the time...managing techniques for stress and anxiety'*
- *'the boundaries I find very difficult with mine'*
- *'definitely one of the biggest stresses for us was how to sort of hold the family unit together emotionally with a certain amount of stability'*
- *'we need support from the Mental Health Services around how to communicate with children about it'*
- *'what age do you bring children in on it if it is their parent or sibling or whatever? There's two younger brothers and they haven't been told but sure they know, they must know like'*

Family members who had previously engaged with training and recovery education spoke of the multiple benefits it has had for themselves personally and their relationships within the family;

- *'we were invited to take part in the DBT education programme. That was helpful because it filled in a lot of the blanks in our knowledge...so the patients did the Endeavour programme and the families had a kind of summary version; a 12 week programme so that we could have an understanding of what our loved ones going through and that was very helpful'*
- *'For me what's helped along the way is that I've done a lot of personal development work and in times of crisis when I think that I am about to break, I can rely back on that so having awareness. So, I do think it's important that you have opportunities to look at personal development and strengthening yourself and resilience and awareness... okay you are doing your best for your relative but that through awareness and personal development courses you can regain that sense of yourself'*

- *'I went to Aware, they have an awful lot of leaflets and information. I went up to Cork four weeks in a row for support that they had for families at the time. It was difficult but I was able to be open and the facilitators were very good and I did find that good. It was a kind of a condensed programme*
- *'my biggest problem was that I was trying to fix and I was told by my psychologist after going to her a few times 'the biggest thing with you now is that you're trying to fix and you will not fix' That was a hard thing [to hear] but it was a good thing in some ways because I try to remind myself I can't fix [service user] even though I thought I could'*

The benefits of recovery education and training for family members cannot be overstated and the overwhelming majority of participants in the focus group expressed a willingness to engage, should such programmes become available.

Recommendation 5.2: Recovery education and training for family members should be promoted by Mental Health Services and opportunities should be provided for all family members to take part.

Chapter 6 - Community Resources and Family Member Peer Support

Much of the research shows that the vast majority of family members feel that supports from the Mental Health Services for themselves are inadequate (NSUE, 2010; 2011, Waterford Parents and Carers Research and Advocacy Group, 2006; Royal College of Psychiatrists, 2013). With a ubiquitous 'lack of resources', staff shortages and increasing pressure on services, it may be necessary to draw from community resources and other supports for family members which may be available outside of the mental health services. Chapter 6 will examine the use of community resources by family members and the potential benefits of Family Member Peer Support Programmes.

6.1 Community Resources for Family Members

Throughout the Research Study family members noted the importance of community-based, early intervention and support for themselves;

- *'I think that all the people here have suffered a lot and there's a lot of trauma. I think what's needed is not to get to this point...they should be in the community and they should be compassionate for family members and they should be much earlier'*

Some participants were accessing informal supports within the community which was found to be beneficial;

- *'our GP was very good to point us in the right direction. She was good for support'*
- *'I have had great support from the Family Resource Centre...absolutely amazing support. I got free counselling. All the people are happy and willing to help if you ring and if you ask for help'*

However, it was surprising to find that a majority of participants had little or no knowledge of where to go in the community for support or how to access support from voluntary organisations etc. There were suggestions from family members that service providers might have a role in signposting them to these services;

- *'one other suggestion is that the person involved in supporting the family would be able to say 'well, this person or this service, organisation or group' If people are given an official referral, they are far more likely to attend'*

- *'if [professionals] could say 'I think this would help you if you went along to that' because there is no one central point where you can get information like that. You are more or less out there in the darkness feeling your way around and it could take a year or two before you find something that could help'*

There are (to varying degrees locally) a number of community resources and voluntary organisations available outside of statutory services which may of be assistance in meeting family members' support needs. Participants in general showed a considerable lack of awareness of such services, although a willingness to engage was evident. There may be some scope for formalised partnership working between Mental Health Service and the Community/Voluntary sector in order to signpost/refer family members for support, should the service lack capacity to provide this.

Recommendation 6.1: Where supports and services within the community are available, this information should be signposted to family members in order to provide addition pathways for accessing support.

6.2 Barriers to accessing informal supports

During the series of focus groups, attention was drawn to the impact of stigma surrounding mental health difficulties on family members.

