GIVING VOICE TO FAMILY AND FRIENDS IN MENTAL HEALTH

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Research Project Team

The project team was set up to draw upon a range of diverse expertise and perspectives. Although some members of the team were involved in the project on a short term basis, their contributions are much appreciated.*

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Thank you to the two mental health teams who agreed to take part in this project. At the time this project began in early 2013, the involvement of families and friends was at its infancy in St Vincent’s Hospital Fairview and HSE Dublin North City and the teams who participated took a risk in inviting critique and being open to hear about how they and their services were perceived by families and friends.

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Research Project Team.

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Glossary of Terms

Community mental health team (CMHT)	A Community mental health team (CMHT) comprises different professionals responsible for delivering mental health services to a specific geographical area
DCU	Dublin City University.
DNC	Dublin North City.
Eolas	A peer and clinician led mental health information programme on recovery from the experience of mental health difficulties, designed for service users identified as experiencing schizophrenia and bipolar and their families and friends.
Holistic assessment	Assessing all aspects of an individual's needs, ensuring they are seen as a whole i.e. physical, social, psychological, spiritual.
HSE	Health Service Executive.
Iatrogenic	Unfavourable response or effect resulting from contact or treatment with clinician.
Integrated Care Plan (ICP)	A documented set of goals and strategies based on the assessed needs of a service user and developed through the co-operation and co-ordination of the individual service user, family members/friends and professionals.
Inter-rater reliability	The degree of agreement across different researchers.
Marino Clontarf CMHT	A HSE Community Mental Health Team providing services within the Clontarf area.
Marino Tolka CMHT	A HSE Community Mental Health Team providing services within the Marino/East wall.
Morbidity	The incidence of a health condition or illness.
Multidisciplinary	A range of professionals from diverse training backgrounds e.g. psychology, psychiatry occupational therapy, and nursing working together towards a common goal.
Northside Carers' Group	A support group for family members and friends of individuals with mental health issues in North Dublin

	run by SHINE. Contact person: Susan Mc Feely, Regional Development Officer, tel. 086 852 5221.
Psycho-educational	An educational approach to helping people understand more about their mental health, allowing them to become more empowered in its management.
Psychosocial	The interaction and development of an individual's psychological characteristics e.g personality, within their social environment.
Re-integration	The introduction of an individual back into their community, following a time of withdrawal due to care.
Rehabilitation Team	A specialist multidisciplinary team focused on the process of recovery from a mental health illness, towards an individual service user's optimum level of functioning.
SHINE	Shine is the national organisation dedicated to upholding the rights and addressing the needs of all those affected by mental ill health, through the promotion and provision of high-quality services and working to ensure the continual enhancement of the quality of life of the people it serves. Tel: 01-860 1620.
SVHF	St. Vincent's Hospital, Fairview.
Transcribed Verbatim	Typing an audio recording word for word.

Executive Summary

- *A Vision for Change* recommends that family and friends[1] who support a person with mental health difficulties are included in all levels of mental health service.
- Due to the complex nature of their support role, family and friends can experience symptoms of psychological and physical stress, compromising their wellbeing and their ability to provide support for the person with a mental health issue.
- Supporting a person with mental health difficulties plays an important role in the person's recovery.
- While family and friends frequently provide the majority of support and care to relatives with mental health difficulties, they are often excluded by mental health services and indeed at times are perceived as part of the problem.
- This research study is a collaborative partnership between families, friends and professionals to explore and promote the involvement of family and friends in SVHF and HSE DNC mental health services.
- The research project began in early 2013 and concluded in late 2014 and involved 20 family and friends, representing 12 families, and a team of researchers from SVHF, HSE DNC, DCU and SHINE.
- The family and friends who participated had relatives attending either the Rehabilitation team or the Marino Tolka CMHT in the HSE DNC area, many of whom also were associated with the services of SVHF.
- There were 5 phases in this Action Research project.
    - Phase 1: Two focus groups were held with family and friends to a) illuminate their experiences of providing support to a relative with mental health difficulties b) describe their experiences of involvement with mental health services and c) identify their needs. Data were analysed using Thematic Analysis from which the key theme conceptualised as "The experience of caring is nightmarish and challenging" emerged. This captures the significant difficulties and, at times, the horrifying experiences participants have in their caring role and in their involvement with mental health services.

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[1] Although the term carer is commonly used in reports, it is a term that excludes some people (Molyneaux et al., 2011.) as many people who provide substantial support do not identify with the term and thus do not respond to efforts to engage them (Kutner, 2001). This study uses the term family and friends to describe people who view themselves as providing significant physical, emotional, domestic or financial support to a person with a mental health issue.

Phase 2: A meeting with family and friends to feedback the findings from the focus groups, to identify their needs and plan an intervention to address the identified needs.

Phase 3: Meetings with each of the two Mental Health Teams who participated in the project to present the findings. The teams reflected on and acknowledged the perspectives of family and friends and considered ways to improve their involvement with family and friends.

Phase 4: Delivery of a psycho-educational and psychosocial intervention for family and friends to promote self-care and wellbeing and to provide practical information about resources within the mental health services and within the community. Feedback was also given on the response of the teams to the findings from phase 1.

Phase 5: Evaluation of the research project. This indicated that family and friends a) valued participating in the project, b) felt they had an opportunity to voice their experiences and concerns, c) felt they had been listed to, d) appreciated the more collaborative involvement between themselves, their relative and services that had commenced, e) were availing of, more opportunities to have their own needs supported by the mental health services f) were availing of opportunities to work alongside services to promote initiatives and service developments.

