

FRIENDS PROJECT EVALUATION

Dr. Aimie Brennan
Agora Research & Learning Alliance



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1.0 About the Friends Project

The FRIENDS (Family Recovery Initiatives by Engaging, Networking, and Developing Supports) project was a pilot initiative that ran from November 2013 to March 2015. The FRIENDS Project was borne out of the Mid West ARI Project in attempt to meet the unique need for further support and inclusion of family members within the Mid-West Mental Health Services. The FRIENDS project was run by a partnership between SHINE, the HSE Midwest Mental Health Service inclusive of Midwest ARI, and the Peer Support Centre Aras Follain.

The project aimed to support relatives of people who experience mental health difficulties by developing a model of recovery, peer support, education and advocacy. The model has been informed by existing learning within the SHINE Family Education course, the RnR training modules (WRAP, self-advocacy and peer support) and the SOS Wellness Breaks and workshops, some of which have been adapted in order to place more of an emphasis on the perspective of family and friends.

The values and ethics of WRAP have provided a useful self-help tool for family members to provide the specific type of support, which is of most use to their relative, while at the same time keeping an emphasis on their own self-care and wellness. In this regard, the FRIENDS project has piloted a model of recovery and self-care for relatives of people who experience mental health issues, in order to enable them to develop the skills and capacity to provide peer support to each other individually and in groups.

Family members and service users have been included in the development of a Family Support Strategy within the Mental Health Services, to inform the inclusion of relatives and carers in the delivery of the services. This entailed a detailed needs analysis and completed strategic plan exploring the possibilities of carers' assessments, assigning keyworkers to families, a joint approach to developing an Information Sharing and Support Protocol, and including relatives in providing in-service training and education initiatives for staff.

Drawing on their strong ethos of inclusion and co-production, family members played a significant role in the evaluation of the FRIENDS project through their engagement with Participatory Action Research. Relatives were trained in the areas of confidentiality, research ethics, and practical research methods. Following training, relatives facilitated focus groups with key stakeholders and contributed valuable feedback on the final evaluative analysis.

"Carers should be provided with practical support/measures...and should have a member of the multidisciplinary team to act as a keyworker/designated point of contact...provided."

(Vision for Change, 2006: X).

1.1 Funding Structure

From strong partnerships established through the ARI process, an application was made for funding from the Genio Trust to support the design and implementation of the FRIENDS project. In 2013, the FRIENDS project was deemed eligible for funding based on its potential to accelerate the availability of proven, cost-effective, personalised supports, to the families of people experiencing mental health challenges.

GENIO works to bring Government and philanthropic funders together to develop better ways to support disadvantaged people to live full lives in their communities. Since 2010, GENIO have awarded funding to 227 projects nationally to provide over 5,500 people with individualised supports in the community.

GENIO offers a valuable opportunity for the public, private and social sectors to collaborate strategically, combining their efforts to achieve sustainable improvements for people at risk of social exclusion. As the chairperson of GENIO, Pat McLoughlin notes, 'by moving to a more flexible system of resource allocation, which offers a better match between needs and services, individuals gain greater independence and resources can be used to best effect in the interests of those requiring support.'

GENIO provided €70,000 in critical funding to support the design and development of the FRIENDS project, including; the hiring of a training and development worker, the training of relatives in peer support, wellness and research skills and an independent evaluation of the FRIENDS project.

1.2 Collaboration & Partnership

Some of the core values underpinning the FRIENDS project since its inception have been collaboration, partnership and co-production. These values are evident in all aspects of the project from design, to implementation and evaluation. On the most fundamental level, the initial GENIO application for the FRIENDS project was a positive outcome of the strong partnerships formed during the ARI (Advancing Recovery in Ireland) process and remains an integral part of the Midwest ARI project.

The goal of the Midwest ARI project is to assist the services and staff in the implementation of a strengths based recovery approach to the delivery of the service. The ARI project is supported by the HSE Midwest Mental Health Service. The embedded nature of ARI, the FRIENDS project and its key partners are outlined in Figure 1 below.



Figure 1 - The relationship between FRIENDS and the ARI project

Upon successfully securing funding, the FRIENDS project steering committee was established. The steering committee was responsible for the day-to-day running of the project, financial out-goings and the hiring of key professionals to support the project. Five partner organisations were represented on the FRIENDS steering committee, alongside relatives of people with mental health challenges.

1.1.1 SHINE

SHINE is a national organisation dedicated to upholding the rights and addressing the needs of all those affected by mental ill health. SHINE has worked with relatives of people with mental health difficulties since its foundation in 1975. An integral part of the work of SHINE is the development and support of a national network of Relative Support Groups. These are primarily facilitated by mental health professionals in the local area, there are four Relative Support groups throughout the Midwest. SHINE developed the Recovery and the Family education course based on needs identified by families, SHINE Regional Development Team and international best practice. SHINE engages with relatives at all levels to ensure their voice is represented at all levels in policy, service and legislative developments. SHINE has worked in partnership with services in a number of projects.

1.1.2 The HSE Midwest Mental Health Service

The HSE Midwest Mental Health Service provides a range of mental health supports and services to a catchment area of in Limerick, Clare and North Tipperary. The HSE Midwest Mental Health Services has gained increased capacity to work in partnership with service users, families and the community and voluntary sectors through a number of previous, very successful Genio projects such as the RnR project, the Sos Wellness Break project, and current projects within the two rehabilitation teams in relation to supporting people to live independently in the community. These projects have resulted in a number of initiatives such as the expansion of the Peer Support Centres and Peer Support projects throughout the region. Staff, service users and family members are increasing their own personal capacities in relation to recovery approaches and using WRAP for self-care.

1.1.3 Aras Follain (Nenagh, Co. Tipperary)

Since 2007, Aras Follain has been a centre for peer support and training in Co. Tipperary. Aras Follain promotes wellness and recovery for people who have experienced mental health difficulties or are at risk of mental ill health through social isolation, family circumstances, relationships, financial circumstances, disability or unemployment. It is a community based centre led by people who use the mental health services within a recovery model with support from professionals on an as needed basis. The centre is run by a Steering Committee made up of representatives from all of the groups, the community and a representative from Mental Health Ireland

Finally, the FRIENDS project has included relatives as partners in the implementation and evaluation of the project. Family members were involved as partners in the co-production of all training materials and in the delivery of training programmes to peer supporters. Relatives were also trained as peer evaluators, to facilitate the data collection process with some support from the independent evaluator. The emphasis on relatives as co-producers recognises that each relative is an expert in their own lived experience and has valuable skills and experience that can benefit the implementation of the FRIENDS project. This approach is consistent with *A Vision for Change* which recommends that 'service users and their families be offered opportunities to give feedback on their experiences and to influence developments within services' (2006; Rec. 10.3).

1.3 Location of the Programme

The Mid-West Region (*the Shannon region*) consists of counties Clare, Limerick and North Tipperary, Limerick city is the regional capital.

All three counties are represented on the FRIENDS project steering committee. In particular, by representatives from the region's peer support centres: Aras Follain in Co. Tipperary.

The Mid-West region spans 8,248 km² and has a population of 339,591. FRIENDS has been particularly cognizant of its regional location and population and has held information workshops and wellness workshops in each of the three counties.



1.4 Core Aims

Aim #1

To develop a model of recovery and self-care for relatives of people who experience mental health difficulties

Aim #2

To identify relatives with skills and capacity to provide peer support to others and develop and deliver training to them to that effect, establishing a panel of Relatives Peer Supporters in the region

Aim #3

To develop a strategy to inform the inclusion of relatives in the delivery of mental health services

Table 1- Core Aims of the FRIENDS Project

1.4.1 Aim 1: A Model of Recovery and Self Care

When designing FRIENDS as an integrated pilot project supporting relatives of those with mental health challenges, it was seen as essential that a strong emphasis be placed on individual wellness and recovery. It is crucial that relatives recognise the importance of their own recovery and needs and have adequate support in maintaining their wellness. Based on the principles of recovery, a model of wellness and self-care was designed by the FRIENDS steering group and implemented in the form of 'wellness workshops'.

Wellness workshops aimed to assist relatives in practicing recovery and self-care and provide a collective space for people to explore wellness in the context of their own recovery. They involved a number of talks and group sessions where experts facilitated and discussed the importance of self-care and recovery. Deepening knowledge of the impact caring about a person with mental health issues has on the family and the skills required for all to manage self-care and at times support their loved one, is crucial to the wellness of the family. Furthermore, attendees were offered an individual holistic treatment to aid their wellness.

Relatives were identified through links within HSE Mental Health Teams, Shine Support Groups and local Peer Support Centres and invited to attend workshops. Local workshops were seen as the most effective way of engaging with relatives. In November 2013, three wellness workshops were held throughout the region, in Limerick, Roscrea and Clare. These initial workshops were used to introduce the FRIENDS project and its aims and objectives to participants. The principles of peer support were introduced to relatives and the FRIENDS Peer Support objective was outlined. In addition, workshops presented an opportunity for relatives to evaluate their experience of the mental health services as it relates to their needs and share their experiences with FRIENDS.

Later in the year, a *FRIENDS Regional Introduction to Peer Support and Self-Care Day* was held in Feakle, Co. Clare. Like previous wellness workshops, the content of the day was focused on identifying and enhancing relatives' recovery needs. In October 2014, an overnight break away including, transport, accommodation and group workshops was provided to the 24 relatives who completed the training programme to become peer supporters. The wellness break aimed to provide a space for relatives to share their experiences, enjoy group activities and focus on their personal wellness.

1.4.2 Aim #2 – A Panel of Relative Peer Supporters

Peer support is an empowering vehicle through which family members can support each other in a mutual, recovery-focused manner. The role of peer support in the context of mental health has evolved since the 1970's, most notably in the area of person centred recovery. As a result, developing a panel of Relative Peer Supporters was a clear choice for the FRIENDS project when seeking to empower and support relatives in the Midwest.

Following engagement with relatives at initial wellness workshops, attendees were invited to self-select as prospective Relatives Peer Supporters. Interested parties were then asked to take part in a 7 week training course, which would further develop their capacities for this role. The *FRIENDS Peer Supporter Training Course* was designed, developed and co-produced by members of the FRIENDS Steering Group, relatives and workers. The course was informed by an extensive literature review and research of best practice nationally and internationally. Reflective learning and sharing of experiences were central in order to facilitate personal development. Table 2 outlines a selection of the key course content. The course commenced in June 2014.

Recovery	Peer Support	Available Supports
<ul style="list-style-type: none"> • Values • Ethics • The Recovery Model • Personal Recovery Journeys • Lived Experience 	<ul style="list-style-type: none"> • Principles of Peer Support • Effective support • Relationship-building • Communication Skills • Boundaries • Confidentiality • Empathy • Information giving# 	<ul style="list-style-type: none"> • Knowledge • Information-sharing • Support for yourself as a Peer supporter

Table 2 - Content of FRIENDS Peer Support Training Course

It was hoped that, the FRIENDS Peer Support Service would be established in Autumn 2014 with Relatives Peer Supporters available throughout the region. Furthermore, it was hoped that, through formalising existing links within HSE teams, referral pathways would be developed from the services to the FRIENDS Peer Support Service. However, while 24 FRIENDS peer supporters have been trained, no Peer Support Service has yet been established.

1.4.3 Aim#3 – A Strategy for the Inclusion of Relatives

From the outset of the project, the need for a comprehensive strategy for the inclusion of relatives in the delivery of mental health services was central. The objective was to bring about sustainable change and to build on existing good practice. It was hope that by including a comprehensive, evidence-based strategy, the FRIENDS project could be the catalyst to assist the mental health services in starting a meaningful dialogue with the relevant stakeholders and developing appropriate methods to involve relatives in the services in ways that are mutually beneficial for everyone especially for service users.

In order to produce a strong evidenced-based strategy, the FRIENDS training and development worker undertook an extensive needs analysis of relatives, people with self-experience and HSE staff and management. This needs analysis comprises of primary and secondary research to identify relatives recovery needs and their appropriate and meaningful inclusion in the mental health services. A series of qualitative interviews were supplemented with an in-depth literature review of policy, research and best practice nationally and internationally.

The FRIENDS strategy report was finalised in November 2014. The report provides clear guidelines and suggestions for the inclusion of FRIENDS relative peer supporters into the provision of services to families of people with mental health difficulties in the Midwest. The FRIENDS steering committee has suggested that the ethos of co-production be carried into the development of the strategy, whereby partners from HSE, relatives' representatives and people

with self-experience would collaboratively plan its implementation into the future.

1.5 Key Interventions

- Establish an interagency steering committee inclusive of all stakeholders and representative of the geographic area (North Tipperary, Limerick and Clare).
- Agree a group WRAP for the project, incorporating the Values and Ethics of WRAP.
- Employ a part time Training and Development Worker to assist with the delivery and implementation of the project plan.
- Carry out a needs analysis of relatives in the Midwest
- Identify relatives with capacity and interest in supporting others
- Provide training to family members, and staff utilising a 'Train the Trainer' approach
- Organise wellness workshops as part of the training and education approach.
- Develop the capacity for one-to-one peer support between relatives
- Support family members and carers to develop their own self-care plans
- Provide education and training sessions for HSE staff in relation to recovery issues of relatives and the support and inclusion of relatives as part of the mental health service.

1.6 Timeline for the Friends Project

Genio Funding was secured in October 2013 and the project began in November. The project was funded for 12 months, until November 2014 (this was later extended until March 2015). A more detailed timeline of the project is outlined in figure 2.

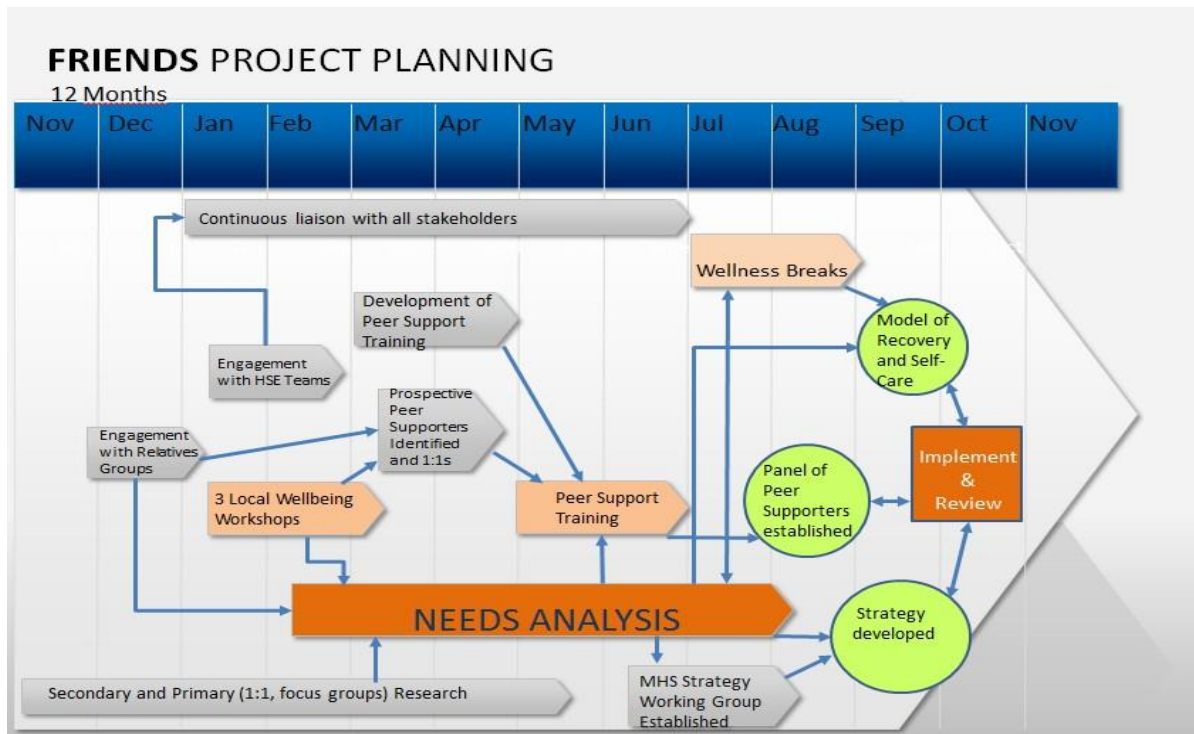


Figure 2 - 12 Month Timeline of the FRIENDS project

Figure 2 illustrates the monthly action plan that developed in order to achieve the ambitious aims and objectives of the FRIENDS project. It illustrates the on-going and complementary nature of all three core aims, i.e. the wellness and recovery strand, the peer support strand and the development of a FRIENDS Strategy for Inclusion.