- *'there's still hiding and embarrassment. People say it's more open now and less stigma but there's not because there are people who are in [local town] who could be at this meeting but they're not here because they don't want to say they were here and that's stigma'*
- *'there's a terrible stigma attached to mental health. Well we have got better but we've a long way to go...I suppose people are getting better but what do we do? We google things? Because where else do you go? Which is the worse thing you could ever do'*
- *'there's no point in talking to people who haven't got the problem themselves'*

Stigma was seen as a factor which reduces the help-seeking behaviour of family members. However, it was recognised by participants that through engaging with people who had a shared experience (ie. other family members), this barrier could be overcome. Many

participants valued the experience of taking part in the focus group since it was their first opportunity of sharing their story and meeting others with similar experiences;

- *'this is my first time now talking like this and now I kind of feel like 'oh there's other people!' [laughs]. We're all in the same boat'*
- *'this is the first time I've actually spoken about it and I find it good'*
- *'even sitting, like this, around a table and talking to other families that are going through the same thing and I suppose you pick up information from other families, even sometimes to talk to somebody'*
- *'even like here this evening – it makes you realise there's so many people suffering with mental health in their family and you're not alone in that'*
- *'I find it good too. If I meet any of ye out now I can say 'well how are you doing?'*

The effects of stigma are a barrier for family members in accessing support and contribute to feelings of isolation and stress, as documented in Chapter 1. A 'safe' space to share their experiences with others was found to be useful for family members in terms of accessibility and openness to discuss their recovery needs.

Recommendation 6.2: Stigma is a barrier for family members in terms of accessing supports in the community. Family members as a group should be facilitated in coming together to share experiences in a recovery-focused manner.

6.3 Peer Support

As a more formalised approach to sharing experiences, peer support in mental health has been growing in prominence internationally and nationally over the past number of years. While peer support groups for people who experience mental health difficulties are now commonplace, a trend is emerging for peer support for family members also. While many participants did not use the language of peer support, there were many responses which suggested the need for such a model for family members;

- *'if you met other people, you could compare notes and say...you're not the only one'*
- *'there's so many patients that come here every week. Every one of them has two or three family members. Is there not something that can be organised here?'*
- *'I think there should be meetings like this for families, just like this with a facilitator. It can get very emotional because everyone is upset but if there's a neutral person in the room that's kind'*

Peer support is an empowering vehicle through which family members can support each other in a mutual, recovery-focused manner. Some of the participants had previous experience of peer support groups, of which they spoke with high regard;

- *'the most supportive part of it is I think we all understand each other's problems whereas other people who haven't been through it don't have that same insight. To me that's a very big part of it so when you talk to people you know they are listening and that they understand'*
- *'it's very painful but at the same time I think it's beautiful what we are doing here [in the peer support group] and also I have felt a lot of support from this group and it has made a difference'*
- *'I attended a group in Talbot Grove which was a concerned persons group for family members of persons with a drink problem and I thought it was brilliant. I got huge support there. There's a group up the country and it's for family members in mental health and it's fantastic. They have wellness days and workshops and I think it would be wonderful if we could bring it to Kerry'*
- *'it [the group] gave me energy, it made me stronger, listening to other people's stories'*
- *'this group here saved my sanity' [many agreeing]*
- *'I think this group – all of us have helped each other so much. Just to be here and to come in and rant'*
- *'we're not a group anymore, we're a family. I love every one of these people here, we're a family'*
- *'we can't solve each other's problems but we can certainly listen to each other. We do learn and we do feel comforted. As ugly as it is, let it out. We've all got our versions of pain and ugly and this is a safe place'*
- *'this group saved my sanity. It helped me with my process and taught me how to step back. The group helped me with that'*

The positive feedback here from family members who had experience of various peer support groups speaks for itself. Furthermore, in a climate of scarce resources and increasing pressure on services, it presents an extremely cost-effective way in which families can be supported.

Recommendation 6.3: Peer support as a recovery initiative for family members should be embraced and nurtured by Mental Health Services and made more widely available to family members seeking support.

Chapter 7 – Planning Future Engagement

It is hoped that this report has given some insights into the views and experiences of family members of those accessing mental health services. Chapter 7 will examine some considerations to be made as plans for future engagement are made.

As regards future engagement with the Mental Health Services and opportunities for capacity-building as a group, family members expressed an overwhelming willingness to engage further. However, there can be challenges in implementing and sustaining meaningful work with family members. Barriers have been shown to include; a lack of recovery-oriented services, lack of staff, time and resources and a lack of continuity and uniformity of services across different areas (Kartlova- O'Doherty, *et al.*, 2006).