- Recommendations:
    - The mental health services make opportunities available for family and friends to meet together for support and information.
    - The mental health teams routinely provide service users, family and friends with information about the services available within the mental health services and signpost other services that may be of interest e.g. SHINE, Northside Carers' Group, etc.
    - Local community mental health and specialist teams provide service users and family and friends with information about local resources, for example, adult education, recreational / employment etc.
    - The mental health services actively encourage service users to include family members or friends as collaborators in their care and treatment.
    - Mental Health teams form collaborative partnerships with family and friends from the start of a person's involvement with the mental health services, as appropriate.
    - The mental health services supports programmes, such as Eolas, which targets both service users and family members and friends.

- The recommendations are applicable across all community and inpatient mental health services and offer valuable learning in the development of collaborative and recovery orientated services in Ireland.
- The report also outlines positive service wide developments that have taken place that supports the involvement of carers and their impact, in particular the Eolas Programme.

Introduction

Giving Voice to Family and Friends in Mental Health Services is a report on a collaborative research project focusing on the involvement of family and friends in SVHF and HSE DNC mental health services. The report describes the background to the project, how the research was conducted, the findings of the research and the recommendations and conclusions arising from it.

Background

Eleven percent of Irish people have direct experience of mental health difficulties (HSE, 2007), which impacts on family, friends and local communities. Supporting and caring for a person with mental health difficulties is important as recovery is associated with the availability and quality of social supports and close relationships (Watkins, 2007 cited in Gordon, 2010), and the level of re-integration into the community (Barker, 2009 cited in Gordon, 2010). However, supporting a family member with mental health difficulties is a complex and challenging process (Veltman et al., 2002) and many family and friends find themselves thrust into a supporting role with little choice (Rethink, 2003) and no preparation (Chien et al., 2004).

Karp and Tanarugsachock (2000) suggest that family and friends who have a relative with mental health difficulties experience a number of turning points in their 'carer career', each of which stimulates a strong emotional response. Initially when their relative shows unusual behaviours they recognise that something is different but are often unsure about what is happening. This is typically a time of uncertainty, fear and confusion. When their relative receives a diagnosis there is often a period of confusion as they try to be compassionate and caring towards their relative and also feel angry and resentful about the diagnosis and its consequences. Typically when family and friends begin to realise the enduring nature of their relative's condition they are confronted with profound grief and sadness. Accepting that they did not cause the problem, cannot control or cure it, but can cope with it, is often the point where they are able to reduce their level of involvement without feeling guilty and may be able to develop a sense of admiration for their relative who is struggling.

Family and friends also find themselves having to navigate mental health systems and deal with professionals who are not always eager to have them involved. Askey and colleagues (2009) describe how the move from predominantly hospital based care to the community has increased the amount of care provided by family and friends. They note that this has resulted in less informal contact between family and friends and professionals, especially for those whose relatives have acute or enduring mental health difficulties and at times has resulted in family and friends feeling that their needs are neglected and their burdens ignored. Karp (2002) has highlighted that tensions between family and friends and professionals tend to arise at key points, for example, family and friends can experience a crisis with their relative as traumatic and chaotic, while for professionals crises are viewed as routine. These differing perspectives and associated responses are often puzzling and frustrating for family and friends (Karp, 2002).

While family and friends frequently provide significant care and support (Gamble and Brennan, 2006) and are in a prime position to influence outcomes (Maurin & Boyd, 1990), they are often excluded from treatment and indeed at times are perceived negatively (Pinfold et al. 2004) or as part of the problem (Higgins et al., 2011). Research also suggests that the burden associated with caring for a relative with enduring mental health difficulties frequently results in family and friends experiencing psychological distress, physical illness, a reduction in their functioning and quality of life, in turn limiting their ability to provide support for the person with a mental health issue and compromising their recovery (Higgins et al., 2011, Maurin & Boyd, 1990).

According to Fadden (1997) involving family and friends in care and treatment reduces the morbidity and mortality of the relative with mental health issues and the frequency of relapse and rehospitalisation. It enables family and friends to support the person more effectively and to maintain their own psychological and physical well-being. Fadden (1997) highlights a number of barriers to the involvement of family and friends. Confidentiality is often used by professionals to avoid involvement of family and friends. Fadden challenges this, highlighting that this is not a barrier once professionals are aware of policies relating to information and the specific types of information that are classed as confidential. Opportunities for involvement can be limited by professionals' perceptions of family and friends as a source of stress or harm for the person with mental health difficulties. Fadden (1997) also points to a lack of experience and education for professionals in working with family and friends as a limiting factor.

Family and friends can also limit their involvement for numerous reasons. Fadden (1997) reports that family and friends can experience unpleasant encounters with professionals or face a system that reacts to them with indifference. She suggests that this 'iatrogenic burden' from their contact with services further increases their stress and hinders involvement. Other barriers that she highlights are the perceptions of family and friends that professionals do not want collaboration, they may fear stigma about having a relative with a mental health issue, and there are times when their relative does not want them involved. Fadden (1997) highlights the responses and practices that family and friends find supportive: a) affirmation of their care giving efforts, b) empathy about the challenges of care giving and c) initiation of contact by the mental health services.

In Ireland, work in this area indicates that: support for family and friends is inadequate, unsuitable or not visible; family and friends are not actively involved in care and treatment; information is not forthcoming and there is little communication between family and friends and the treatment system (Kenny, 2011; Higgins et al., 2011; Mental Health Commission, 2011; National Service User Executive, 2011). This is despite the fact that Ireland's main mental health policy document, *A Vision for Change* (2006), recommends that family and friends who support a person with mental health difficulties are included in all levels of mental health services.