2.0 LITERATURE REVIEW

2.1 Strand One – Wellness & Recovery

2.1.1 Mental Health and Wellbeing in Ireland

'The mental health sector is starting to see the benefits of a cultural shift toward an approach that promotes the recovery of patients, rather than simply the management of patients, as being at the heart of mental health services' (Taylor & O'Brien, 2012). According to the Chief Executive of the Mental Health Commission, 'recovery is central to modern thinking on mental illness'. For family members, this emphasis on recovery and self-care is equally important as international research, into relatives' experiences have shown that there can be negative health implications on those who support a loved one who experiences mental health difficulties.

Family members in the UK were 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). In Australia, the 'burden of care' was found to be a barrier for family members to participate in social and health activities (O'Connell *et al.*, 2003). Furthermore, in a cross-country comparison carried out by the OECD, the prevalence of mental health difficulties amongst family members was almost 20% higher than amongst those who did not support a family member in this manner (OECD, 2011).

In Ireland, *Care Alliance* investigated the health and well-being of relatives of those with mental health challenges. They found that family members presented 'a considerably less positive picture of quality of life compared to the general population' (2008: 4). The report revealed that in the previous 12 months to the study, over 40% of carers experienced stress and tension, almost 18% experienced depression and 22% experienced anxiety. Almost 30% of carers stated that their health had been directly impacted by their caring role (2008: 4).

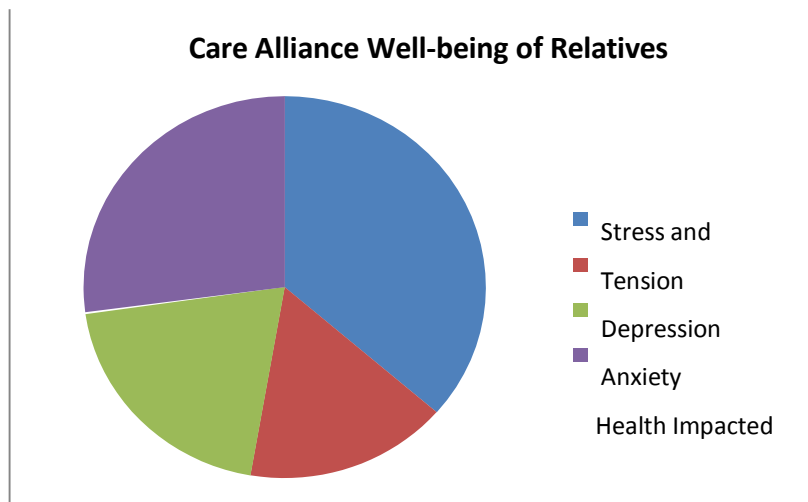


Figure 3 - Care Alliance Ireland (2008)

In their publication 'Every Mother's Son', *Waterford Parents and Carers Research and Advocacy Project* found that 93% of family members supporting those with mental health difficulties, felt that their emotional wellbeing was affected as a result of their supporting role. Conflict within the family was identified as a major contributing factor to relatives experience of well-being.

2.2 Strand Two – Relative Peer Support

2.2.1 Peer Support in Mental Health

Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. It is about understanding another's situation empathically through the shared experience (Mead, Hilton & Curtis, 2001). Unlike clinical help, peer support helps people to understand each other because they've 'been there', shared similar experiences and can model for each other a willingness to learn and grow. In peer support people come together with the intention of changing unhelpful patterns, getting out of 'stuck' places and building relationships that are respectful, mutually responsible and potentially mutually transforming (Mead, Defining Peer Support').

The role of peer support in the context of mental health has evolved since the 1970s, most notably in the area of person centred recovery. Initially, an organized movement of people who had experienced poor services, negative treatment and rights violations within the mental health system, began introducing various types of mutual aid supports such as peer support. In the United States, 27 states have collaborated to create a scoping and guidance document for peer support (Daniels et al., 2010). Peer workers have also been employed in various different roles and settings in Australia (Franke et al., 2010), New Zealand (Scott et al., 2011) and various parts of Europe (Castelein et al., 2008). In the UK, peer support has long

played a central role in voluntary sector and user-led services/groups (Scottish Recovery Network, 2011; Faulkner & Kalathil, 2012; Mental Health Foundation, 2012) but peer worker roles in statutory services have been slower to establish.

Peer support now has an established and demonstrated role in the spectrum of mental health services (Grant, 2009) In America, the Centre for Mental Health Services has embraced and promulgated the role of peer support in the recovery of people with mental health difficulties. Similarly, in Australia, a peer mentoring for mental health program (1997) claims that the narrative therapy which emerges from peer mentoring supports a positive outlook on life.

Peer support programmes have been implemented in many cases to compliment and support other care services but also to provide alternative supports which deviate from the traditional forms of treatment. Peer support provides a vitally different framework, which does not rely on labelling but rather on mutual understanding; "People who have seen themselves as powerless suddenly find that they are not alone in their perceptions. Through shared experience people find validation and acceptance" (Mead, 1995: 4).

2.2.2 Peer Support for Relatives

Peer support is an empowering vehicle through which family members can support each other in a mutual, recovery-focused manner. Peer Support is not based on psychiatric models and diagnostic criteria. It is about understanding another's situation empathically through the shared experience. This connection with a peer is without the constraints of traditional (expert model) relationships. Further, as trust in the relationship builds, both people are able to respectfully challenge each other when they find themselves re-enacting old roles. Peer support, therefore, represents a most effective recovery initiative for family members.

Figure 4 outlines a model of peer support presented by ARAFEMI – an Australian organisation that supports family members of people affected by mental health difficulties. As family members can encounter both medical and psychological models of recovery interchangeably on their road to recovery, figure 4 represents the 'bringing together' of both. ARAFEMI's model then borrows positives from each in order to outline a model for Family Peer Support.

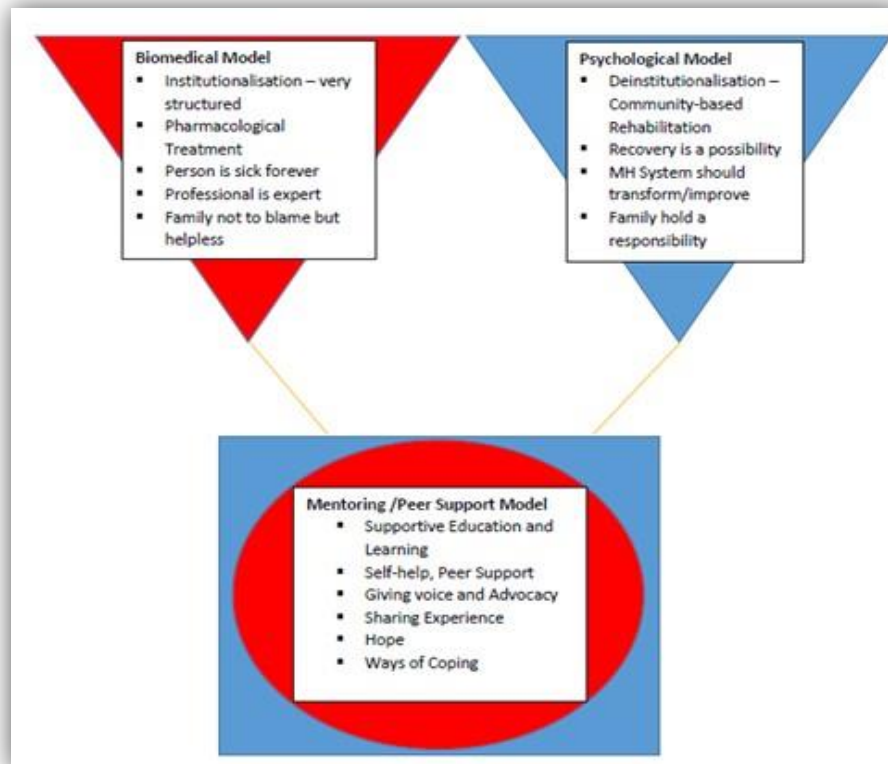


Figure 4 - Model of Peer Support for Relatives (ARAFEMI, 2008)

ARAFEMI advocate a 'Carer Mentoring/Peer Support approach and the purpose of this model is to 'bring together, in a positive way, the Medical and Psychological Models; by shifting the basis of carer services more toward a paradigm of support, learning and education' (Cassar Bartolo & Sanders, 2008). The FRIENDS project has gleaned important learning about the development of training and self-care from projects like ARAFEMI (2008). In particular, FRIENDS has developed an educational model of support by upskilling and training relatives in the topics of peer support, self-care and wellness and evaluation.

2.2.3 The Benefits of Peer Support for Relatives

The benefits of peer mentoring are widely researched and verified. According to the *Mental Health Foundation*, the benefits of peer support are wide ranging for those receiving the support, peer-supporters themselves, and for the mental health system as a whole (2014). One of the key benefits of peer support is the personal warmth and support provided by someone who has lived experience of the difficulties associated with being a relative. Relatives and relative peer supporters gain empathy and respect. Relative peer-supporters could experience an increase in their self-esteem, confidence, and positive feelings that they are helping another relative.

Alongside the considerable benefits to the Peer Supporter and family member being supported, there are benefits for the teams and organisation at the same time. Firstly, in a time of scare

resources and increasing pressures on services, both statutory and voluntary, an integrated programme of peer support for relatives presents an extremely cost effective way in which families can be supported.

On an ideological level, peer support has been identified up as a catalyst in changing the culture of mental health services towards embracing a truly recovery-focused approach. As pointed out by Repper, 'the introduction of peer workers is a powerful way of driving a recovery-focused approach within a team...they challenge negative attitudes of staff and provide an inspiration for all members of the team' (2013b; 11). On a practical level, both supporter and peer gain significant benefits from a face-to-face service which is relatively low cost. However, for a Family Members Peer Support Service to become established, a collaborative approach must be taken whereby by HSE staff and management, Community/Voluntary Organisations and trained Peer Supporters work in partnership, responding to needs of families and creating sustainable and effective alternatives to traditional family support work.

2.3 Strand Three – Needs Analysis and Strategic Plan

The primary aim of the FRIENDS Family Support Strategy is to support the Mental Health Services in their inclusion of family members in service delivery. The Family Support Strategy has been developed from the recommendations set out in the FRIENDS Action Research Report and proposes practical steps which will enable us to improve supports and services for family members with mutual benefits for all stakeholders.

The FRIENDS Family Support Strategy presents a timely, innovative and practical response at local level to recommendations outlined in national policy. Of particular note in this regard is a key recommendations of *A Vision for Change* as it pertains to family members and their support and inclusion. As follows:

'Carers should be provided with practical support/measures such as; inclusion in the care planning process with the agreement of the service user, inclusion in the discharge planning process, timely and appropriate information and education, planned respite care and should have a member of the multidisciplinary team to act as a keyworker/designated point of contact with the team' (Recommendation 3.6).

Moreover, the strategy aims to respond with practical actions to priorities set out in the Mental Health Division Operational Plan 2014. Of particular note are two key deliverables outlined in Mental Health Service Priority Area 1:

'involving service users, family members and carers – moving from consultation to co-production... and 'over-arching model of care – making step change in recovery focus and enhancing clinical excellence' (2014; 3)

As acknowledged by the Operational Plan, culture change is key to achieving meaningful recovery-oriented services and partnership with service users and family members. The FRIENDS Project, having come about under the auspices of the ARI initiative, is firmly rooted in values of partnership and co-production and is the result of engagement with service users, staff and family members across the Midwest Region.

2.3.1 Proposed Implementation & Evaluation

Informed by the research and needs analysis, the FRIENDS Family Support Strategy proposes actions for Mental Health Teams and staff members around inclusion and support of family members. It is hoped that, initially, the strategy could be piloted at local level with the support of one of the Community Mental Health Teams. The FRIENDS Project is being evaluated by an independent evaluator who, as part of her research, will evaluate and appraise the pilot of the Family Support Strategy and make recommendations for further review and implantation. This presents an excellent opportunity for services to improve their supports for family members in a standardised way and engage in practical steps to achieve meaningful involvement of family members in services.

2.4 Relatives Interaction with the National Health Service

Dealing with the National Health Service can be a challenging endeavor for relatives who have loved ones experiencing mental health challenges. In general there is a dearth in Irish research into the experiences of family members accessing mental health services. As a result, there is very limited learning or feedback for the National Health Service to improve the experiences of relatives. The following sections outline some of the barriers relatives experience which have been discussed briefly in other research.

2.4.1 Social Factors

Barriers to social participation as well as a lack of recognition and respect for their role have been identified repeatedly as having a negative impact on family members who provide support for a relative. Factors such as low income and a lack of 'respite' breaks have been pointed to as contributing to poor health amongst family members in supporting roles (Carers UK, 2009, Carers Northern Ireland, 2007). Furthermore, isolation has been shown to be a major issue for both people with self-experience of mental health difficulties and their family members (Hynes *et al.*, 2008).

Research points to the lack of supports for family members as a contributing factor to this isolation resulting in a lack of time off to engage in social activities or participate in the wider community (Carers Association of Ireland, 2008). In 2012, research was carried out into the situations and experiences of family members providing support in West Cork. The

subsequent report, '*Time to Care, Time to Live*', presented snapshot of people's experiences. Isolation was found to be a 'major factor impacting on the health and wellbeing of around two-thirds of Carers/Support Persons' (2012; 5).

These findings echo national and international research, which states that family members quality of life was directly affected by their care roles. Relatives stated that barriers included isolation, stress, ill-health, poverty and lack of time to socialise. They often experienced a lack of recognition for their roles alongside frustration, lack of sleep and emotional strain (2012).

2.4.2 Contact with Mental Health Services

When mental health difficulties occur in a family it can be a time of fear, confusion and upset for all concerned. The first contact with the mental health services is crucial in terms of supporting all members of the family through, a potentially challenging time. In their 'Family Support Study', Katlova-O'Doherty *et al.* reported that 'the first encounter with treatment provision was associated with shock, devastation, uncertainty and vagueness of the participants with regard to what was happening to their relative' (2006; 185).

In addition, research has articulated the needs of family members including; the provision of information and recovery education at the time of first contact with the mental health services (Refocus, 2013; NSUE, 2010 & 2011, Waterford Parents and Carers Advocacy Group, 2006). In response to family members' needs, *A Vision for Change* recommends 'a member of the multidisciplinary team to act as a keyworker/designated point of contact [for family member] with the team'. Thus, acknowledging that there is an inadequate level of support available for family members who care about a relative experiencing mental ill health.

2.4.3 The Mental Health Trialogue

The Department of Health proposes a holistic view of mental illness in a '*Vision for Change*' (2006) which recommends an integrated multidisciplinary approach to addressing the factors that contribute to mental health problems. This policy envisions an active, flexible, and community-based mental health service. The holistic perspective of *Vision for Change* acknowledges the importance of interactions between one's family and peers. Furthermore, it emphasizes the active participation of service users and families in providing essential feedback to service providers.

The CLASS (Carers Liaison and Support Service) project in Kilkenny aim to 'provide peer support for carers, family and friends of people experiencing mental health distress'. In doing so, they implement a '*Mental Health Trialogue*' approach. According to CLASS, this is a model whereby, service user, carer and health professional work together and share information at each and every stage of the process. The interaction between all three groups can affect positive change and effective services.

A similar model, called the '*Triangle of Care*', was developed in the UK by Carers Trust and the National Mental Health Development Unit. The model proposes a supportive alliance between service user, family member and professional. Rooney & Worthington claim that the benefits of partnership and information sharing with family members is that '*carers are usually the first to be aware of a developing crisis – often at times when professional help has not yet been established or is unavailable. They are often best placed to notice subtle changes in the person and usually the first to notice the early warning signs of a relapse*' (2013; 7).