7.1 Family Members Perspectives

Participants in the Research Study, for the most part, noted improvements in how Mental Health Services supported and engaged with family members. In terms of future engagement with the services, participants in the Research Study had the following suggestions;

'in my humble opinion, it's just inviting and offering the opportunity to gather people every week. Just having the space, a neutral space so that people don't feel 'I'm being seen'. Just having a space where we could share. Share not only conversations but we could, for example, bring healthy food, snacks and just gather as a family. It doesn't have to have a title, just gathering'

In terms of capacity-building, the previous chapter has outlined some of the suggestions as regards training and recovery education needs for family members. As has been shown, there is an eagerness to gather as a group for both support and to develop a collective voice in order to improve supports and services. Barriers were identified however in terms of organising collectively. For example;

'there's a stigma as well about coming out as a group. A lot of people would say 'oh you know let's support the reduction of fossil fuels in the environment' and that's very good because everyone accepts that's needed. But if we stood up and said our children have suffered from this, it's terrible'

In terms of planning future engagement also, it is important that considerations are made regarding people who are working and unable to attend meetings during the day. As this participant puts it;

'I suppose the main stumbling block is that the services are Monday to Friday, 9 to 5 and for young people like ourselves, we work. We can't take time off work to meet these people. What about evening times or weekends? That's when we could engage and help out. Work is kind of a stumbling block...need to be more flexible'

Therefore, a flexible approach to working with family members needs to be taken in order to promote engagement and overcome some of the access barriers mentioned above.

Recommendation 7.1: In terms of planning future engagement with family members, services must be cognisant of the barriers which are experienced, especially the (perceived or otherwise) impact of stigma and the lack of flexibility of services.

7.2 Organisational Commitment

There is a responsibility on the organisation also to promote meaningful work with family members at all stages of service design and delivery. While notable improvements have been made over the last number of years (see for example, Partnership for Change (2017), the establishment of the Office for Service User and Family Member Engagement and the continued roll-out of the Advancing Recovery in Ireland (ARI) Project), challenges continued to be experienced in terms of the overall commitment of the organisation to change in this regard. Leggatt (2011) has pointed out some of the challenges as follows;

1. Work priorities; family work being seen as an 'add-on' or extra task. It is not core business and not integrated with case management and other responsibilities.
2. Stressful periods in mental health work (particularly acute crisis) take precedence over family work, which can then be neglected.

3. Case loads are considered too large; there is not enough time for service users, let alone families.
4. High staff turnover. Where staff have been trained, people have left their jobs and moved elsewhere, resulting in failure to maintain the work unless more staff are trained.
5. Workers who want to work with families experience a lack of support, especially from middle management.

Similarly, the Mental Health Division Operational Plan 2017 has identified the following as a key risk in terms of its delivery; ‘the challenge in achieving the culture change required to move to genuinely recovery focused services with full service user, carer and family members involvement’ (2017; 6). Therefore, as well as the recommendations outlined above for services locally, there must be an organisational commitment to the inclusion of family members in Mental Health Services.

Recommendation 7.2: A culture change within the organisation is required in order for family members to be involved in a meaningful way and it is fundamental that management within the HSE are supportive to that end.

Chapter 8 – Concluding Remarks

8.1 Additional issues arising

Due to the limitations of this small-scale research study, a thorough analysis of every issue raised, is beyond its scope. While the above Chapters present a thematic arrangement of the primary findings, a number of further issues for participants were raised and may be summarised here as follows for the sake of brevity;

- Participants concerns around the overuse of medication and a lack of choices/holistic approaches to treatment
- The further exclusion of friends who support someone accessing the services
- Difficulties in having medical cards renewed and the added stress that this brings
- The lack of public transport in rural areas as a further barrier to accessing services

8.2 Opportunities for further development

From the findings presented in this report, it is clear that there have been many progressive steps taken by individual service providers and Mental Health teams in terms of supporting and including family members. As has been noted, however, this seems to be taking place in an ad hoc manner and is perhaps the result of the particular practice approaches of individuals rather than a systematic approach of the services in general. Nonetheless, these improvements should be celebrated and, as documented throughout this report, the examples of good practice which have been found should be acknowledged and expanded upon.

Furthermore, some of the findings documented here present considerable opportunities for further development and innovation in family support work and inclusion of family members in HSE Mental Health Services. The recommendations given throughout this report serve as a starting point from which meaningful change can be realised. Building on good practice currently being carried out and learning from the evidence presented here, there is a need for ‘action steps’ to be derived from the recommendations in order to translate these into practice.

For example, there may be the opportunity to develop from this point a Family Support Strategy proposing practical steps on *how to* improve supports and services for family members. Drawing from the findings documented here, policy and best practice guidelines, such a piece could serve as a 'road map' for partnership with and involvement of family members with HSE Mental Health Services. Further recommendations around what might be included in such a strategy are as follows;

- In collaboration with HSE teams, the development of family members' needs assessments and recovery plans to be used by service providers,
- Development of information-sharing protocols and information sessions on understanding consent and confidentiality,
- Further development of the suggestions around training and education for family members; a thorough examination of learning needs and proposed for content and the development and delivery of such training,
- Training around peer support for family members and the possibilities of developing a peer support network in the region.