This Action Research (Kagan et al., 2008) project sought to actively promote the involvement of family and friends in SVHF and HSE DNC mental health services by meeting with family and friends to explore a) their experiences of supporting a person with mental health difficulties, b) their experiences of being involved with services who provide care and treatment to their relative and c) to identify their own support and care needs. This information was used to develop and deliver a tailored intervention to family and friends who participated based on identified gaps and unmet needs. The information was also used to increase awareness of the experiences and perspectives of family and friends and to explore opportunities within the teams to respond by developing initiatives to improve access and involvement for family and friends. The research project was evaluated by family and friends and also by reviewing outcomes in terms of new initiatives implemented in the SVHF and HSE DNC mental health services. The research project was devised initially by a team of researchers comprising staff from SVHF and HSE DNC in partnership with DCU and family experts from SHINE. DCU and SHINE bring a wealth of experience to the project through their research expertise and experience of working in partnership with mental health service providers, service users and family and friends. The research project developed over its duration in conjunction with the participants who collaborated in designing the intervention for family and friends and determining valued outcomes.

The Rationale, Aims and Outputs of the Project

Rationale for the project:

- Families and friends play a vital role in the lives of people with mental health difficulties.
- Families and friends often provide the bulk of help, support and caring to the person with mental health difficulties.
- Partnerships between service users, family and friends and service providers maximise resources and optimise recovery.

Aims of the project:

- To provide a forum to facilitate and promote the involvement of family and friends in their local mental health service.
- To hear from family and friends about their experiences.
- To share these experiences with mental health teams.
- To raise awareness with service providers about the issues and needs of family and friends, this in turn can influence practices.

Outputs agreed at the commencement of the research project:

- An intervention delivered by the research team geared to address the identified needs of family and friends.

- A meeting for feedback of the findings and discussion with family and friends.

- Meetings with the two respective mental health teams for feedback and discussion of possible family and friends initiatives.

- Provision of a report on the project to family and friends, the Rehabilitation and Marino Tolka Mental Health Teams and the management teams of SVHF and HSE DNC mental health services.

- Publication of an article in a health related journal.

The Research Project

In this section of the report the key guiding principles of the research project are outlined and each phase of the research is described in detail.

Research project principles

From the outset, this research project adopted a partnership approach between family and friends and professional groups that appreciated the unique contributions of all involved. Therefore, an Action Research (Kagan et al., 2008) methodological approach was taken. This method seeks to define a problem and devise ways to address this over the course of the project with key stakeholders, in this instance family and friends and service providers of those with mental health difficulties attending the particular teams involved.

Taking an Action Research (Kagan et al., 2008) approach requires that key stakeholders are committed to the research process and are agreeable to implement appropriate changes as the research process unfolds. Therefore, at the commencement of the research, the team agreed to devise and deliver an intervention/response for family and friends in recognition and appreciation of their contributions to the project. However, it was not clear at the outset what this intervention would look like as it was developed on the basis of needs identified in phases one and two of the study. The research team also sought and obtained commitments, prior to participation, from the two teams involved to implement changes to enhance the involvement of family and friends as indicated by the findings of this research.

Phase 1: Focus Groups

Recruitment

Family and friends whose relatives were attending the Rehabilitation and Marino Tolka teams were invited to participate in a focus group. Focus groups involve having an organised discussion around a particular topic and generally have 6-10 participants. They are a useful data gathering method as they can encourage participation from people who feel they have little to contribute or who may be reluctant to be interviewed alone. They also capitalise on communication between research participants in order to generate data (Kitzinger, 1997).

To recruit participants, invitation posters were displayed in the respective team clinics. Clinic staff also informed family and friends about the project and invited their participation. Those interested in participating in the focus groups contacted the researcher who provided them with written details of the study. Written consent was obtained prior to participation.

Data gathering and analysis

To gain a rich and in-depth account of the experience and views of family and friends, two focus groups were held in May and June 2013. Participants were invited to attend one. Two experienced facilitators, who were not SVHF/HSE DNC clinicians, used a topic guide developed by the research team to conduct the focus groups.

The focus groups were recorded and recordings were transcribed verbatim. The data were analysed using Thematic Analysis (Braun & Clarke, 2006). This involved undertaking an in-depth analysis of each group separately and subsequent analysis across both groups to explore similar and divergent themes. The findings were drawn together into a number of key themes that captured the experiences and perspectives of family and friends. Areas deemed important for more constructive involvement with mental health services were also identified. To enhance rigour, data were analysed independently by two analysts who then discussed the findings until consensus was reached. The date were reviewed by other members of the research team to ensure inter-rater reliability.

In the findings section, direct quotes from the focus groups are used to illustrate and add depth to each theme. Participants had an opportunity to see and hear the quotations used and consented to these being used publicly as part of this research project.

Participant profile

Twenty (20) participants representing twelve families took part. 75% (15) identified as parents of adult children with mental health difficulties (table 1) and 70% of them were female (table 2). They ranged in age from 40 years to 80 years. 35% (7) lived with their relative and 60% (11) had almost daily contact with their relative (table 3). The minimum number of years they had cared for their relative was 4 years and the maximum was over 40 years, with just over half of them supporting their relative for more than 11 years (table 4). Family and friends typically provided emotional support to their relative and 18 of them reported they provided multiple levels of support (table 5).