Involvement of family members has shown to have positive impacts on service user outcomes and a reduction in hospitalisation rates (Pharoh *et al.*, 2006; Fadden, 1998). Amongst other supports, family members can provide vital information, which can greatly assist professionals in supporting the individual. If the family member is made feel part of the individual's support system, they will be empowered as an active partner in the recovery process and encouraged to continue giving practical, emotional, social supports.

The collaboration between relatives, service providers and people with self-experience has been at the forefront of all FRIENDS interventions. The FRIENDS training and development worker has championed an open communication process between professional in the mental health services, family members and people with self-experience.

2.4.4 Inadequate Support for Family Members

Much of the research has shown that the vast majority of family members feel that the support they are receiving from Mental Health Services is inadequate (NSUE, 2010; 2011, Waterford Carers and Parents Research and Advocacy Group, 2006; Refocus, 2013). Within the recessionary context in Ireland, services and professionals are struggling to cope with increased caseloads, reduction in staff, increased pressure on services etc. In light of this, supports for family members in the community/voluntary sector are providing recovery opportunities for family members outside of traditional statutory services.

Mental Health support organisations outside of HSE Mental Health Services play a crucial role in supporting family members and optimising recovery outcomes. According to the *Family Support Study*, 'voluntary support resources such as support groups, booklets, helpline, counselling and lectures were viewed by all participants as the best, and sometimes only, source of support specifically designed for families. Educational programmes...were also considered helpful (Kartlova O Doherty *et al.*, 2006; 157). However, a lack of awareness of these services and their potential benefits seems to pervade amongst family members.

2.5 The Importance of Language

The FRIENDS Project is underpinned by a recovery ethos and informed by values of empowerment, partnership and inclusion, amongst others. As part of an anti-oppressive approach, awareness of language is of fundamental importance. FRIENDS are aware of the contentious nature of much of the language used in the lexicon of mental health. Labelling people with pejorative, medicalised terminology can have profoundly oppressive effects.

Of particular note with regard to the FRIENDS Project, is the use of the term 'carer' in practice and policy to describe an individual who supports another in a health or social care context. In their critique of the universal adoption of the term 'carer', Molyneaux *et al.* argue that 'the term may imply burden and therefore devalue the individual who is cared for and in this way polarises two individuals who would otherwise work together' (2010; 422). In advocating for a relationship-based description of caring, they stress the importance of acknowledging the pre-existing relationship – whether partner, friend, relative etc. Similarly, Pilgrim (1999) advocates for the abandonment of the notion of the 'carer' in favour of labels which pertain to specific roles and contexts such as; relatives, friends, supporters and advocates.

In light of the research cited above and in line with the underpinning ethos of the FRIENDS Project, the terms 'family member', 'relative' and 'supporter' will be used to describe those who care about and support relatives experiencing mental health challenges. Family members, in the FRIENDS project, range from siblings, to parents, to extended family. Family members may live with the person with mental health challenges or may be in frequent contact with the person they care about. It is hoped that this terminology will more accurately reflect the lived experiences of participants in this project.

2.6 Key Challenges

Improvements in the experiences of family members in terms of support and involvement are to be celebrated. However, there are very real challenges for services in terms of implementing Family Support Strategies. From the family member perspective, shortcomings within the system of service provision were identified by family members who took part in the national *Family Support Study*. The perceived drawbacks were; 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). Similarly, research has shown that challenges on a systemic level create a barrier to supporting and including family members in a meaningful way. According to Leggatt (2011), there are a number of problems associated with the implementation of Family Support Programmes (see figure 5).

Work priorities:

- *Family work is seen as an 'add on' – an extra task. It is not core business and not integrated with case management and other responsibilities.*
- *Stressful periods in mental health work (particularly acute crises) take precedence over family work, which is then neglected.*
- *Caseloads are considered too large; there is not enough time for patients/clients, let alone their families.*

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.*
- *Workers who want to work with families experience a lack of support, particularly from middle management.*

Figure 5 - Challenges Faced According to Leggatt (2011).

The FRIENDS project has developed and piloted a strong recovery-oriented service, which relies less on staff and professionals by empowering family members to support each other. However, it is crucially important that the FRIENDS project be implemented in conjunction with the Mental Health Service in order to maintain continuity and uniformity of the service across the Midwest.

3.0 Methodology

The purpose of the independent evaluation is to examine the project in depth, to examine its impact, to examine the experiences of people who have been involved and to assess and review the progress to date in achieving the original aims and outcomes. It is hoped that through this independent evaluation, the FRIENDS steering group can learn from those involved with FRIENDS and that some of this learning can be applied to future work and a model of best practice in terms of supporting relatives.

Barry (2007) suggests that evaluation is less of a discrete activity and more of an integral part of a project's core activities in order to fine-tune programme activities to respond to changing circumstances. As a result, the independent evaluator was hired in June 2014 in order to perform on-going evaluation and assessment of the FRIENDS project. This chapter will outline the participatory action research approach adopted in this evaluation and the numerous facets of the evaluation plan.

3.1 Aims of the Evaluation

1. Appraise the work to date
2. Examine FRIENDS' approach to the work
3. Assess the project as regards its effectiveness in meeting the aims and objectives
4. Evaluate the impact of the project from the perspectives of each of the groups of stakeholders – people with self-experience, family members and service providers

3.2 Methodological Approach (PAR)

Participatory Action Research (PAR) is a "systematic investigation, with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or effecting social change"(Israel et al. 1992: 78). With origins in the work of Kurt Lewin (1944), the school of action research stresses the active involvement of those affected by the problem in the research through a cyclical process of fact finding, action, and reflection, leading to further inquiry and action for change. With its emphasis on co-learning and action based critical reflection, PAR also takes influence from educator Freire (1982), who emphasized the importance of critical reflection and collaboration.

According to Kemmis and Taggart, 'participatory research is an alternative philosophy of social research. It has roots in liberation theology and neo-Marxist approaches to community development but also has rather liberal origins in human rights activism. Three particular attributes are often used to distinguish participatory research from conventional research (see table 3).

Community-based participatory research “emphasize[s] the participation, influence and control by non-academic researchers in the process of creating knowledge and change” (Israel, Schulz, Parker, & Becker, 1998, p. 184).

Shared ownership of research projects

Community-based analysis of social problems

An orientation toward community action

Table 3 - Attributes of PAR (Kemmis & Taggart, 2007: 273)

Israel et al. (1992) claim that PAR must be participatory in nature. It must be cooperative by engaging community members and researchers in a joint process in which both contribute equally. It must be a co-learning process for researchers and community members. Overall, it should be an empowering process through which participants can increase control over their lives by nurturing strengths and problem-solving abilities. Therefore, ‘the criterion of success is not whether participants have followed the steps faithfully but rather whether they have a strong and authentic sense of development and evolution in their *practices*, their *understandings* of their practices, and the *situations* in which they practice’ (Kemmis & Taggart, 2007: 277).

‘In an effort to achieve greater and more meaningful community participation in research, a rise has taken place in the number of projects that engage “peer researchers.” Peer researchers (sometimes referred to as PRs) are members of a research project’s target population who are trained to participate as co-researchers’ (Flicker, S. et al., 2010). In this research, relatives of people experiencing mental health challenges, specifically those who had completed the training to become Relative Peer Supporters self-selected to become Relative Peer Evaluators.

3.2.1 The Benefits of using PAR

The benefits of using PAR often realized through authentic partnership approaches between the evaluator/trainer and the community member, in this case the relative. In this evaluation relatives were thought to bring expertise informed by life experience to the evaluation of the FRIENDS project, including personal insights into support services and the National Health Service. Furthermore, ‘the participation of community members in research is believed to enhance the validity of research findings and assist in ensuring that research results are used to inform and foster change at the local level’ (Flicker, S. et al., 2010). ‘The benefits of community involvement in research are well recognized, they include:

- ✓ Improved access to and greater representation of marginalized groups in research
- ✓ Data that are richer in quality and more authentic in their representation
- ✓ The creation of opportunities for local capacity building and empowerment.

3.2.2 Key Characteristics of PAR

The key characteristics of Participatory Action Research, as presented to the Relative Peer Evaluators are outlined below. These characteristics were central to the design of the evaluation methodology and overall approach adopted by the independent evaluator in June 2014.

- PAR is a collaborative approach to research used to gather information to use for change on social or environmental issues.
- PAR is driven by a group of people who have a stake in the environmental issue being researched, rather than an outside sponsor, funder or academic
- PAR offers a democratic model of who can produce, own and use knowledge
- PAR is collaborative involving discussion, pooling skills and working together
- PAR is intended to result in some action, change or improvement on the issue being researched.

3.2.3 Key Challenges Associated with PAR

Conflicts of Interest:

Relatives may be more inclined to participate in a study if approached by a known peer. Care needs to be taken to ensure that the likelihood of coercion is limited. In this instance, the independent evaluator requested participation, thus removing any risk of coercion. Furthermore, conflicts of interest can arise when a researcher has more than one role (e.g. relatives as peer evaluators, relatives as peer supporters, relatives as recipients of support from FRIENDS). The concern is that participants may become confused about the difference between these roles and may feel they have to participate. It is difficult to determine whether role overlap had an impact upon individuals self-selection process. However, the fact that just six out of twenty-four of the relatives engaged in the evaluator training process suggests a lack of pressure to participate.

Confidentiality:

Confidentiality is always an issue in research. Peer researchers, like all staff with access to private information, need support and training to adopt careful protocols around privacy and confidentiality. However, their training needs may be slightly different (Flicker et al., 2010). The concept of confidentiality may be newer for them. Luckily, in the FRIENDS project, confidentiality was a key aspect of the Peer Support training programme. Therefore, relatives had some grounding before engaging with the additional Peer Evaluator training.



Emotional triggering and the need to provide special support:

According to Flicker et al., (2010), emotional triggering is experienced most acutely by peer researchers who had past experience with the topic under study. They highlight that the level of on-going support and supervision necessary to ensure that project needs are met should not be underestimated. Relative evaluators were made aware of the supports available to them from both the independent evaluator and the FRIENDS training and development worker.

3.3 Adapting PAR in this Evaluation

The ethos of co-learning and co-production adopted by the FRIENDS project since its inception played a fundamental role in how the independent evaluation was conducted. In April 2013, FRIENDS requested tenders for an evaluator who would facilitate, train and support relatives as 'Peer Evaluators' or partners in the evaluation process. Agora Research and Learning Alliance was the successful candidate and began working in June 2013. A detailed outline is below.

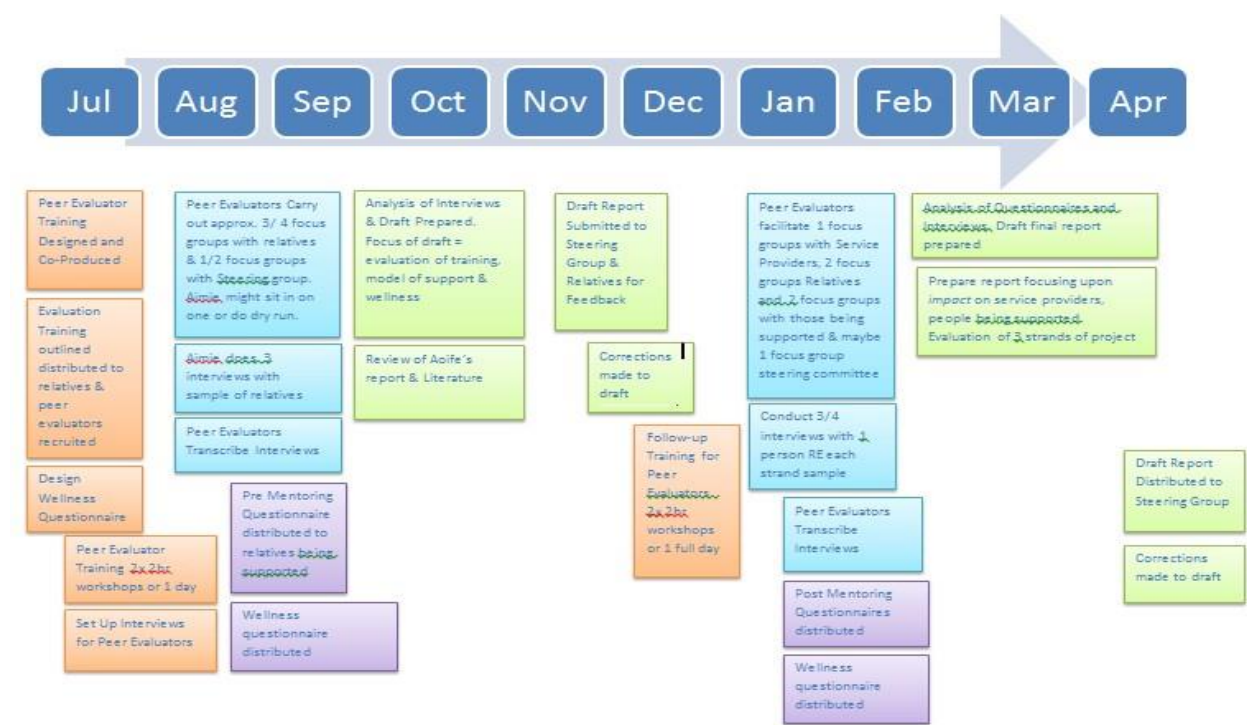


Figure 6- Par Evaluation Plan

The Evaluation plan outlined in Figure 6 illustrates that Relative Peer Evaluators have been integrated as partners in three elements of the evaluation process, i.e. in the design of training; in the collection of data (including design of questions); and in the compilation of the final evaluation report.

3.3.1 Peer Evaluator Training

Training was designed, co-produced and implemented with a group of **six** self-selected relatives who had a keen interest in research, evaluation and upskilling. The training programme was an intensive day course. Learning Outcomes and Content of Peer Evaluator Training are outlined in table 4. Training included practical exercises, role play and group discussion so that the independent evaluator was confident that the Relative Peer Evaluators had gained the necessary knowledge and skills to facilitate data collection in the field.

Background	In the Field	Post-Fieldwork
To Understand: <ul style="list-style-type: none"> the purpose and value or Evaluation Confidentiality Research Ethics Types of Evaluation Types of Questions The Objective & Subjective Self The aspects of the FRIENDS project in need of Evaluation 	<ul style="list-style-type: none"> To facilitate focus groups with other relatives in training To facilitate focus groups with Steering Committee To facilitate focus groups with People attending Wellness Workshops To use a Dictaphone / recording device Consent forms & Data Protection To have the Skills to ask follow on questions, simplify questions 	<ul style="list-style-type: none"> To transcribe all audio data to text To read and contribute to the final report in terms of feedback To have the Knowledge to Voice a Concern and/or Look for Support

Table 4- Content & Learning Objectives of Peer Evaluator Training

Often, the success of evaluations can hinge upon the collaborative nature of the process. As such, the independent evaluator was committed to providing an inclusive environment where all stakeholders were equally important in the development and progression of the evaluation. Furthermore, the evaluator learned from the input of relatives who helped to co-produce the training, research questions and final report, rendering it a co-learning process.

3.3.2 The Role of FRIENDS Peer Evaluators

There were four key duties associated with becoming a Relative Peer Evaluator. Firstly, relatives were required to commit to engaging in a one-day intensive evaluation training workshop. Secondly, all peer evaluators who attended the training were required to get involved on some level in the data collection process. In this instance, relatives were asked to facilitate focus groups and note-take in focus groups.

Following the successful collection of data, relatives were asked to self-select to transcribe the

focus group audio recordings. Similarly, relatives were asked to self-select to give feedback on the evaluation report produced based on the data gathered. All relatives who engaged in elements of the evaluation were remunerated for their time.

3.3.3 Time Commitment of Relative Peer Evaluators

The Independent evaluator and FRIENDS steering group were cognisant of relatives already busy schedules. In response, a maximum time commitment was given to all relatives prior to them committing to the evaluation process. I believe this to be good practice, in that it adjusted evaluators' expectations and successfully reduced the number of relatives who dropped out of the process.