There is a clear commitment from many of the service providers and the broader ARI Project to recovery principles and the development of innovative practice in partnership with service users and family members. While further action is required in order to develop and expand upon the recommendations outlined, it must be noted that there is enormous potential for improvements in how services respond to family members and for capacity-building with the group.

Bibliography

Avon and Wiltshire NHS (2011) *Good Practice Guide: Confidentiality and Information Sharing with Friends, Relatives and Carers*. Mental Health Partnership NHS Trust.

Baronet, A. (1999) 'Factors association with caregiver burden in mental illness: A critical review of the research literature' in *Clinical Psychology Review*, Vol. 19, No. 7; 819 – 841.

Care Alliance Ireland (2008) *Health and Wellbeing of Family Carers in Ireland*. Dublin: Care Alliance Ireland.

Crawford, (2004) 'Suicide following discharge from in-patient psychiatric care' in *Advances in Psychiatric Treatment*, Vol. 10, No. 6; 434 - 438

Daniels, A., Grant, E., Filson, B., Powell, I., Fricks, L., & Goodale, L. (2010) *Pillars of peer support: Transforming mental health systems of care through peer support services*. Christchurch: University of Canterbury.

Department of Health (2006) *A Vision for Change*. Dublin: Stationery Office.

Fadden, G. (1998) 'Research Update: Psychoeducational Family Interventions' in *Journal of Family Therapy*, Vol. 20; 293 – 309.

Health Service Executive (2017) *Mental Health Division Operational Plan 2017*. Dublin: Department of Health.

Henderson, J. (2001) 'He's not my carer – he's my husband': personal and policy constructions of care in mental health' in *Journal of Social Work Practice*, Vol. 15, No. 2; 149 – 159.

Hynes, *et al.* (2008) *Between Worlds: The Experiences and Needs of Former Family Carers*. Dublin: Trinity College Dublin.

Kartlova-O' Doherty, Y. & Tedstone Doherty, D. (2009) 'Satisfied Carers of Persons with Enduring Mental Illness: Who and Why?' in *International Journal of Social Psychiatry*, Vol. 55, No. 3; 257 – 271.

Kartlova-O' Doherty, Y., Tedstone Doherty, D. & Walsh, D. (2006) *Family Support Study: A Study of Experiences, Needs, and Support Requirements of Families with Enduring Mental Illness in Ireland*. Dublin: Health Research Board.

Leggatt, M. (2011) 'Families as Partners in Mental Health Care' in *New Paradigm*, Summer 2011, Victoria: Psychiatric Disability Services of Victoria.

Machin, G. (2010) *Carers and Confidentiality: Law and Good Practice*. Available from: <http://www.mhcarers.co.uk/EasySite/lib/serveDocument.asp?doc=7086&pgid=7218>

[Mental Health Commission \(2009\)](#) *Code of Practice on Admission, Transfer and Discharge to and from Approved Centres*. Dublin: Mental Health Commission

National Mental Health Consumer and Carer Forum (2011) *Privacy, Confidentiality and Information Sharing – Consumers, Carers and Clinicians*. Canberra: NMHCCF.

National Service User Executive (2010) *Second Opinions Report*. Dublin: NSUE.

Paul, M., Ford, T., Kramer, T., Islam, Z., Harley, K. & Singh, P. (2013) 'Transfers and transitions between child and adult mental health services' in *British Journal of Psychiatry*, Vol. 202; 36 – 40.

Pharoah, F., Mari, J., Rathbone, J. & Wong, W. (2006) 'Family Intervention for Schizophrenia' in *Cochrane Database of Systematic Reviews*, Volume 4.

Pilgrim, D. (1999) 'Who Cares?' in *Openmind*, Vol. 98, No. 15.

Royal College of Psychiatrists/ REFOCUS (2013) *Who Cares? Listening to the needs and experiences of carers of people with mental illness*. Dublin: College of Psychiatrists.

Waterford Carers and Parents Research and Advocacy Group (2006) *Every Mother's Son: Summary report on the needs and responses of families working to remove barriers in caring for adult children and family members with mental health difficulties*. Waterford: Waterford Carers and Parents Research and Advocacy Group.

West Cork Carers Support Group (2012) *Time to Care, Time to Live – The Situation and Experiences of Family Carers/Support Persons in West Cork*. Cork: West Cork Carers.