Table 1: Relationship with the person with a mental health issue

Parent	Spouse/Partner	Sibling
15 (75%)	1 (5%)	4 (20%)

Table 2: Gender

Male	Female
6 (30%)	14 (70%)

Table 3: Amount of weekly contact with their relative

Lives with relative	6-7 times per week	3 or less times per week	No contact
7 (35%)	5 (25%)	6 (30%)	2 (10%)

Table 4: How long they have been supporting their relative

Less than 4 years	4-10 years	11-20 years	21-30 years	Over 30 years
0	9	5	1	5

Table 5: The kind of support given (can be more than one type)

Financial	Emotional	Domestic	Physical	Other
12	18	11	11	2

Findings

It is important to provide a context for the findings from the focus groups. The participants are providing support to relatives who have severe and enduring mental health difficulties, typically having been diagnosed with schizophrenia or bipolar disorder. Family and friends have been involved with numerous mental health services prior to their current involvement with the Rehabilitation and Marino Tolka teams. Some lived in other geographical areas in the past and were involved with other public hospitals. Others were involved with private hospitals, and many have been involved with a range of services including day hospital, day centres and supported accommodation. Thus, their experiences and views reflect the totality of their experiences and are not solely reflective of the two teams who agreed to participate in the research study.

The themes reflecting their experiences of caring for a relative with mental health difficulties and of dealing with mental health services are summarised in table 6 and discussed in detail below. The issues they identified for more constructive engagement with mental health services are outlined in the next section.

Table 6: Experiences of caring for a relative and being involved with mental health services

Key theme	**Main themes**
Caring and dealing with mental health services is nightmarish and challenging	Caring for someone with a mental health issue is all consuming
	Engaging with mental health services is a rocky road

Key theme: The experience of caring and dealing with mental health services is nightmarish and challenging

The key theme that captures participant experiences of caring and being involved with the mental health services reveals that this is **nightmarish and challenging**. This experience ranged from having sporadic challenging episodes to constant and persistent turmoil. For some participants the nightmare experience centred on the time they realised that their relative had mental health difficulties and they struggled to come to terms with this. Other participants have extremely challenging episodes on the occasions when there is a crisis affecting their relative. These situations can be exacerbated by increased involvement with mental health services coupled with a perceived lack of support and / or difficulties communicating and negotiating their needs. While for others the nightmare is constant and unrelenting as they witness and try to manage the day to day difficulties their relative encounters, such as; their relative refusing to engage in treatment, displaying bizarre or risky behaviour, struggling with social isolation and withdrawal, being ridiculed and/or not being able to access recreational, vocational or employment opportunities. It is also challenging to manage their relationships with their relative and with other family members and friends, especially if there is a conflict of needs.

> *It has been a nightmare because I was thrown totally into a situation I knew nothing about. I found it very difficult to get information not only was I trying to figure out what was going on with [relative], what could be done for her but I was also trying to look after [relative's family].*

Main theme 1: Caring is all consuming

The caring role is a priority for participants and signifies an important commitment in their lives. They have a strong desire to do the best they can to make life more satisfying and less difficult for their relative. Being aware of the enduring nature of their relative's condition leads to high levels of worry about their relative and their future.

> *I'm really concerned because I want to make sure that [relative] can be looked after in case anything happens to me.*

They take on responsibility for their relative and make sacrifices that have adverse effects for themselves. Family needs and issues are put on hold while the relative's mental health needs are attended to. Thus, they sometimes compromise their own needs. This impacts their physical and psychological health, damages family relationships and curtails social and recreational activities. They feel uncomfortable in circumstances where their own needs take priority, seeing themselves as letting their relative and themselves down or feeling that they do not have permission to look after themselves.

> *I gave up work. I stopped working so I could care for [relative] and I used to sleep on the couch beside the bed and [relative] would start at about 9 o clock at night...and it got to the stage where I could not cope.*

They struggle to cope with their emotional reactions to challenging situations and to resolve conflicts within themselves. They grapple with feelings of frustration, guilt and self-blame when they have to limit their involvement with their relative or are unable to help them.

> *It took me a long time to learn to step back emotionally somewhat and to deal with it you know because it is the emotion, it is the guilt that drains the living hell out of you.*

Sometimes family and friends find they compromise their own values and integrity, for example, acting out of character or being compelled to do things they would not have imagined doing in order to get help for their relative or themselves.

> *So in the end I had to lie to get in to see the psychiatrist. I told a lie. I walked in and I said 'oh yes, I have my son's permission'. Halfway into the interview I said 'I had to lie to get in to see you'. But that's dreadful that's so childish.*

Although exposed to strange and sometimes frightening and threatening behaviours, they feel a responsibility to accommodate and tolerate their relative's behaviours. For some of them this involves coming to terms with odd rituals and behaviours while for others it involves a deep concern for their own safety or the safety of their relative.

> *[Family member] slept with a chair under the handle of the door at night time because everyday [relative] was threatening to kill [family member].*

The impact that these struggles have on families differs depending on how they negotiate the caring role. Having sufficient family support is important to prevent burn out of some members. Some families pull together and share the caring roles, sometimes one person is left with the bulk of the responsibility, for others relationships become tense and strained, and some families are torn apart.

> *The effect it has had on the other members of the family you know it has had a terrible effect.*

Being cognisant that their relative's life has been compromised can engender a sense of loss and sadness and this was likened to a grieving process.