Training	1 full day workshop in Limerick 10am - 4pm
Focus Group Facilitation	1hr per focus group x2 + travel time
Transcription	3hrs per 1hr Audio File transcribed
Feedback	Any time that can be given

Table 5- Maximum Time Commitment for Peer Evaluators

3.4 Methods

A combination of both qualitative and quantitative research methods have been used in this evaluation. Questionnaires, focus groups, and one-to-one interviews were used by the independent evaluator, relative peer evaluators and the FRIENDS training and development worker in order to gain on-going feedback on elements of the programme. Further details are outlined in the following sections.

3.4.1 Qualitative Research Methods

Qualitative research can be defined as the use of methods to extract a subjective, information rich account of its research subject. According to Bryman, 'there is a simultaneous expression of preference for a contextual understanding so that behaviour is understood in the context of meaning systems employed by a particular group in society' (1984: 78). For the most part qualitative methods are unstructured and often participant led. Their purpose is to learn about some aspect of the social world and generate new understandings that can be used' (Rossman & Rallis, 1998). In this evaluation, the qualitative research methods used have been focus groups and one-to-one interviews.



Focus Groups

Focus groups are a type of group interview whereby a small group of about 6 people has a conversation about a given topic, in this case FRIENDS project interventions. The aim was to obtain diverse ideas and perceptions of participants' experiences of the FRIENDS project in a relaxed, permissive environment that fosters the expression of different points of view (Marshall & Rossman, 1999).

FRIENDS Focus groups lasted between 30 minutes and one hour. All focus groups were facilitated by Relative Peer Evaluators. The peer evaluator created a supportive environment, asking focused questions to encourage discussion and the expression of differing opinions. A second trained peer evaluator was always present for support, advice and in case of emergency. The second trained peer evaluator helped the facilitating peer evaluator by taking notes and observing during the focus group conversation. Focus groups were arranged through the training & development worker, thus encouraging a positive response.

All focus group participants attended voluntarily and signed a consent form. Focus group conversations were recorded using Dictaphones and also via a note-taker / observer. Peer evaluators then transcribed focus group interviews. In total, 3 focus groups were facilitated:

- ✓ 1 x relatives who completed Peer Support Training
- ✓ 1 x members of the steering group
- ✓ 1 x relatives who attended the wellness break

One to One Interviews

In addition to facilitated focus groups, the FRIENDS steering group requested that the independent evaluator conduct some interviews with key stakeholders about the running of the programme. Each interview was recorded subject to permission from the interviewee. As with focus groups, questions were semi-structured and devised in conjunction with relatives and were based on the objectives of the FRIENDS project. In total, three interviews were conducted in October and November 2014:

- ✓ 1 x SHINE representative
- ✓ 1 x FRIENDS training and development worker
- ✓ 1 x Relatives who completed Peer Support Training

3.4.2 Quantitative Research Methods

Quantitative research can be seen as the use of precision, scientific based methods in order to gain results that can be replicated by an outsider (Bryman, 1984). Quantitative methods gather statistics that are hoped will yield an unbiased result, generalizable to a larger population (Given, 2008). In this evaluation, a series of questionnaires were used to gather quantitative data.

Feedback Questionnaires

General feedback questionnaires were designed and distributed by both the FRIENDS training and development worker and the independent evaluator over the course of the project. The aim was to garner the immediate impressions of family members after their engagement with the FRIENDS interventions. Feedback questionnaires were used to gather brief but on-going data at the end of wellness workshops, peer support training workshops and evaluation workshops. Samples of these questionnaires are included as Appendices. Results are included in the impact analysis section on page 31 of this evaluation.

CWS Questionnaire

As previously mentioned in this evaluation, the FRIENDS Project is underpinned by a recovery ethos and informed by values of empowerment, partnership and inclusion, amongst others. As part of an anti-oppressive approach, awareness of language was of fundamental importance. In particular, the FRIENDS project made a conscious effort not to use the term 'carer' when describing relatives who support family members in a mental health context. However, the term 'carer' is widely used in practice and policy in the mental health and social care context and the FRIENDS project recognized the importance of using verified robust methods of data collection. For that reason, the FRIENDS project allowed the use of the Carer Well-being Support Questionnaire as a method for quantitative data collection.

The Carer Well-being Support Questionnaire was developed by Quirk et al., in 2007 in response to a call from government to re-think a previous carer questionnaire called the Carers' and Users' Expectations of Services – Carers' (CUES-C). A broad range of outcomes are assessed on the CWS questionnaire because care-giving impacts on several aspects of carers' lives (as outlined in Table 6).

Background	Well-being	Support
<ul style="list-style-type: none"> • Background Information • About You • About the Person you Care for • Taking a Break • Other Comments 	<ul style="list-style-type: none"> • Your Role as a Carer • Your Relationship with the Person you Care for • Your Relationship with family and friends • Your Financial Situation • Your Physical Health • Your Emotional Well-being • Stigma and Discrimination • Your Own Safety • The Safety of the Person you Care for 	<ul style="list-style-type: none"> • Information and Advice for Carers • Your Involvement in Treatment and Care Planning • Support from Medical and Care Staff

Table 6 - Topics Assessed in the CWS Questionnaire

CWS questionnaires were distributed to relatives who attended Peer Support Training prior to the commencement of the first training workshop in July and after the completion of the peer support and wellness training in January 2015. By comparing the results of these pre and post questionnaires for each individual relative, the impact of the FRIENDS project on family members' well-being and support has been quantified. The results are outlined in section 5.3.0.

Part One:

Analysis of the FRIENDS project from June 2014 – December 2014



4.0 Research Findings – PART ONE

The research findings outlined in Part One of this report evaluates FRIENDS success in meetings its three core aims. That is, to develop a model of recovery and self-care for the relatives; to identify and train relatives with skills and capacity to provide peer support to others; and to develop a strategy to inform the inclusion of relatives in the delivery of mental health services in Ireland.

This chapter has been compiled using both qualitative and quantitative data from focus groups, one-to-one interviews and feedback questionnaires. Data has been collected from family members, trained peer supporters and steering group members (See table 7).

Focus Groups	One-to-one Interviews	Feedback Questionnaires
1 x 4 Peer Supporters	1 x training and	20 x Peer Supporter training
1 x 7 Steering group	development worker	questionnaire
members	1 x representative from	2 x Peer Evaluator training
1 x 6 Relatives attending	SHINE	questionnaire
Wellness workshops/break		
1x 2 Peer Supporters		

Table 7 - Number of Participants Taking part in Data Collection

4.1 Outcomes of the Peer Support Strand

The FRIENDS project presents peer support as an empowering vehicle through which family members can support each other in a mutual, recovery-focused manner. Relatives of people experiencing mental health difficulties, who were interested in becoming Relative Peer Supporters, were asked to attend a 7 week training course. The *FRIENDS Peer Supporter Training Course* was designed, developed and co-produced by members of the FRIENDS Steering Group, relatives and workers.

The FRIENDS Peer Supporter Training Course aimed to 'develop the capacity for one-to-one peer support between relatives'. In total, 22 out of an initial 26 relatives finished the course in full. These 22 relatives have enhanced their skills and capacities for peer support in a reflective, supportive and educational manner. At a basic level, the FRIENDS project has been successful in 'establishing and training a panel of relative peer supporters' for the Midwest region. These relatives are ready and willing to help others when a system of referral is established.

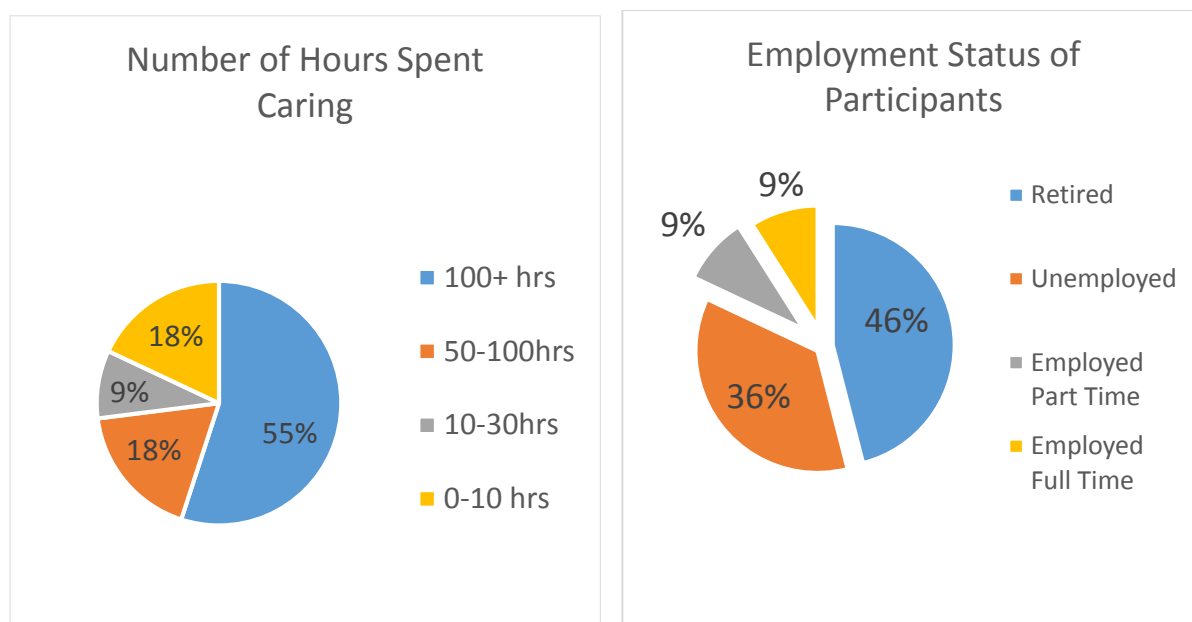
Feedback for the following sections have been derived from a focus group with 6 peer supporters, one facilitated by a relative peer evaluator and one facilitated by the independent evaluator. The findings suggest that the design, development and implementation of *the FRIENDS Peer Supporter Training Course* was extremely well received.

Relatives gained huge benefits from attending the programme in terms of learning, creating friendships, practicing self-care.

4.1.1 Profile of Participants

The peer support training offered by the FRIENDS project attracted interest from a wide variety of people with different lived experiences. 18% of participants were male and 82% were female. The majority of participants (46%) were retired and a further 36% of participants were unemployed (see Figure 7 below).

Of all the relatives who engaged in the training, 20 people were supporting one person with self-experience and four people were supporting two or more family members with self-experience. The number of hours spent caring for their family member varied widely, as outlined in Figure below. The majority of participants lived with their family member and supported them on a daily basis, whereas others (18%) chipped in with other relatives or professionals to support their loved ones.



Participants were so keen to take part in the peer support training that they were willing to travel to Limerick city from across the Mid-West region to attend. Four family members travelled from Co. Clare, and eight travelled from Co. Tipperary in order to attend the training workshops in Limerick. A further ten family members based in Limerick were trained. Participants ranged in age from 33 to 83 years. The FRIENDS training course provided a welcoming environment to all who were willing to embark on a journey of recovery.

4.1.2 Learning Derived from the Programme

As outlined in Table 2 on page 10, the *FRIENDS Peer Supporter Training Course* covered a wide variety of topics including; boundaries, self-care, listening, relationship building and utilizing personal experiences. The aim was to inspire and facilitate relatives' learning. It is

clear from the feedback that the FRIENDS project has excelled in its aim to **'identify relatives with capacity and interest in supporting others'**¹, and enhance their knowledge and skills in the area of peer support and recovery. Relatives had diverse learning experiences, a number of which are detailed below:

'This has been a huge education for me. I would say personally, if somebody wants to help somebody who is sick, who is unwell, the first thing that they need to do is to educate themselves. I have been around illness for years; people talking about it, people suffering. But this has been the most positive and most constructive thing that I have experienced in all that time' (Family Member).

'To me the power of language was very strong. I really understood that when you speak to somebody it means so much more to actually think of what you are going to say before you say it, especially if it's something very important' (Family Member).

'I found that I was a rescuer all my life and I never really understood about being a rescuer. I am so much more aware of it now. Hopefully I'll get out of that. That was very strong for me personally' (Family Member).

'I came away feeling great and learned an awful lot. I really admired the facilitators and how they prepared the programme. I have tried to live my life of standing back and getting more out of life' (Family Member).

The learning derived from participation in the FRIENDS peer support training will be invaluable to family members, not only to their role supporting a relative with self- experience, but most importantly in their own recovery and self-care. Family members have acknowledged the importance of learning and recovery for every family member.

4.1.3 Benefits of Group Relationships

The atmosphere created by the facilitators of the training course was collegial, supportive and induced collective sharing. Relatives worked together to understand models of recovery and approaches to mental health. They performed role-play to enhance their listening and empathy skills and they shared their own personal recovery journey with the group. The combination of the supportive atmosphere created by the FRIENDS facilitators and the enthusiasm of participants created a strong bond of friendship and support amongst relative peer supporters. Relatives highlighted the benefits of group relations:

'It was very comforting being in a situation with people that had similar experiences to you and even if your story was a bit off the wall or if their story was a bit off the wall there was no shock factor. Everybody was at the same level' (Family Member).

¹ All bolded sentences in this section represent a key intervention proposed in the FRIENDS GENIO application in October 2013

'There was a great support from everybody, all the peers together, everybody shared the one experience. To know that is there, and you are not alone. It was a great course. I'd love if everyone in my immediate family would do it' (Family Member).

'It was a very comforting environment and at the time, that was what I needed because [my relative] ended up back in hospital during the course and I got support. I didn't feel like going, but when I went people would understand. It was very helpful that way' (Family Member).

'I thought the training programme was great because you could relate to people in different circumstances, as a carer or you know we all connected in the one, and like there is recovery' (Family Member).

'The biggest benefit of course was being with other people who know what it's like to be in our situation because it's very, very hard for people to understand what it's like unless you have that problem yourself' (Family Member).

Family members clearly gained a lot from listening and sharing lived experiences with others who found themselves in similar circumstances. FRIENDS training facilitators were incredibly attuned to the needs of the group and dedicated appropriate time to building group relationships. Since the training has finished, a number of Relative peer supporters have kept in contact with each other, stopping for a quick chat in the street or organising to meet for a chat. It is clear that family members have benefited from forming peer relationships and supporting each other in their journey of recovery.

4.1.4 Adopting the Principles of Self-care and Recovery

An emphasis on recovery underpins the FRIENDS approach to the inclusion of family members in mental health services. As such, self-care and recovery were strongly integrated into *the FRIENDS Peer Supporter Training Course*. Feedback suggests that relatives gained a new perspective on mental health and became more aware of the need for self-care and personal recovery. This is a hugely significant finding, as the recovery of family members can be often be decentralised when supporting a relative in need. Relatives noted:

I learned that you definitely need time out because you will get mentally affected otherwise, it can be very intense and hard going. When it's bad like it's very bad. It's good to have somebody to talk to. You do need that (Family Member).

'I learned that the tips about resilience are as applicable to me as they are to anybody else who has "diagnosis". Have the courage to be imperfect. It's okay to take time out for yourself. Get a good night's sleep, all those things' (Family Member).

'For me the learning was around the concept of mental health being a family issue. I heard that before, but couldn't really grasp it. The course kept focusing back on us as participants, saying that we had to recover as well. I think, you are so focused on the person who has a diagnosis, that you forget that it is affecting everybody and by looking after ourselves we are going to help that person more. It is only by

taking a step back from that drama triangle that you can enable someone. So there was huge awareness there' (Family Member).

In fact, evidence suggests that relatives began to behave differently based on the learning derived from the training course. Family members began spending more time on their own personal development by taking up new leisure activities and giving themselves time to reflect on their own feelings. Relatives described:

'I noticed that I'm doing things for myself more. You know that If I don't look after myself I feel that I won't be strong enough if something happens to [name] again you know so while he's well now I can look after myself better' (Family Member).

'Yesterday morning I did an hour and half of Pilates, that was the start, I've taken on ballroom dancing, I've taken up art. And last night was another sort of step out of my comfort zone, that all came as a result of the group, I helped chair a SHINE group in limerick, that was a major big step for me' (Family Member).

'I've been out every night this week with one thing or another and I'm not normally like that. I've even gone to Pilates as well' (Family Member).

4.1.5 Benefit for people with self-experience²

After completing the FRIENDS peer supporter training course, relatives found that they were better able to identify the dynamics in their family system. This heightened awareness helped them to reflect more on their own behaviour and begin to respond differently to the relative they care about. Relatives said:

'I feel 100% different. I was always focused on my son. I was ok if he was ok. But actually I wasn't ok, you know, and now I separate the two things. All the time I was trying to help him and he needed to be able to help himself. That has changed now, how I'm reacting to him' (Family Member).

'It's important not to have the person 100% in your focus, trying to do everything for them. As much as we need to do it for ourselves, they need to do it for themselves. I know now that you need to be able to let them. It's good for them to do their thing separate from you as well as its good for you' (Family Member).

Whether relatives are being more cognisant of the language they use, or showing more confidence in the capabilities of their family members, relatives have begun to behave differently towards the person they care about. Often, as family members, there is a tendency to try to rescue the person who is cared about. However, when this strategy is unsuccessful, it can cause tension and frustration in the family. Relatives who have developed a different perspective on their caring role have the ability to reduce their frustration in the situation

² It should be noted that no people experiencing mental health challenges were involved in this stage of the evaluation. The impact of the FRIENDS project on people with self-experience has, therefore, only been assessed through the perspective of family members involved in the FRIENDS project.

and help to empower their relative experiencing mental ill health.

4.1.6 Appreciation to FRIENDS

Relative peer supporters voiced their appreciation to both the independent evaluator and the FRIENDS training and development worker for the opportunity they were given in engaging with the FRIENDS project. Family members' experiences have been extremely positive and very encouraging as a model for family support in the Midwest. Relatives said:

'I would like to take this opportunity to thank everyone involved in the FRIENDS Peer Support Training Sessions. The whole experience was a new learning curve for me, engaging with fellow family members and the facilitators was a new recovery journey for me. The training sessions provided social, emotional and intellectual stimulation over the seven weeks' (Family Member).

'In a nutshell there was a wonderful ethos of kindness in the group and that is what I will take away from the training. Life is hard enough, learning to be kinder to ourselves and those around us on a daily basis seems simple but sometimes the simplest ideas are the most difficult to put into practice consistently' (Family Member).

'A very enjoyable inclusive course and because of that I looked forward to coming in each Thursday. I really enjoyed the course on so many levels. It was both exciting & challenging and trusting the process was very beneficial. One of the many challenges for me was that as a peer to peer supporter I don't have to have answers, I found this very liberating' (Family Member).

The FRIENDS project has made a significant impact on relatives appreciation for self-care and recovery, understanding of peer support and in some cases has gone some way to change the dynamic between them and their relative experiencing mental health challenges.

4.1.7 Recommendations for the Course

Finally, relatives were asked for any suggestions to improve the content, delivery or structure of the FRIENDS Peer Supporter Training Course into the future. It should be noted that relatives were hugely eager to praise the course and its delivery. However, some excellent practical recommendations were put forward that relatives would have 'done differently' to improve the overall running of the course.

In relation to course content, relatives recommend:

'I found a lot of the language was for people who already had an understanding of a recovery type language, which I felt could alienate some people. I know that a lot of the research comes from outside of Ireland (like America or Australia). I felt that sometimes that came across in the delivery of the programme, kind of

psychobabble. People coming to this for the very first time have absolutely no concept, like myself. Some things went completely over my head' (Family Member).

In relation to course location / structure, relatives recommend:

'I would have preferred a different setting. I would have preferred a table. I know maybe- funding and that, but it would have been nice, I mean you are there trying to struggle on your lap' (Family Member).

'I suppose in the sense that its peer to peer. Possibly you could be paired with somebody. You might support that person and that person would support you in the course. You could give feedback to a facilitator to see if you were doing it the right way' (Family Member).

'I think an extra bit of training would be very beneficial, because it was always about the clock. You have to have a structure. But sometimes it's nice not to have too much of a structure, that people can talk a bit more if they need to' (Family Member).

In relation to National Approaches to Mental Health. One Relative Recommends:

'Everybody needs to learn how to cope with whatever problem comes up and learn how to enjoy things. We all have mental health. To me more courses, even for the likes of professional people in regards mental health, are needed. We all need to learn what's going on for the person, it's not just about medicine. We all need to learn the human side of it as well' (Family Member).

In relation to course delivery, relatives recommend:

'Most courses you go on, you get a text book or some kind of a workbook, it would have been nice to have something like that, to go through and to be reminding yourself. If you had a little workbook, each week you could be writing in your reflective practices. Because with anything you go away and you know you forget about it, but if you are writing things in and six months down the line there is a crisis, it would be helpful to have that little workbook to look over' (Family Member).

'Extra role-play would have been great. It would have meant that you would get into the experience and you know how to handle every experience much easier because you are actually doing it' (Family Member).

'It would be good if you could get a handbook, like a glossary of that section or whatever. You could get abbreviations and definitions of terminology and things like that. So you could understand' (Family Member).

In response to the course delivery recommendations it should be noted that the FRIENDS training and development worker has prepared and distributed an in-depth workbook, which includes all the slides used during the training course along with all of the theory and

literature covered during the course. Finally, and most for family members, the workbook has recorded all the learning and feedback from participants as a group. For example, in a creative group exercise, relatives were asked to get in to small groups and draw a good peer supporter. The results, which are included in the FRIENDS peer supporter manual are illustrated in Figure 7.



Figure 7 - A Creative Exercise Included in the FRIENDS Peer Supporter Manual

Using their new workbook, family members can take the opportunity to identify, review, and reflect upon their recovery journey whenever they may need into the future.

4.1.8 Informing Relatives about the Project

In focus groups, family members were asked how they initially found out about the project and their understanding when signing up for the project. Interestingly, the majority of relatives reported that they knew very little about the project when they arrived at the first day of the training course. Relatives said:

'I didn't really understand about the project, what it involved. I had never done anything like it before, so I was wondering what would happen (Family Member).

'I knew that it was being run by Shine. Other than that, I took from the name, that it was something to do with family or friends of people with mental health issues (Family Member).

'I went in with an open mind. I had no experience of the thing. The induction day made me interested' (Family Member).

'It should be more advertised because it was only really by accident that I had heard about it. [Name] just said that it would be sociable for me and I said ok. There was no major notice that I saw anywhere. It was just a fluke' (Family Member).

The training and development worker has noted that, through a travelling roadshow, a series of information talks were given both at wellness workshops and to family support teams around the region. The aim was to introduce the project to teams and distribute leaflets so that professionals on the ground could understand the objectives of the project. FRIENDS then used those people as a vehicle to recruit relatives. Perhaps when these teams were introducing the project to relatives there was some miscommunication.

However, the steering group also note that family members were asked to sign an expression of interest form. This would suggest a disconnect between the perception of the family members and the actions/perceptions of the steering group. Perhaps, family members need to experience the process of recovery before they can fully appreciate their value and capability to support others.

4.1.9 Thoughts about the Future of the FRIENDS Project

Relatives have dedicated their time and energy into developing and enhancing the FRIENDS project. It is not surprising that when asked about the future of the project, relatives are concerned that their capacity may be lost. Not only are they concerned for those who they are willing to support but also for their own recovery and the collegial bonds they have formed with other peer supporters. Relatives note:

'It would be very disappointing if this was the end of it. You know a flash in the plan, you were lucky to get it. It would be nice if it could be once a month or once every two months or something like that. Keep the momentum going. And the space that it creates for people' (Family Member).

'I would hope that it wasn't just the one off, that there would be a follow up to it, that this wouldn't be the end of it' (Family Member).

'I am determined to become a Peer Supporter because I feel so empowered after this course, and I want to unlock my potential to enable people I meet to transcend their difficulties' (Family Member).

'It's a unique opportunity. And it's the way things need to be going. I know personally if you walk into a psychiatric hospital, you won't see something like this up on the wall or you won't be taken aside by a medical professional, and say look, you are a family member this would help, or this has helped other people. If I had known about something like this six or seven years ago I would have been straight into it' (Family Member).

FRIENDS Relative Peer Supporters are currently trained and ready to support other relatives in their local area. They have engaged enormously with all aspects of the FRIENDS project, from the Peer Supporter Training Course, to the wellness workshops, wellness break and even the Peer Evaluator Training Course and evaluation facilitation. It is hoped that the FRIENDS project will get the necessary support from the Health Service Executive to continue the project to the next stage, including piloting the FRIENDS peer support model.

4.2 Outcomes of the Wellness & Recovery Strand

When designing the FRIENDS interventions, it was considered essential that a strong emphasis be placed on individual wellness and recovery. It is crucial that relatives recognise the importance of their own recovery and needs and have adequate support in maintaining their wellness. Relatives were presented with an opportunity to engage in a series of wellness workshops and/or a wellness break including a night away in Killarney. The wellness workshops and break were aimed at assisting relatives to practice recovery and self-care and provide a collective space for people to explore wellness in the context of their own recovery.

4.2.1 Impact of Wellness Workshops

In total, 44 relatives attended and engaged with FRIENDS wellness workshops around the Mid-West, namely Limerick, Clare, Roscrea and in the Ciunas Centre in East Clare. In total, 34 feedback forms were completed and returned to the FRIENDS training and development worker. This represents an excellent 77% response rate.

Table 8 outlines the overall feedback from three out of the four information and wellness workshops (Limerick, Clare and Roscrea). Table 8 indicates that the vast majority of relatives found all aspects of the wellness workshops very good. In particular the inclusion of guest speakers was well received.

	Fair	Good	Very Good
Overall organisation		7	19
Content of the workshop		8	18
Guest speakers		3	23
Venue	1	6	19
Discussions/Group work		7	18

Table 8 - Feedback from Wellness Workshops

When asked which part of the day they you find most useful, most relatives cited group sharing as very beneficial. Relatives said they enjoyed '*listening to other people's stories*' and sharing their own experience in a safe environment (relative 1). In addition, relatives were particularly grateful to be given an opportunity to '*to feed back into services with staff present*' (relative 2). They enjoyed hearing about the '*improvement of mental health services*'

(relative 3) and learned about *'services that [they] had not realised were available'* (relative 4).

However, relatives were keen to highlight the need for more equity when discussing personal stories. A number of relatives felt that some people were allowed to dominate the discussion, saying that they *'took over the meeting'* (relative 6) and *'took a lot of time'* (relative 7). This feedback is crucial for group facilitators who need to be mindful that relatives are volunteering their precious time to attending and are all equally willing to share experiences.

Finally, relatives provided constructive feedback for the running of future wellness workshops. In a practical sense, relatives felt that *'more notice'* should be given when recruiting participants, as relatives have significant commitments (*Family Member*). Similarly, for those who have to travel there might be the option of *'organised transport'* or at the very least car-pooling (*Family Member*). Relatives felt that they learned a lot from others who attended the workshop and suggested that workshops *'could be held once a month'* so that they could continue to derive benefit from their attendance (*Family Member*). Finally, in relation to the content of the workshops, relatives suggested that slides be printed and given to attendants and that more *'more information on all of the mental health organisations, such as where they are and contact numbers'* should be handed out at each wellness workshop to ensure that relatives are fully supported (*Family Member*).

4.2.2 Impact of the Wellness Break

Relatives who took part in the peer support training were invited to attend an overnight stay in Killarney in 2014. The weekend included; transport, talks and workshops, group activities, food and accommodation at no expense to the participants. More than half of the trained relatives, 14 in total, attended the wellness break. Six relatives who had attended took part in a focus group facilitated by a peer evaluator, to discuss their experience of the FRIENDS wellness break. Furthermore, two steering committee members were asked for their thoughts about the objectives and benefits of the wellness break. The findings are outlined in the following sections.

Understanding the Wellness Break

Relatives were made aware of the purpose and benefit of the wellness break during the peer support training programme. Relatives noted that they were not entirely sure about the content or structure of the weekend when signing up but that they trusted FRIENDS to do a good job in organising a beneficial wellness break. Relatives said:

'Well the word Wellness to me is marvellous anyway because I'm so used to the word Mental Illness, that when the word wellness is used it's so much better. I was delighted to hear about the wellness break because after the course I felt at a loss because like, will we ever meet all those people again' (Family Member).

'I understood that it was a respite, a weekend towards our own wellness as carers, that it would be a break for us' (Family Member).

Social Support

The findings suggest that relatives derived a significant positive impact from attending the weekend in Killarney. Relatives said that the most notable benefit was meeting up with the people they had met on the peer support training course because of the bonds they had developed with the other relative peer supporters. Relatives noted:

'The best part of it meeting everyone again and understanding what was going on in everybody's lives' (Family Member).

'There was the social aspect of meeting everyone again. We had some fun, a singsong and a bit of dancing, it was nice' (Family Member).

'I wanted to attend because I wanted to meet up with everybody again. I had made a lot of contacts and friendships and a bit of space for myself too' (Family Member).

It was the connectedness. Knowing the people, that was the vital thing. Because we all had shared our emotions at an intimate level, that intimacy was there on the wellness break. That feeling of safety was there for me and that showed up the night of the music. Being able to just cut lose and get up and dance and it didn't matter who was looking because I was in the moment (Family Member).

I would suggest that the impact of strong group bonds was crucial to the success of the wellness break. Relatives were more likely to step outside their comfort zone when they were surrounded by familiar faces who had shown them such warmth and support during training.

Self-Care and Recovery

The underlying ethos of the FRIENDS wellness break was to provide a space to concentrate on recovery and self-care outside of the peer support training course. A number of talks and workshops were held over the course of the weekend focusing on Wellness and Recovery. Workshops included; what recovery means, how to implement wellness tools into day-to-day life, mindfulness and energy therapy. These workshops were facilitated by the FRIENDS training and development worker. Feedback suggests that relatives derived great pleasure from engaging in workshops and came away feeling re-invigorated and motivated to make a change in their lives. One relative noted:

'I have a new way of looking at things since the weekend. Particularly in looking after yourself and getting yourself up and going because, in the very beginning you do cut yourself off from others and it's a very lonely place. You can stay there if you don't get someone to give you a push. It is tough because you do feel the victim at times. I'd say the course and the weekend definitely helps with meeting other people and helps you lift yourself out of that lonesome place' (Family Member).

Similarly, one relative was inspired to overcome his fear of the water. One of the group activities organised by FRIENDS was a boat trip around the lakes of Killarney. Not only did the relative go ahead with the boat trip, as he felt supported by all the other relatives, he was also

inspired to enroll in swimming lessons when he got home to his own county. He said:

'The last time I was in the water was 1968. One of the benefits of the weekend was facing my fear of water, I got onto the boat. I actually signed up for swimming this week' (Family Member).

Personal break from other commitments

Some relatives indicated that the wellness break successfully provided them with an opportunity to take time for themselves, away from their many other commitments. One relative pointed out how difficult it is for her to organise a break away with her partner or other family members. Therefore, the FRIENDS wellness break was successful in giving relatives a space to concentrate on self-care and recovery. Relatives said:

'The benefit for me was just the break for myself. A night off. The phone wasn't ringing all the time and there wasn't loads of texts. [My family] managed without me. I remember saying to myself, I must do this again' (Family Member).

'I was really looking forward to it because I hadn't really had a break in 6 months and it was absolutely lovely to have a break on my own. I feel the better of it now' (Family Member).

There is no doubt that family members dedicate significant time and emotion to caring about their relatives with self-experience, whether it is in a formal or informal capacity. While most family members would not change their arrangement, it is vital that relatives are shown appreciation and care by mental health support services. A break away to focus on self-care and recovery can be hugely beneficial. Therefore, I would recommend that wellness breaks be continued, not as respite but instead as an enjoyable space for relatives to concentrate on their own recovery.