> *I think you go through without knowing it in the initial phase and when I look back I think it was grief I had about my son. It is like as if something died in both of us. It was like a grieving process.*

Their relative with mental health difficulties was not the same, their dreams and expectations for the future are changed and his/her needs are different and ongoing.

> *Grief over the potential that they will never reach, and what they could be, but because of this illness, they won't.*

In summary, they describe how living with somebody with a mental health difficulty causes a level of chaos. The normality they had been used to is lost, relationships are changed, routines disrupted, home loses its sense of sanctuary and the future becomes uncertain and worrisome. To some this is like an unexpected blow with ongoing repercussions. They take on responsibility and try to accommodate to their relative, often sacrificing their own needs in the process. Thus, caring is all consuming leaving little space at times for family and friends to lead their own lives.

Main theme 2: Being involved with mental health service is a rocky road

Family and friends have different experiences of the mental health services and the professionals with whom they have contact. Some experiences are positive and family and friends feel involved and invited to work collaboratively with staff. Other experiences are more problematic. At times family and friends feel excluded from mental health services in various ways, leading to them feeling isolated, frustrated, undervalued and dismissed.

Given the enormous burden associated with being a carer, family and friends are immensely frustrated that the impact mental health difficulties has on the entire family is not acknowledged or proactively attended to. Some family and friends expect that once their relative is involved in the mental health services that they too will be offered support. They can be shocked, frustrated and disappointed when this does not happen.

> *It hasn't been recognised that this illness in my view has impacted on the families so greatly. It's not just the person who has the illness it's the whole family and the needs of the family.*

They express concern that overall there is a lack of information made available to them about available services, what is happening with their relative and how to manage a crisis situation. They want to be involved in important decision making about their relative that can determine their future pathway in life.

> *When [relative] went into hospital first there really was an information deficit. We went to an initial interview ... but we were told nothing. I think they thought we were two eejits who just didn't understand anything.*

Participants perceive that mental health professionals working with their relatives have skills and strategies that could be shared to assist them in dealing with their relative's difficult behaviour. They feel unsupported when they are not given advice that may help reduce their anxieties and their uncertainties.

> *You're kind of left to your own devices to cope and learn skills and to develop ways and techniques…I've never had it in my experience anyway that a psychiatrist came and said 'This is what you can expect…This is how you deal with it, this is how you talk to him.' You know you never got that practical day to day advice.*

Some family and friends found it particularly upsetting that the only advice they are given for managing crises is to call the Gardaí if they are worried that their relative may be a danger to him/herself or others.

> *I've been told if [relative] gives trouble, you know what to do. Ring the police. That's what I have to do. Imagine he had a bad heart if his heart gave him trouble, ring the police. It's so degrading to your relative and to you.*

Participants are suspicious about and critical of services and professionals who say they cannot communicate with them because of patient confidentiality. They feel this is used without any real thought given to what can be communicated without breaching confidentiality. They understand that their relative might disclose private and personal information to professionals that should not be shared with them. However, they want to help their relative and feel restricted when important information is withheld. For example, when their relative is being discharged from hospital to live with them, as they provide the bulk of care but are often not included in discharge care planning or ongoing community treatment.

> *I don't want to know what secrets my [relative] tells his psychiatrist but I do want to know how to care for him…we need to know how to care for them and how to care for ourselves by*

Family and friends are resources for their relatives in lots of ways and feel this is not acknowledged by services. They view this as particularly worrisome and shortsighted when, for example, their relative may be reluctant to share how they are actually doing due to fear of hospitalisation. They are critical of services for operating a double standard, whereby services sometimes contact family and friends to inform them about a problem with their relative. These communications seem to carry an implicit expectation that family and friends can resolve the problem and it feels like the responsibility is being handed back to them. Whilst at the same time, contact that is initiated by family and friends is viewed as problematic, unwelcome and intrusive by services.

> *I was astonished I got a phone call from somebody up here one day and you would actually think she was a vice principal in a school and that [relative] had not done his homework. It was this woman who said he is not keeping his appointments, he doesn't seem to be taking his medication….and I said I'd just like to describe [relative] to you, he is not actually a puppy. I cannot massage his coat and make him take medication*

Not only do family and friends perceive that their perspectives are not taken into account they also feel blamed and judged by services.

> *Following a suicide attempt when [relative] came to, the doctor said 'why did you do this?' and I was sitting at the side of the bed and [relative] pointed at me and said 'because of him' and the doctor just looked at me. I felt so small. I'm not throwing bouquets but I gave up everything. I used to run marathons and do karate, I done everything and stopped everything so I could be 100% with [relative] who needed help and that's what I think is wrong with the system.*

When family and friends feel excluded, unheard, dismissed or indeed blamed they feel like outsiders. They have to battle for what they and or their relative needs, such as basic information, specific services that they believe their relative would benefit from, and support for themselves to cope with the stresses associated with being a carer. However, despite asking for what they need for themselves or their relative, sometimes there is no follow-up from services, which leads to tension and sometimes conflict between them and the services.

> *This is the exhausting part you keep ringing; you keep fighting, lying to get your way in, pushing shoving all the time.*

In contrast, others feel well supported, which reduces the level of burden they experience. It helps when others share the responsibility and particularly when mental health services are seen to be actively involved.

> *The care system that's she's in is so great because they do keep an eye on her. There's so many people around watching what she's doing, which is good.*

Family and friends sometimes experienced working well with mental health professionals with whom they good relationships and with whom they could share their worries and work collaboratively. From their perspective, when they have more input into assessment, treatment and planning, they perceive goals to be more fitting and attainable, as they are based on more contextual, realistic and holistic assessments of their relative's needs and preferences.