It should be noted, in relation to the Wellness and Recovery strand of this project, FRIENDS did not achieve as much as they had set out in their original GENIO application. In many ways, the FRIENDS project was hugely ambitious in its original aims and objectives, particularly given its tight timeframe of just 12 months. It is not surprising perhaps that one element of the project received less attention than the others. In this case, an enormous amount of effort was directed at both the peer support strand of the project and in generating a needs analysis and corresponding Family Support Strategy, both of which were very significant and are hoped to have major benefits for family members. If the FRIENDS project had received additional funding or an extended timeline, it is fair to suggest the Wellness and Recovery strand of the project would have been further developed.

4.3 Outcomes of the Strategic Plan

4.3.1 Conducting a Needs Analysis

In order to develop the Family Support Strategy, an action research study was carried out by the FRIENDS training and development worker. The research was qualitative by design. Data collection was carried out by means of a needs analysis which comprised interviews and focus groups with participants who represented all stakeholders i.e. service users, family members and service providers in the Midwest. 'Calls for Participants' were sent to HSE teams, service users and family member support groups. Participants then self-selected from across the region. Numbers of participants are outlined in Table 9.

	One-to-One Interviews	Focus Groups
Family Members	5	2 (13 participants)
Service Users	2	1 (6 participants)
Service Providers	5	1 (30 participants)
Mental Health Support Organisation	1	

Table 9 - People Involved in the Needs Analysis

By listening to service users and staff at local and regional level, the FRIENDS training and development worker gathered valuable primary evidence which informed the 'FRIENDS Family Support Strategy'. The aim of the needs analysis was to get ideas for the development of the Family Support Strategy from relatives, including what they needed, what is their lived experience, what would work for them?

The needs analysis was then used to design a FRIENDS Family Support Strategy. The strategy includes practical protocols around supporting family members and involving them in partnership processes at all levels of mental health service planning and delivery. According to the training and development worker, *'The FRIENDS strategy is almost like a 'how to' in including families, to make sure that family members are represented at all levels of service delivery'*.

The training and development worker has acknowledged that the needs analysis is based on a relatively small sample of participants and does not claim to reflect the views and experiences of all service users, family members or service providers. However, it does represent the coming together of staff, family members and voluntary agencies to produce a working strategy to improve the delivery of services to family members in the Midwest.

4.3.2 Challenges Constructing the Family Support Strategy

The FRIENDS needs analysis and corresponding Family Support Strategy were constructed

using vital primary research from a combination of key stakeholders i.e. family members, service users and service providers. One of the biggest challenges faced by the training and development worker when conducting the research was accessing participants, particularly members of senior management in the Health Service Executive. She said:

'Many members of HSE management expressed great support for the project and a commitment to including family members in Mental Health Services. It was important for us to include their views and experiences as part of the needs analysis but unfortunately, due to increased demands and numerous other priorities, most were unable to take part in the primary research which was a pity' (FRIENDS T&D worker).

The FRIENDS team has responded to the HSE's need to expand their service to include relatives in the delivery of mental health services, as outlined in a *Vision for Change*. The team has made a significant effort to construct the Family Support Strategy around the HSE Key Performance Indicators in order to help them adopt the principles of the FRIENDS project. Furthermore, the team has collaborated with HSE service providers in both in the needs analysis and on the steering committee. It is therefore, hugely disappointing that the Midwest management team has not taken the opportunity to familiarise themselves with the workings of the project, or indeed contribute to the construction of the FRIENDS strategy.

The FRIENDS training and development worker also found it difficult to deal with a variation in the extent of 'buy-in' from different service providers. She felt that some people perceived the project to be a nice side project but not integral to the primary clinical work of the service providers. She said:

'Going into teams when introducing the project I could see a difference straight away, different people's reaction, different levels of belief in it. Don't get me wrong, there are some amazing individuals who are passionate about the project and will drive it from the inside, but there is not a service wide commitment' (FRIENDS T&D worker).

In contrast, feedback from service users and family members was extremely positive. Individuals were keen to get involved, to share their lived experience and to offer advice on their needs, while also accepting the current level of pressure on Mental Health Services in the region. The training and development worker found focus groups with service users (people with self-experience), very fruitful. She said:

'Focus groups with services users was great, people had great ideas and insights. People have had very mixed experiences of their family members involvement. Some service users wanted family members involved more than others. It's interesting when you look at the family because dynamics and different stages of the recovery story play a significant role in people's perceptions. It was very important to have the service user's voice included and that our objectives lead towards the service user' (FRIENDS T&D worker).

In this sense, focus groups with service users also confirmed the importance of the FRIENDS focus on recovery for family members.

4.3.3 Content of the Family Support Strategy

From the Recommendations proposed in the needs analysis, the FRIENDS training and support worker produced a grounded, evidence-based strategy for the inclusion of relatives in the Midwest Mental Health Service. This report outlines both the vision and needs of relatives, while also providing comprehensive guidelines and protocols for the health service executive. The action guidelines outlined in the FRIENDS Family Support Strategy fall into the following key areas:

- Supporting Recovery for the Family – Staff Training
- Provision of General Information to Family Members
- Family Members Needs Assessment
- Family Members Recovery Plan
- Information Sharing Protocol
- Checklist for Family Support

The strategy has been designed and written using the Key performance Indicators of the Health Service Executive in mind. In this sense, it speaks their language so that senior management can engage with it and see where it fits in the national plan for service delivery. Relative Peer Supporters presented the FRIENDS Family Support Strategy and needs analysis to the HSE in December 2014.

4.3.4 Key Actions for the FRIENDS Family Support Strategy

The strategy is informed by research and needs analysis carried out as part of the FRIENDS Project. Table 10 outlines the key recommendations from the needs analysis report and suggests corresponding action steps.

	Recommendation	Action Step
1.1	Services should recognise, value and promote the role of family members in supporting an individual's recovery.	Family Member Awareness Training for staff to be developed
1.2	Family Members need to be supported in their role and have their unique recovery needs holistically assessed.	Family Members' Needs Assessments
2.1	Family members should be provided with appropriate information during their first contact with the services. Basic information on service delivery and supports should be available for all family members	Information Pack/Resources for Family Members to be developed
2.2	Recovery education should be promoted by mental health services and opportunities should be provided to all relatives to engage in recovery education.	Pathways for <i>Recovery and the Family</i> and other recovery education initiatives to be included in Relatives Needs Assessment
3.1	A designated key worker/point of contact should be available to family members who are supporting an individual using the services.	To be incorporated into Family Members Needs Assessments
4.1	The benefits of information-sharing and partnership working should be promoted and there should be open communication and clarity for all stakeholders around confidentiality. Where possible, a tripartite approach to information-sharing should be taken with family members involved as key partners.	Information Sharing Protocol to be developed
4.2	Clarity needs to be provided to all stakeholders around consent and information sharing. Distinct options should be made available for service users as regards consent to share information and standardised processes be made available.	See Information Sharing Protocol
5.1	A partnership approach to discharge planning must be taken and communication involvement of family members in a solution-focused discharge plan is to be emphasised.	When consent is given, family members to be involved in discharge planning as soon as possible after service user is admitted.
5.2	Attention needs to be given to family members' experience of Involuntary Admissions and information on crisis supports and Authorised Officers be made available	Information on involuntary admissions procedure and authorised officers to be given to relatives as part of information pack

Table 10 - Findings from the Needs Analysis & Suggested Actions

4.4 The Management of the FRIENDS Project

4.4.1 Identifying a Need for the FRIENDS Project

For people experiencing mental health problems, the importance of relatives and family is a crucial part of their recovery. There are gaps in the current mental health service in the Midwest which can lead to an over reliance on family members. Sometimes family members are asked to take on roles that the mental health should be fulfilling. Therefore, family members can find they very quickly become involved in the care and support of their relative with self-experience.

Despite the reliance of the Mental Health Service on family member's support, relatives say they still feel very isolated from the service. Relatives have highlighted the need for a family member support system that acts in tandem with the Mental Health Service so that they can work in partnership with the mental health service and they can also feel supported in their own caring role. However, family members are understanding of the pressures on the mental health service in the Midwest. One family member said:

'Nurses and doctors haven't time with carers and families when they are so stretched with patients or the people they have to look after. They can't give the time a lot of them would like to give to listening to the carers and talking to them and helping them. In my mind it is wonderful to see an outside group and organisation like FRIENDS that can listen and help so wonderfully well' (Family Member).

According to the FRIENDS training and development worker, the project is an opportunity not only for family members to connect on a peer to peer level, it also provides the space for families to advocate for their needs, to form as a group rather than be the silent carers of the past, and to become more politicised in their needs. Furthermore, feedback from the Principle Social Workers involved in the FRIENDS project has been very positive. They say:

I am delighted that FRIENDS is highlighting a group of stakeholders who traditionally were not really heard. I think the whole idea is to empower the relatives / supporters / carers to really support each other and not to suffer in silence (Principal Social Worker – Clare MHS)

'The whole team is so excited and energised by all the good work that has been happening in Aras Follain and seeing how the peer support model has been so powerful in people's recovery and would be very supportive of that been extended to family members because we have seen it in action and know how well it works' (Principal Social Worker – North Tipperary MHS).

4.4.2 Collaboration

As with all multi-agency projects that bring together members of the statutory agencies, voluntary agencies and representative agencies, managing the project was a challenge. It was important that every key stakeholder group was well represented and worked together for the shared goal of the FRIENDS project.

Initially, a core group of representatives came together to get the project started, to hire the training and development worker and address financial outgoings (see table 11).

Core Steering Group	
Ann Marie Flanagan	Representative from SHINE
Laura Thompson	Principle Social Worker North Tipperary
Paul	Principle Social Worker Clare
Margo Roche	Representative from Aras Follain

Table 11 - Core Steering Group Members Nov 2013

At this early stage, family members were not represented. The lack of family representation and a lack of geographical representation was recognised by core steering group members. As one member said:

One of our concerns was that there wasn't representation from relatives. Another concern for us was that we wanted to have the steering group representative of the geographical area, bearing in mind the wide spread of the region (Steering Group Member).

As a result, the core steering group started to recruit new members for the steering group. By January 2014, the steering group had evolved to include a wider group of voluntary agencies as well as family member representatives with lived experience. However, the lack of family representation in the initial months of the project, when some of the main design decisions were being made, was a failing of the project. It would have been more true to the co-partnership approach to the project if a family member was involved as early as the application to GENIO for funding. One steering group member notes:

It would have been nice if we could have brought on board our family member representatives earlier. I remember thinking we are making a lot of decisions here and we are not fully representative of the project, so part of it didn't feel true to the aims of the project so it would have been nice if we had figured out a way to do that beforehand, however, there was evolution. It has evolved into the most amazing course and a huge commitment by a huge number of people so it shows the progression (Steering Group Member).

Despite this learning, it was essential that an interdisciplinary group stepped up to drive the project in the initial stages. Findings indicate that steering group members showed great passion and commitment to the project. With the exception of minor differences, steering

members shared the vision and values of the FRIENDS project and their input was invaluable in progressing the project.

'I found working with the steering group great. To have many different perspectives, many different agencies coming to the table with a shared vision. I have to say that our values, our vision for the project was shared undeniably amongst all members of the steering group. Operationalising those values was challenging at times but there is no doubt that there was whole-hearted commitment from everyone, there was passion there, in that sense it was a really positive experience' (Steering Group Member).

'This is such an exciting project and no matter what happened I was going to make time for it. I wanted to be involved in this in every aspect of it. It is powerful and brilliant – who wouldn't want to be involved?' (Steering Group Member).

Indeed, steering group members felt it was very exciting that an interdisciplinary team was formed and was working together to improve the experience of family members. One member said:

'The exciting part was that the project was recognised by the senior management team as one of the best examples of the ARI project as it showed how different agencies both voluntary and statutory could sit down together, even with all our differences, our different hats and different perspectives, and work very well. It was a tremendous success. I'm sure there were difficulties and difference of opinions but we worked through a lot of it' (Steering Group Member).

Other challenges faced by the FRIENDS multi-disciplinary steering group included shared time commitments. Some partners felt that there was a lack of clarity around the expectations of input from all individual members. As one member noted:

'While there were three partners in the project, there was no expectations. At one point, I felt I needed to step back because I didn't have the capacity within my working space. I really felt very conflicted' (Steering Group Member).

The variation in commitment from partners is always challenging because people who represent organisations, whether they are voluntary, statutory or otherwise, have different constraints on the use of their time. The FRIENDS Group have been cognisant of people's differing capabilities and have tried to respond. For example, one steering group member said:

'It is complex. It is something we shouldn't run away from. One of the things we discussed was to actually have written agreements from the organisations so that they can be clear what is possible for them to bring to the table early on in the process, rather than putting down equal partnerships' (Steering Group Member).

In multi-disciplinary groups, representatives can be working full-time, part-time, can be paid to attend steering meetings, or can be attending in a voluntary capacity. In order to accommodate the complex working situations of representatives, steering groups have to be

flexible in their approach. While written agreements may enhance the clarity of expectation from the outset, in reality circumstances change and resources can become scarce overtime, therefore, flexibility is the key to maintaining harmony and a collegial working environment on the steering committee.

Finally, like many other collaborative projects, the FRIENDS steering group faced challenges around the ownership of the project. While each steering member brings a different perspective to the table, who makes the final decision particularly where there is not a clear majority. Furthermore, who is ultimately responsible for delegating tasks or constructing the framework for the project. Ideally, all members contribute equally and a full consensus is reached before any decisions are made. However, when the timeframe is as short as one year in the case of the FRIENDS project, is a full consensus possible? Steering group members commented on the challenge of ownership:

'I think there is always an issue in collaborative projects about where the decision making authority lies. I think even now there is a lack of clarity on who owns this project? Are we making decisions as a collective? I think that discussion needs to be had early on in these kinds of projects' (Steering Group Member).

'It's not imbalanced it's not totally balanced but everybody's heart is in it, people are genuine in it and that's as balanced as I have got in most other partnerships I have been involved in' (Steering Group Member).

One key decision, which progressed the project immensely was to employ a full-time paid worker. The training and development worker who was hired in November 2013 by the steering group has been driving the project at a tremendous rate. She has achieved an enormous amount within her 12 month contract. As one steering member noted:

'I think it really helps to have a paid worker. We were so blessed to have her. That helped. I think it is amazing to have someone who has been able to keep the continuity, keep all the balls in the air. At the same time, I think maybe that allowed some of us to step back' (Steering Group Member).

Feedback from steering group members would suggest that more time needed to be spent at the beginning of the project refining some of the structural and managerial aspects of the project. However, it is clear that, instead of discussing the management of the project, time was spent driving the project interventions, without which the project would not have achieved so much in its short time-frame. It is hard to argue with the enthusiasm of project members and their commitment to the family members involved in the project. Therefore, in this case it is perhaps better that the management of the project was not as much the focus of the steering group.

Part Two

Analysis of the FRIENDS project January 2015 – April 2015



5.0 Research Findings – PART TWO

Given the immense work that was done to develop a comprehensive and applicable strategy before the end of December 2014, the GENIO foundation decided to grant a requested extension on the spending of the awarded grant until April 2015. Therefore, Part II of this report evaluates the progress of the project from January 1st 2015 until April 1st 2015. During these months, some significant steps were made to support a more peer-led steering group and promulgate the FRIENDS strategic plan in order to gain some stability into the future.

5.1 Impact of a Re-imagined Organisational Structure

Between January and April 2015, changes began to take place in the overall management committee of the FRIENDS project. Firstly, the contract for the FRIENDS coordinator ended and she moved on to other employment. Her absence meant that tasks needed to be distributed more evenly amongst members of the steering group. Representatives from the lead organisations were keenly aware of their limited capacity to commit time to the project beyond the initial pilot phase of April. As a result, an effort was made to involve more peer supporters as members of the steering committee, with a view to the project becoming wholly-peer led in the future. In an interview, one steering group member described some of the changes that took place;

"In January, we invited everyone who did the peer supporter training to be part of the steering group. We have a core group including some of the chairs [representative from SHINE & Aras Follain]. We then began sending the minutes of our meetings out to everybody, even if they don't attend, letting them know they are welcome" (respondent 4).