> *I think one of the helpful things is to have a [professional] that you have a good rapport with I think it's just so important it has been very important for me. If you've got somebody who understands you, you can explain you're trying to sing off the one hymn sheet.*

Many of them have worked with professionals who openly include them in dialogue and who enquire about their wellbeing and the well being of their relative. Family and friends value this humane response by professionals and feel supported and acknowledged.

> *The community mental health nurse contacted me she asked me how I was, how the children were. She actually regards you as an equal human being she doesn't regard you less than herself. Then you realise 'oh yes all the rest of them actually consider themselves superior.*

In summary, when family and friends feel excluded from the services they fight to get into services, once in, they fight for information, advice, support and services. The types of exclusions they experience result in tensions between the family and services, and leave families and friends feeling undervalued, taken for granted and angry, as they are aware that they have an important role to play in the life of their relative. However, when they feel respected, listened to and consulted about important issues and decisions regarding their relative, they feel less burdened and more empowered as a carer. They also relate better with the services and are prepared to work with them to achieve the best outcomes for their relative. However, they emphasise that this is a two way process.

> *If there are issues with [relative] I will ring the doctor and I will say...you know something has occurred that you need to be aware of. But they don't have the same regard for me. I've always said if there is an issue or you need me to do something, pick up the phone and ring me. That's something that has never been done.*

What facilitates constructive engagement with mental health services?

- ✓ **To be treated with respect**

  Family and friends need to be listened to in relation to their concerns and for their experiences to be validated.

> *My biggest grievance is against the system and in all those years no one has ever rang me, written to me, spoken to me. They have never asked my opinion as to my (relative's) condition. They never asked how I was or the*

- ✓ **To be involved**

  Family and friends have important knowledge about their relative and the challenges they encounter on a daily basis. This expertise can inform assessment and care planning. They value collaborative and co-ordinated care, for example, when a relative is being discharged from hospital to community mental health services,

- ✓ **Family friendly and accessible services**

  Services that are inviting towards family and friends make them feel welcome and included which helps to ease their anxieties. Services that proactively involve family and friends and provide easy access to professionals facilitate meaningful involvement in their relative's recovery.

> *We also attended meetings in the private hospital you know where the parents were called in and boy were they intimidating…and this was like their version of like family communication or something. So they do have systems, there are systems that are in the health service that they’re not really that family friendly!*

✓ **Practical information and advice**

Family and friends want access to basic information about services and support structures, such as, employment, grants, education, accommodation, leisure, activities etc. They can also benefit from practical advice, for example, about what to expect and how to manage troubling behaviours and crisis situations and how to prepare and plan for the future.

> *Through all the years I would have loved more help. Where to go with (relative) for a bit of employment? When you get older ... so you know I am saying to myself Jesus I better have (relative) settled … and I said before anything would happen to myself.*

✓ **Appropriate and safe services**

Family and friends have concerns about the potentially negative impact of how services are configured and delivered. This leads to concerns about their relative in relation to issues such as the effects of inappropriate age mix and exposure to extreme levels of mental distress and behavioural disturbance in services.

> S*he got panic attacks I swear she got that in the hospital because she was scared out of her life. If there was one thing I could do for anyone young today starting off please don’t put them in the psychiatric ward with older people because to this day I know that is where she got her panic attacks from.*

- ✓ **Personal support**

  Given the demands of the caring role, family and friends want their needs to be acknowledged and addressed. Family and friends want services to offer support if required and to signpost other services and supports so that they have choices about what might be most helpful at a point in time.

> *I cannot praise SHINE enough. They run a number of family courses, they run carers courses. …They also have counsellors there as well, if you need to see a counsellor and also your relative can see the counsellor there too. I mean SHINE gave me my sanity back.*

Phase 2: Feedback of Findings

Hearing the findings was an emotional experience for family and friends. They identified with the findings and felt that they had been heard and understood. This process engendered a sense of equality, which raised concerns for them about whether this might continue in the longer term. Family and friends wondered if their involvement in the study would influence the system and lead to tangible outcomes that would benefit them and their relative, given that their motivation for involvement was driven by a desire for change. Given the level of investment involved in participation, it was important to ensure a feedback mechanism that would allow them to determine if their efforts had been successful in influencing positive change. Therefore it was agreed that the project report would be communicated to them.

The content of the intervention that the research team would deliver to address their needs was discussed. They requested that information about the support structures and services be made available to them and an opportunity to engage in experiential activities to support their self-care and wellbeing.

Phase 3: Discussion of Findings with the Mental Health Teams

Both teams acknowledged the pain and difficulties that family and friends have experienced and the immense suffering that many of the participants had shared. The teams expressed sadness and regret that people have had these experiences. They noted that sometimes they do not know how to respond helpfully to family and friends and also at times feel that family and friends have unrealistic expectations of what they can do particularly in crisis situations. They noted that these were uncomfortable times for them and acknowledged that sometimes their responses inadvertently isolated family and friends and created obstacles for involvement. In reflecting on what they had heard from family and friends about their experiences and on their own practices, they expressed a desire to be more helpful and proactive towards involving family and friends. They undertook to take on board some of the recommendations and to implement practices that are more family friendly and proactive.

The Marino Tolka team subsequently introduced a number of measures to increase the involvement of family and friends.