Initially, the transition from having a project coordinator to dealing with multiple steering group members for different roles proved difficult. People took time to adjust. For example, one steering group member said: *"for me it's been a little bit confusing not to have one identified person to be able to ring or to contact"* (respondent 2). This comment echoed general feedback from other members, thus suggesting that perhaps more of a formal approach and improved communication was needed in response to the transition.

The movement of the management structure towards a peer led model was an ultimate goal of the steering committee. Once peer supporters became more involved in the steering committee, a new sense of ownership began to emerge, which better represented the underlying ethos of the FRIENDS project. One steering group member explains:

"The current structure of the steering group really typifies the ethos of the project, the ownership of the project I would think, needs to be with the family members, you know, that voice needs to be the strongest voice because that's what makes this project different. We're moving more towards that now (Respondent 3).

Both professionals and family members identified benefits to having a greater representation of relatives on the steering committee. In particular, both groups experienced a degree of demystification about the other. They said;

"As a family member, there is less of a "them and us" because we actually put faces to people and you become more relaxed around professionals" (Respondent 5).

"From a professional point of view, it helps for us to work in partnership with family members because sometimes we can become very focused, too focused on the way we, as professionals, think about things so to have everybody's view-points well represented makes a big difference to helping us have a better view on what the issues are and how best to help people" (Respondent 4).

Furthermore, the increase in the number of family members participating in the steering group enhances how the FRIENDS committee works. In particular, it removes notions of tokenism which were a concern when the project was in its first stages. Increased collaboration also encourages family members to feel valued members of the project. Practitioners and family members both commented on the improved collaborative structure of the steering committee:

'It's not tokenism. We make decisions as real partners. I think the process of the training and the focus on recovery means that each of the family members who has been involved in the project has brought a huge, genuine commitment to partnership' (Respondent 3).

'With the inclusivity of family members in the project, we've always felt very valued from the first time we came to the first meeting, and we're treated very much as equals. It's our project as well' (Respondent 5).

Anyone who works with families know that it is very difficult to engage family members. The fact that so many family members have been trained and are willing to stay involved in the project is evidence that the project is beneficial and is having a positive effect on people's lives. As one practitioner noted:

'The number of family members involved in the project, at this late stage is proof that there is something special at work here. It's strong evidence for the project itself that people are passionate about it & want to stay involved' (Respondent 3).

Family members suggested that future funders should consider the benefit of keeping the management structure in its current form, that is; with a high proportion of family member representatives and a number of practitioners working as a team. One family member said:

"The project would be very weak without family members who buy into, believe and practice the notion of family recovery...then bring that to the management of the project, and the peer support. It is the key to [FRIENDS] success" (Respondent 1).

It is clear that increasing the involvement of family members in the management of the project, and sharing ownership in a more meaningful way was a positive step. The true collaborative nature of the project has increasingly evolved and enhanced the management of the project in 2015. Each family member has contributed to the development of the FRIENDS project since its inception. Once GENIO funding has ceased, they will be fantastic ambassadors for the project. However, it is essential that they get support from the HSE or other funding bodies so that their good work can be continued.

5.2 The Impact of the FRIENDS Project on Peer Supporters

In this evaluation, quantitative findings from the Carers Wellbeing and Support (CWS) have been assessed in order to supplement the qualitative findings and testimonials from participating family members. The CWS questionnaires were distributed to family members who attended FRIENDS peer support training, firstly; prior to the commencement of the first training workshop in July 2014 and secondly; after the completion of the peer support and wellness training in January 2015. By comparing the results of these pre and post questionnaires for each individual family member, the impact of the FRIENDS project on family members' feelings of well-being and support has been quantified.

Results indicate that almost one third (31%) of participants felt that their overall feelings of well-being improved during the course of peer support training. Detailed results are outlined in Table 12 below. Most notably, 38% of participants felt the relationship with the person they care for had improved quite a bit. In interviews some participants noted that they had gained a greater understanding and confidence in their family member:

"I've started to say to [my family member] there will be two days a week when we won't be collecting you and and you will have to fend..... and suddenly we discovered "I'm ok mum, that's ok, go and have your two days". All the time we had felt he couldn't do without us, that he would be ill if we left him to fend for himself. We've discovered he is quite relieved even. He's saying "don't worry about me, I'm grand for the two days". We don't have to worry about it" (Respondent 2).

"I realised I can cope better with any situation, if I can feel relaxed, if I can be happy in my life, that that will reflect on to everybody around me. Sometimes if I am always focusing on [my family member] I'm kind of smothering them, whereas if I treat them more normally, and I'm not always fussing about them, or trying to analyse everything that they do, and just try and relax then we get on much better" (Respondent 1).

	Improved	Declined	Unchanged
Your Role as Carer	34%	25%	40%
Your Relationship with the person you care for	38%	15%	46%
Your Relationships with Family and Friends	32%	14%	48%
Your Financial Situation	36%	24%	40%
Your Physical Health	37%	18%	46%
Your emotional Wellbeing	39%	21%	40%
Stigma and Discrimination	18%	18%	64%
Your Own Safety	20%	28%	62%
The Safety of the person you care for	21%	9%	70%
Overall feelings of Well-being	31%	19%	50%

Table 12 - Impact on Peer Supporters Feelings of Well-being

A significant findings of the CWS questionnaire is that almost 40% of respondents witnessed an improvement in their own feelings of emotional wellbeing. This is a very positive results as it is evidence that FRIENDS wellness workshops, wellness break and training around self-care have indeed made a difference to the lives of family members who engaged with the FRIENDS project. Participants' comments further illustrate the impact of the project on their emotional wellbeing:

"The course has helped because I was a completely different person before I got involved. I was very easily agitated, would get upset very easily. I was inclined to magnify things worse than what they were and I couldn't see light at the end of the tunnel. I've learned to deal with things. I am no longer that person. I have patience now, I have endurance and I feel I can cope, that the worst part is over, for me" (Respondent 3).

"I have learned to focus more on the family rather than the actual person with the mental health difficulty. Not to keep re-hashing over the past, just take it day in day out. It has helped me to put things into perspective and to learn not to try and fix the situation" (Respondent 5).

'I have become more aware of, say, things that you say to start an argument, and ways that bring you back to being a rescuer in every situation. I try now to give everybody in the family a bit more space to be able to fend for themselves. That way I get more time for myself as well, to help myself mentally to relax, to have a good time, to have timeout; I go dancing' (Respondent 4).

While the majority of respondents felt that they still had concerns related to their financial situation and their own physical health and their safety, almost one third of respondents felt that these concerns had lessened over the course of the training programme. Perhaps respondents were better able to deal with concerns, using the skills they had learned with the group.

It is clear that the carefully designed content of the course, the co-production and collaborative method of course delivery, and the safe and supportive atmosphere fostered by both the facilitators and participants, when brought together, were successful in affecting change and improving the well-being of participants across a number of sectors. Figure 8 diagrammatically illustrates the

significant improvements that participants experienced as a result of their participation in the FRIENDS project.

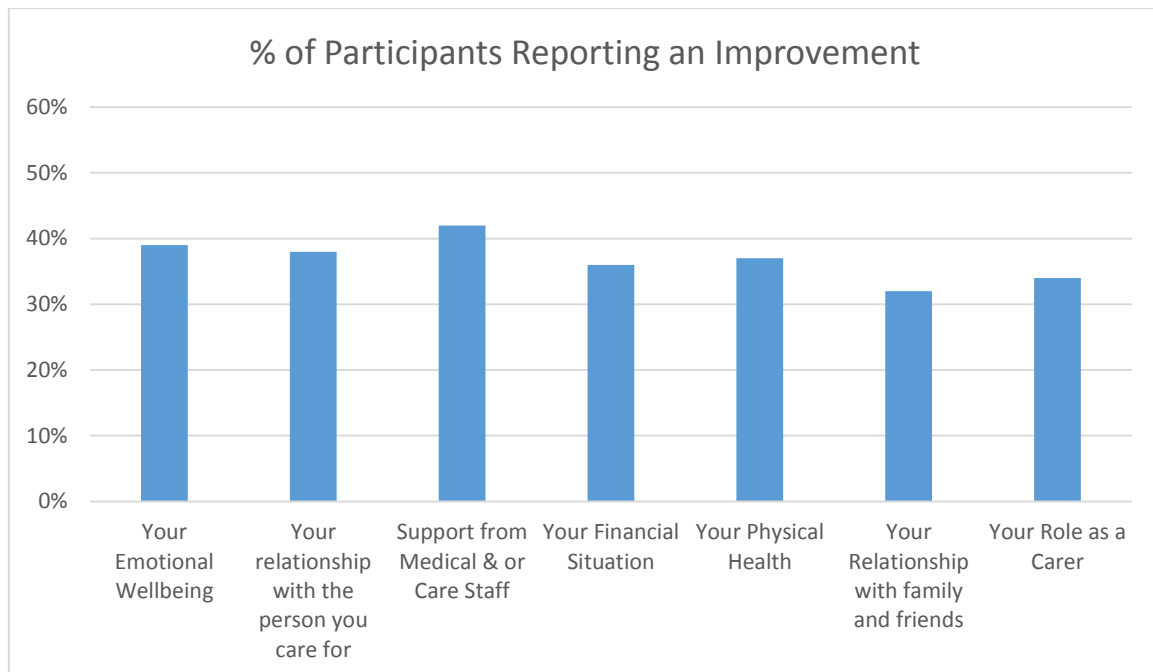


Figure 8 - % of Participants Identifying an Improvement in their Well-being & Support

In relation to the support structures that are available to family members who are supporting family members experiencing mental health difficulties, results suggest that throughout the duration of the training course, family members became more aware of the deficits in support that they received. Table 13 below indicates that, as a result of sharing their experience with other relatives, and through their increasing understanding of the FRIENDS project objectives, family members' contentment with the supports available to them declined significantly.

	Improved	Declined	Unchanged
Information and advice for carers	3%	47%	50%
Your involvement with in treatment and care planning	18%	32%	50%
Support from medical and or care staff	42%	11%	47%

Table 13 = Impact of FRIENDS project on Participants Feelings of Support

Table 13, 47% of participants felt less happy with the information and advice that was available to them after completing the FRIENDS training course. A further 32% felt that they were less content with their level of involvement in the care planning of their family member's treatment plan. These respondents would like the professionals working with their family member to collaborate more with them so that everyone can work together to support the individual experiencing difficulty.

Encouragingly, Table 13 also demonstrates that a significant 42% of participants increased their contentment with the support they were receiving from professionals and/or care staff. The professionals and care staff discussed in this instance are all those who were involved and engaged in the FRIENDS project. For example, a number of professionals and care staff from the HSE, SHINE, Aras Follain etc. were active members of the FRIENDS project. Their presence was felt on the steering committee, in the delivery of training and in numerous wellness workshops. These FRIENDS professionals provided guidance and support to participants and clearly made an impact on how supported they felt during the project.

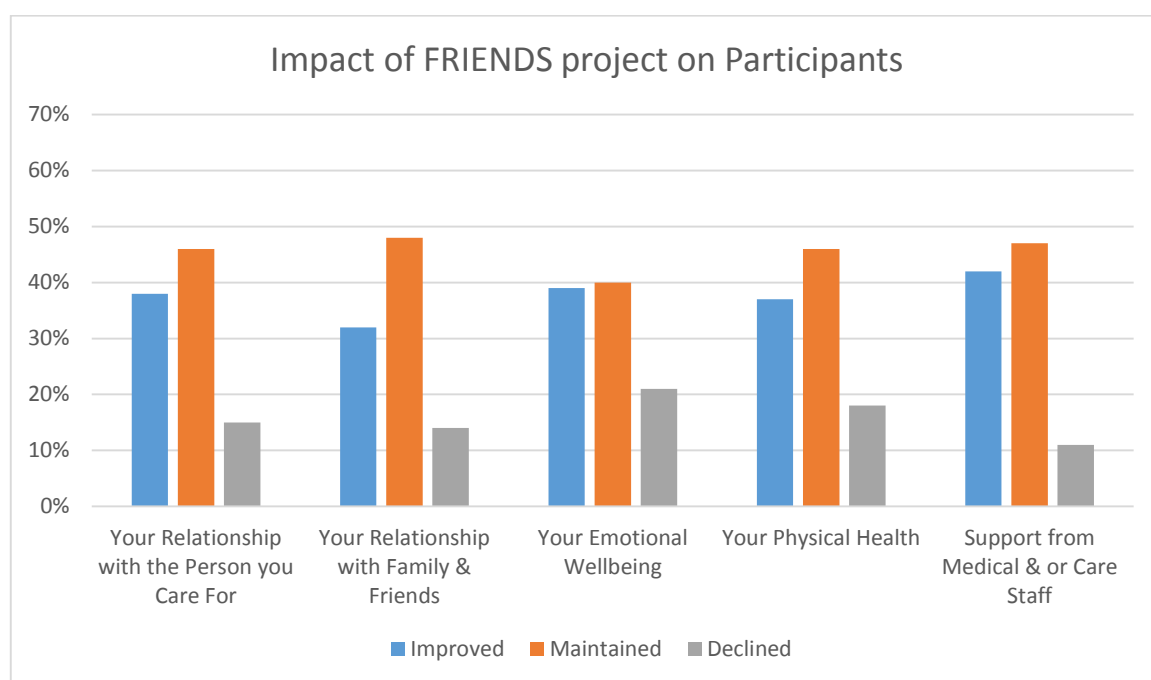


Figure 9= Overview of the Quantitative Impact of the FRIENDS project on Peer Supporters

The overall impact of the FRIENDS project on relative peer supporters is outlined in Figure 9 above. While the majority of participants remained unchanged on certain issues, a significant proportion of respondents alleviated their concerns and improved their family relationships.

5.2.1 Applying Skills to Everyday Life

Feedback gathered through focus groups with FRIENDS peer supporters correlates strongly with the quantitative findings outlined in section 5.3.0. Firstly, family members highlighted the learning & skills that have been developed throughout the FRIENDS process. Although peer supporters were not paired with peers in need of support as of April 1st 2015,³ some of the family members suggested that they had been exercising their peer support skills with friends, family members and even people they don't know. During focus groups some family members gave examples of times they felt they supported another person:

³ Family members have not yet been paired with peers in need of support primarily due to a lack of an established referral pathway and a lack of formal support for the strategic plan from the HSE mid-west.

"I have tried to become a better listener with people I meet from day to day, and not dash in with my 'tuppence ha'penny', and try and listen and try and remember what the person has told me previously about other stuff, family and friends who I meet from day to day, ask them did such a thing come about right; whatever problem they had" (respondent 3).

"I definitely notice myself using the skills I learned. This one day, I was talking to this lady, who was a very, very strong lady, she opened up to me and told me her problems. I had been to her a few times before, but on this occasion – we always got on well, but we never talked personally – but she opened up to me and told me her problems about another person who was stressing her out, and told me the whole story because I had said to her I was doing some courses on peer support. It was a great experience and I listened to her story and she was very appreciative and I felt I actually did her good" (respondent 5).

"I have used my [peer support] skills informally, trying to listen more and to relax more when a person is telling me their story even at the dancing, you can meet people when you're chatting and having the cup of tea, just take time to listen to the person and keep my own mouth zipped" (respondent 4).

These comments illuminate the positive impact that the training had in honing individual's listening skills. It also highlights the enormous benefit these trained peer supporters could be to other relatives in need for support. I would recommend that a referral pathway be established as soon as possible so that skills used for the benefit of others in a more formal, supported and long term capacity.

5.3 The Success of Co-Production

The core ethos of the FRIENDS project from inception was that of co-production. For the FRIENDS steering committee; *"co-production means that everybody has a voice and that everybody's voice is heard and then through hearing what everybody has to say then, something is produced from that"* (Steering Committee Member). As such, co-production became a key factor in every element of the project; training programme & evaluation development, training & evaluation delivery and the management of the project in general.

In the management of the project, family members were invited to take part in the steering committee, they were asked to co-produce the content of the training and to help in facilitating the training. Relatives played an important role and often brought invaluable personal experience to discussions. For example, one family member noted:

"In the delivery of the training, I related to my own family experience, reliving the experience of having to be a support as a family member, my own holistic experience, my self-difficulties meant I had something to contribute" (respondent 1).