- The CMHT participated in the HSE's Enhancing Teamwork Initiative, which was designed to: help teams function more cohesively in developing better systems of work; involve service users and family and friends; and improve networking with other services. This provided a further opportunity to engage with both service users and family and friends to hear what they thought of the service they received.
- At the first visit of a service user, who is likely to continue attending the team, the service user is proactively asked for the name and contact details of a family member or friend whom they would like to be involved in their care and treatment. Thus involvement is encouraged from the start of the person's contact with the team.
- Development of a leaflet, in collaboration with service users and family and friends, about the team and the services available through the mental health services.
- Development of a booklet, in collaboration with service users and family and friends, to signpost local community resources, including support groups for family and friends.
- The team introduced the Eolas programme (Higgins et al., 2011).

The Rehabilitation Team in response to the findings from the research project looked at their current work in which they include families/carers/relatives. The following decisions were made recently to formalise this practice and introduce some new measures.

- The Rehabilitation Team invites family members, carers and significant persons to each MDT care plan meeting and is committed to ensuring that carers, relatives and significant persons are included in the treatment process with the consent of the service user.

- The Rehabilitation Team have developed their own feedback form for carers, relatives and significant persons so they are actively included in the care planning process. This is now an agreed part of the Integrated Care Planning process.
- The Rehabilitation team have committed to an annual service user / family day where service users, families and carers can meet the team in an informal setting.
- The Consultant Psychiatrist has committed to offering an appointment to Family Members every Thursday at her outpatient clinic.

Phase 4: Intervention for Family and Friends

The intervention involved a psychosocial and psycho-educational event delivered by the research team for family and friends. It comprised 4 elements:

1. A discussion of the progress of the research project

   Feedback was given to family and friends about how the findings had been received by the mental health teams. The main feedback was the recognition by the team members of the “pain” that family and friends experience in their daily lives coping with a relative with mental health difficulties, how the practices and attitudes of mental health staff can isolate family and friends and their commitment to working with family and friends in the future. Family and friends were surprised and heartened to hear that the teams had acknowledged and validated their experiences. They were hopeful about the possibilities for change based on the teams’ responses.

   Family and friends were informed of the initiatives that had developed in the mental health services since the start of the project as outlined in phase 3. Participants were encouraged to hear that the Eolas programme had been introduced and that the research team had negotiated that everyone involved in the Family and Friends project would be invited to participate in Eolas. Some participants who had already become involved in Eolas gave positive feedback about this experience. While it was acknowledged that there is much progress to be made in terms of developing the involvement of family and friends, the concrete progress to date generated a sense of hope in the group that positive changes were taking place. Family and friends reported a sense of pride and achievement that they had played a part in instigating these changes by participating in this research.

2. Support services for family and friends

   The Regional Development Officer with SHINE outlined the services it provides to service users and families. Written information was made available about SHINE and other voluntary bodies. Family and friends involved with SHINE gave positive feedback about their experiences, while others had not previously heard about SHINE or other supports available to them. It was acknowledged that this type of information would be most helpful if it was made routinely available to them at the time they became involved with mental health services.

3. Self care needs and well-being exercises

   The group explored their self-care needs and engaged in exercises to help them evaluate their self care practices and plan how to promote and consolidate these. They shared their experiences about what they found helpful in relation to managing and coping with their daily lives. The group participated in exercises designed to enhance their wellbeing, such as, mindfulness, relaxation and guided imagery.

4. Evaluation of the entire project

   Participants were invited to complete an evaluation form related to each component of the project, which would be incorporated into the final report on the project.

Phase 5: Evaluation of the Project

To evaluate the participants' experience of being part of this project, family and friends were asked to comment on the four areas described in the table below (table 7) and there was also space for additional comments. This qualitative approach was taken to ensure that the participant's evaluations were noted and included in the project. Below is a summary of participants' responses (n=10).

The Family and Friends Project overall

The dominant theme in this section centred on how group members felt that they were being heard. They felt understood and supported, they felt as though someone cared, and they felt that the group was a safe space in which they could open up.

Table 7: Evaluation of the focus groups

	Poor	Fair	Good	Very Good	Excellent
The first group meeting where you shared your experiences		1	5	2	1
The information you received before that meeting			5	3	1
The format / structure of the meeting	1		2	5	1
How the meeting was facilitated		1	1	3	3
The venue (St Lawrence's Road or the 245 Club Drumcondra)	2	1	1	1	3

> *"Being able to talk about our own experience and to hear other people's experience and know we are not alone"*
>
> *"To be able to talk about what you were experiencing and were heard and understood, the feeling that at last someone cared was good"*

The feedback meeting where the findings were shared with family and friends

The dominant theme emerging from this section centred on the family and friends perceptions that they had been listened to throughout the research process. Family and friends reported feeling relaxed and able to discuss their feelings. The feedback meeting was evaluated as mostly excellent (table 8).

> *"The whole setting for all meetings was very relaxed and everyone seemed very comfortable discussing their own feelings"*

Table 8: Evaluation of the feedback meeting

	Poor	Fair	Good	Very Good	Excellent
The format / structure of the meeting			1	1	4
The quality of the presentation			2	1	4
How the meeting was facilitated			1	1	4
The venue (SVHF)			1		3

The half day intervention for family and friends

The main themes emerging from this section revolved around how useful and enjoyable it was to learn more about other available services, such as SHINE. Participants also described how important and interesting it is to have contact with professionals and to be listened to, as well as hoping that something positive will come from the project in future. The evaluation of the intervention was mainly positive and the varied responses perhaps indicating the diverse needs and preferences within the group (table 9).

> *"It was very helpful to meet people in a similar situation and talk. I think also it is very important to keep up contact with the professional people involved."*

Table 9: Evaluation of the intervention for family and friends

	Poor	Fair	Good	Very Good	Excellent
Feedback from teams			3	4	3
Mindfulness body scan		2	3	3	2
Self care		1	4	2	3
Guided imagery		1	3	3	3
Overall content			3	2	4

Would participants recommend that other family and friends become involved in similar projects?

Group members unanimously voted "yes" in response to this question, and provided a variety of reasons as to why. Being involved in this project helped some family and friends to feel less alone, and they enjoyed being involved in a process that might bring about some positive outcomes for the future. Being involved in the group and learning from the experiences of other group members was a positive benefit. One group member expressed the fear that the group may promise or appear to offer more than it might be able to realistically deliver.

> *"Because it is good to be involved. It helps give people strength to keep going and they are not alone."*

Additional comments

Participants reiterated how good it was to have some support, and it was suggested that some would like the meetings to continue on an annual or bi-annual basis. While peer meetings are important they also feel it is important to have regular contact with or access to professionals. They asked to be kept up to date with the impact of the research project and the research team reassured them that each of them would be informed about a report on the research once completed.

Recommendations

- The mental health services make opportunities available for family and friends to meet together for support and information.
- The mental health teams routinely provide service users, family and friends with information about the services available within the mental health services and signpost other services that may be of interest e.g. SHINE, who provide services for people with mental health issues and their family and friends, Northside Carers' Group, who provide a support group for carers etc.
- Local community mental health and specialist teams provide service users and family and friends with information about local resources, for example, adult education, recreational / employment etc.
- The mental health services actively encourage service users to include family members or friends as collaborators in their care and treatment.
- Mental Health teams form collaborative partnerships with family and friends from the start of a person's involvement with the mental health services, as appropriate.
- The mental health services supports programmes, such as Eolas, which targets both service users and family members and friends.

Conclusions

This research project was a collaborative partnership between family and friends and professionals from different backgrounds and organisations who successfully brought the project from inception to conclusion. The project emerged from recognition of a gap between policy and practice in relation to family and friends involvement in mental health services. Therefore, the methodological approach taken actively involved family and friends in the project from the outset. It achieved its aims by giving voice to participants who helped shape each phase of the project.

The findings highlighted the plight of family and friends the burden of caring and the challenges they encounter with the mental health services. It also identified ways to promote positive engagement of family and friends that ultimately serve the best interests of the service user. The mental health team involved in the project initiated changes in their practices to acknowledge the contribution that family and friends can make and to promote their involvement with mental health services.

Since the project commenced there have been significant developments within SVHF and HSE DNC mental health services to involve and support family and friends (appendix 1), which may indicate a wider shift towards appreciation of family and friends in their caring role and their involvement with mental health services. It may also reflect progress toward enactment of the values enshrined in and the practices recommended in national mental health policy.

Research is encouraged in mental health services as a means of developing innovations, evaluating services and enhancing quality assurance and standards. While the teams involved have made changes in their working practices as a result of the research process the findings also need to be highlighted and reviewed by appropriate managers in SVHF and HSE who have responsibility and accountability for implementing recommendations and developing resources.

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Appendices

Appendix 1: Progressing the Involvement of Family and Friends

This is a sample of some of the activities taking place in St Vincent's Hospital and HSE DNC mental health services that involve family and friends.

St. Vincent's Hospital

Staff, a family member and a service user advocate collaborated to review and update the communications policy pertaining to patients on St Louise's Unit in St Vincent's Hospital, Fairview.

Staff, a family member and a service user advocate collaborated to review and update the visiting policy pertaining to St. Vincent's Hospital, Fairview.

Mental Health Teams

Staff and a service user have been involved in the development a collaborative leaflet on community resources for service users and family and friends.

Staff and a family member have been involved in the development of a collaborative leaflet about the Marino Tolka team and the services available to service users and family and friends.

Service users are encouraged to have a family member or friend involved in their care and treatment and these details are requested from any new service user attending the Marino Tolka team.

EOLAS

The Marino Tolka team along with the Marino Clontarf team have delivered the Eolas programme, which is an 8 week programme for service users and family and friends. To date this had been run on 3 occasions and it commenced in October 2013.

Participants in the research project were invited to attend one of the Eolas programmes.

Three people who completed Eolas have trained as peer facilitators and have been involved in the delivery of the most recent programme.

Staff and participants who were involved in the first Eolas programme presented their experiences to the SVHF journal club attended by consultant psychiatrists and junior doctors.

Family and friends who completed the Eolas programme suggested a monthly support group for family members and this runs on an ongoing basis.

Family and friends also suggested a regular social event where they and their relative could socialise with the support of staff. This has involved a number of outings and activities, such as, bowling, a barbeque, trips to the National Concert Hall and various other places of interest.

Eolas facilitators supported service users and family and friends to attend a HSE meeting, which was one of a series of national meetings whereby the HSE were seeking the experiences and views of people who used their services.

Following the success of the Eolas programme in the Marino Tolka and Marino Clontarf teams the programme is now being delivered by other community mental health teams, thus expanding the involvement of service users and family and friends within DNC.

The HSE have launched National Clinical Care programmes for self-harm, early intervention in psychosis and eating disorders. The purpose of the National Care programmes is to ensure that service users with these issues receive good quality of care that is standardised across services. All three programmes promote the active involvement of family and friends. Standard care in the early intervention in psychosis programme involves families of people who are newly diagnosed with psychosis being offered family therapy.