Sharing personal experiences and relating topics such as self-care and listening skills to personal experiences encouraged other family members to engage with the material, to share their stories and to relate well to those delivering the course. As respondent 1 noted;

"I suppose really for me, co-production, particularly in the training, was more the listening and sharing from the heart, you know, the true depth of honesty, connection that comes through co-production and really validating and valuing each individual experience, as uniquely belonging to the individual but yet, in another person's experience might be completely the opposite, that equally valuable for their heart as well you know, the heart, for me it's that the co-production brought some heart or some humanity into it" (respondent 1).

Involving relatives in the co-production of the project and the evaluation clearly benefited the FRIENDS project team. It also benefited the relative co-producers themselves. A number of family members developed and enhanced skills through the co-production process, as it required them to perhaps move outside their comfort zone and engage more deeply and personally with the project. From her participation on the steering group, one relative co-producer noted;

"I have developed new skills, and enhanced skills that I had already. At the end I could see that I was more confident, and maybe more clear in communication around listening and sharing and seeing others perspective - being more open and equal" (respondent 3).

Similarly, in relation to the PAR (participant action research) evaluation, relative peer evaluators also noted significant skill development. They described the PAR experience as 'new' 'interesting' and 'worthwhile'. One relative described:

"[Being a co-evaluator] was a very positive experience, I really enjoyed it and would recommend it to anyone who gets the opportunity to participate. It was very good for building self-esteem, learning that gaps or silences are very important in the art of listening – facilitating conversation is not all about talking" (respondent 3).

As with all project objectives, some challenges were experienced in relation to the co-production ethos of the FRIENDS project. Firstly, relatives could have been involved on the steering committee at an earlier stage when key project decisions were being made. However, relatives were successfully involved in the design and delivery of peer support training and evaluation from start to finish which was extremely positive.

However, the use of co-production, on a relatively small scale project such as FRIENDS, can have potential to overburden participants. In this case, some relative participants were involved in the steering committee, the training and the evaluation which is a significant time commitment. Care needs to be taken to ensure that each individual participant is not required to give more time or energy to the project than they wish.

Relative participants received training in core evaluation skills such as focus group facilitation and the importance of qualitative research. Participants were pleased to be part of the evaluation both in terms of skill development and being valued as peers. In particular, relatives gained a greater understanding of the need for evaluation and the potential challenges associated with focus groups. They felt some ownership for the project and its success into the future and were grateful to other relatives who gave their time to the evaluation. As one respondent noted:

"the [PAR] experience was interesting, we are dealing with peoples life experience, and it created space for relatives to reflect on their own particular situation, both as an individual and as a family member and helped us all to understand that they are not alone" (respondent 2).

Finally, given the short time frame of the project (dictated by the GENIO funding timeline), time to build relationships and establish trust between relatives, professionals and other services providers in the initial phases of the project was limited. As one respondent notes, time is a key ingredient for successful co-production;

"Time is really important, time to build a relationship, because to co-produce - that relationship needs to have foundations in respect, in equality, in listening and that needs time to develop. It's really talking it out together, figuring it out together, creating it and doing it together" (Respondent 1).

It is evident from feedback that the co-production ethos of the FRIENDS project benefited the project, the relative co-producers and the relative participants. Yet, in many project, particularly in project evaluations, it is an underutilized method. I commend the FRIENDS team for building for championing a co-production ethos, developing such strong relationships and involving so many relatives in the core elements of the project. I would also recommend that an ethos of co-production is maintained as the project changes and develops into the future.

5.4 Implementation of the Strategic Plan

The FRIENDS strategic plan was designed and developed by the FRIENDS team in 2014, in conjunction with family members, peer supporters and professionals. In the second part of the evaluation, the researcher was asked to assess the impact of the integration of the strategic plan on professionals and family members being supported by the project. However, the strategic plan has not yet been put into action.

The FRIENDS steering group presented the strategic plan to HSE professionals and the evaluator made a series of recommendations around the integration of the programme into the Mid-West mental health service in December 2014. Unfortunately no action has been taken on the part of the HSE to embed the FRIENDS peer support service into any existing service structure. It is hoped

that with further information and briefing sessions, the HSE mental health team will recognize the value of the project and will implement strategic plan going forward.

As an alternative to assessing the impact of the integration of the FRIENDS strategic plan, the researcher assessed the current level of support for the FRIENDS project, amongst HSE staff and mental health professionals in the Mid-West. The researcher also queried and identified the additional strategies needed to help professionals integrate the service.

5.4.1 Feedback from Service Providers

The feedback included in this evaluation has been gathered from just five practitioners who agreed to respond to a practitioners' survey. The results suggest that there **is** support for a peer support project such as FRIENDS. In total, 100% of professionals questioned said they would refer relatives to the FRIENDS service for peer support. Despite their support for a peer-to-peer support service for families, some professionals voiced concerns around the organization of such a service and the quality of the training received by family members. When asked if they think '*peer support is a good method of supporting family members*', some professionals said:

"Peer support is a good method as long as the peer supporters are trained and appropriately supervised and supported" (respondent 3)

"In some instances - can be tricky when dominated by individuals with different agendas - may need a facilitator, although I understand that does not always lend itself to the true meaning and philosophy behind Peer Support" (respondent 2)

As a peer-led programme, the FRIENDS project strategic plan should tackle any concerns practitioners may have around the organization of the project, particularly in relation to agendas. Furthermore, the quality of the training received by FRIENDS peer supporters is evidenced throughout this evaluation report. Results indicate that service providers recognize the benefits of integrating the FRIENDS project into the mainstream service. One professional noted;

Integrating the project would "allow carers and families of service users to get better informed and supported and ask questions they may not feel able to ask doctors staff or even their relatives" (respondent 2).

Similarly, one service provider noted the benefits of supporting family members for service providers themselves. They noted, working with the FRIENDS peer support service would "*help the services to see the wider context of the situation [of the person with mental health difficulties], and address the wider needs of the family system*" (respondent 3). A service like FRIENDS would "*ensure a holistic approach to individuals care plan*" (respondent 4), as suggested by current policy.

Given the recognized benefits of the FRIENDS approach, and the clear support for service, then why has the project not been taken onboard to date? When asked about the barriers to embedding the FRIENDS project, issues such as '*client confidentiality*', '*lack of communication*' and '*mixed messages*' were cited as the main barriers. However, these are issues which were addressed by the FRIENDS coordinator in her discussions with practitioners, service users and family members when compiling the FRIENDS strategy in 2014. Unfortunately, it would seem that practitioners are either not aware of the availability of the detailed strategy or further discussions around client confidentiality need to be addressed before the FRIENDS service can be integrated successfully.

Practitioners have suggested that more information needs to be disseminated about the project, such as; how it runs, where it is located etc. It was also suggested that a focus group with HSE relatives could be undertaken to establish need for the project, however, need has already been established through these means and the results have been included in the FRIENDS strategy 2014). Finally, one professional suggested that *"Maybe if [peer supporters] could attend Acute Unit/Day hospitals on a weekly basis and run clinics for information sign posting their services and taking referrals, that might work"* (respondent 5).

The FRIENDS steering committee has tried to open discussions with HSE Mid-West management teams during the development of the FRIENDS strategy and in presentation of the findings of both the evaluation and the focus groups with service providers. However, I would recommend that the FRIENDS strategy be discussed at length with managers and practitioners in the Mid-West via a series of workshops or presentations in the near future. Practitioners need to be made aware of the unique peer led structure and management of the FRIENDS project and the results of quantitative and qualitative feedback from participants over a 12 month period.

I would suggest that it is not until practitioners become more comfortable with the details of the project that they will begin to champion the integration of the project. In addition, it is imperative that all practitioners and HSE Mid-West managers be open to meeting members of the FRIENDS steering committee, asking pertinent questions, and reading the FRIENDS strategy in-depth so as to help integrate this invaluable and much needed service to support relatives of people with mental health difficulties.

5.5 The Future of the Project – Relatives Perspectives

As the GENIO funding comes to an end, the FRIENDS pilot project is beginning to change direction and develop more organically into a peer-led project with an uncertain future without any current commitment from the HSE Mid-West. The FRIENDS project has certainly achieved its objectives in that it has provided the Mid-West with a team of fully trained relative peer supporters who are ready to give back to the community and share their experiences with others. Numerous discussions have been had about the potential future of the project and feedback has been

recorded from participants. Needless to say, everyone is hopeful that the project will be supported into the future. Relatives noted:

"At the end of the course I felt sad that it was over, I really enjoyed the course, but I'm very hopeful that this will continue into the future because I think this is the way of the future and hopefully the HSE will take it on board, and that we will be doing peer support. I'm very hopeful that it will go ahead" (respondent 4).

Now that relatives have developed the necessary skills and are applying their learning in their everyday lives, they are more than ready to start supporting others. They said:

"I have about twenty three years at least, of experience of dealing with all these mental health issues within my family you know, and that's a wealth of experience really...so why wouldn't I go forward with it?" (respondent 3).

Participants have concerns about the future. Some relatives have said:

"I feel sad that it seems to be coming to an end because I enjoyed the camaraderie and all the learning and the education side of it, with [the FRIENDS team]" (respondent 5).

"The HSE has got huge budgets to cope with and so forth, but I feel that I have learned a lot in my own life, and the people who did the course have learned a lot to deal with their own situations and we would love if we were able to pass that on to other people and I'd be sad if it didn't happen" (respondent 1).

Critically, when asked where they would like to see the project located, participants varied in their responses. Some people wanted to maintain an element of control over the project for the peer supporters themselves whereas others want to see the HSE take over the project entirely. They suggested:

"I would honestly like to see the project continue as a relative-steered committee. I think it can be done, I think that with the backing of the HSE then it can be done. Questions are being asked at the highest levels of the HSE now - "what are you doing about peer support?" "How are you linking in, how are you supporting them", and I do think there are ways they can support us which allowing the project to be relative-led" (Respondent 6).

"I think with the HSE myself that there needs to be a big shift between them and us, you know....I mean it's all right for a small group to be doing this, but if you go with the HSE it would be more countrywide, it needs to be countrywide" (respondent 2).

According to the relative participants, it is important to receive support from the HSE going forward, whether the project is in fact run by HSE professionals or remains a peer-run programme. The FRIENDS project team have made every effort to gain the support of the HSE including aligning it's strategy with the Key performance indicators of the HSE Mid-West

in order to ease the transition from pilot project to integrated service. Furthermore, while the FRIENDS project has not been cost neutral it certainly has been value for money, as one participant noted; *"it's a hell of a lot cheaper than the model of service delivery used at the moment"* (respondent 6). The project team is still hopeful that the service will find some form of financial support soon so that peer supporters can begin their important work.

6.0 Conclusion

It is most likely that the initial motivation for family members' participation in the project was to get assistance for their loved one. However, through the process of self-recovery, family members have gained the confidence to make a change to the dynamic with their relative. They have begun to implement aspects of self-care in their own lives, by making more time for themselves and understanding family dynamics. Relatives have also developed and enhanced their skills and are now ready and willing to support others in their recovery journey.

While details around the management and location of the project still need to be ironed out in discussions with the steering committee, the lead organisations and the HSE, there is no doubt that the FRIENDS project has immense potential. The GENIO foundation has shown on-going support for the project. Relatives, professionals and service providers have been impressed at the level of commitment and the progress achieved in such a short time frame. Objectives have been met and the project team has achieved great value for money. This evaluation provides evidence that the project has indeed had a positive impact on all those who participated and has made recommendations for the continuation of the project in the Mid-West.

7.0 Summary of Findings

Wellness Strand	Peer Support Strand	Strategy for Inclusion
<ul style="list-style-type: none"> • 44 relatives attended FRIENDS wellness workshops around the Mid-West • 14 trained relatives attended an overnight wellness break in Killarney. • Feedback indicates that wellness workshops were well organized and enjoyable. • The wellness break inspired personal development in participants & proved a break from commitments • The social element of the wellness break was a significant draw • Wellness workshops/ breaks were a good reminder of the importance of focusing on recovery & self-care 	<ul style="list-style-type: none"> • 24 family members attended 7 weeks of peer support training, with a focus on recovery. • Family members trained ranged in age from 33 years to 83 years. Each individual benefited from their involvement. • Through the training process, a significant bond developed between family members • 31% of participants felt that their overall feelings of well-being improved over the course of the FRIENDS peer support training. • 38% of participants felt the relationship with the person they care for had improved quite a bit. • Relatives gained a greater understanding of recovery and practiced principles of self-care. 	<ul style="list-style-type: none"> • The FRIENDS Strategic plan was prepared by the coordinator who conducted a detailed needs analysis • The FRIENDS strategy explores protocols for including relatives in the provision of services to family members. • Strategy is aligned with HSE Key Performance Indicators • FRIENDS Strategy Includes views of service user, relative & service provider • The team faced challenges when trying to gain input from service providers • Strategy presented to HSE Mid-West in November 2014 with the hope that it would be integrated into HSE strategic plans 2015

8.0 Recommendations

8.1 Strategic Plan

- **It is recommended that the FRIENDS project be supported and integrated into the service plan of the HSE Mid-West.** This was a capacity building project and it was successful in its aims. Trained family members are available and represent a significant resource that should be utilized.
- **It is recommended that the FRIENDS strategy be discussed at length with managers and practitioners in the Mid-West via a series of workshops or presentations in the near future.** A number of professionals in the HSE mid-west were unfamiliar with the FRIENDS project and thus uninclined to show formal support. Practitioners need to be made aware of the unique peer led structure and management of the FRIENDS project.
- **Following from the above, it is recommended that the FRIENDS strategic plan be printed and sent to all members of the HSE Mid-West mental health service team.** It is necessary for the steering committee members to take control of promulgating the project and seeking additional funding and support.
- **As a method of implementing a Vision for Change, it is recommended that practitioners receive training in relation to supporting families of people with mental health difficulties.** Following the ethos of co-production laid out by the FRIENDS project, it is suggested that a team of family members work with some practitioners to implement a training programme to upskill professionals. This training course can be designed using the detailed needs analysis carried out by the FRIENDS coordinator.
- **It is recommended that further discussions around client confidentiality be addressed.** Client confidentiality was a key concern of service providers who took part in the practitioners' survey. It would seem that this is an issue which needs further discussion before the FRIENDS strategic plan can be successfully implemented.

8.2 Peer Support Strand

- **It is recommended that the families of people with mental health difficulties be supported by other family members through peer support.** This evaluation has highlighted the benefits of peer support as a method of service provision for the family members of those with mental health difficulties. Not only does peer support empower family members with crucial life experience, it also represents incredible value for money. In the FRIENDS project, all participants were valued and remunerated for their time, yet the overall spend for a period of 18 months was less than €80,000.

- **It is recommended that the training programme designed by the FRIENDS coordinator be used to train further family members.** The training programme, with a unique focus on self-care and recovery, has been designed using verified methods and considered exercises. The training programme has worked well for all the FRIENDS participants and should be utilized when training all future family peer supporters.
- **It is recommended that all peer support training and support include a strong self-care and recovery element.** The FRIENDS family members benefitted on a personal level from their interaction with recovery and wellness workshops. In fact, the training provided a launch pad for relatives to focus on their recovery first in order to become ready to provide support to others.
- **It is recommended that peer supporters (i.e. trained family members) be supported by professionals in carrying out their role.** This support may take the form of one-to-one reflective sessions, group support or professional meetings.

8.3 Collaboration & Co-Production

- **It is recommended that the ethos of co-production be maintained in the management of the project going forward.** A fundamental aspect of the project was the underlying ethos of co-production, championed by the steering group. This ethos encouraged family members to enhance skills and take ownership of the project, while also serving as a reminder to professionals that family members are experts and have significant contributions to make. Co-production should, therefore, remain a key element of the project and indeed any similar project going forward.
- **It is recommended that in the initial stages of the project, a formal agreement is made by all partners to dedicate equal time and financial support to the project.** In order to ensure smooth collaboration at all times, individual steering group members must be aware of the commitment expected of them. In order to avoid unequal ownership or decision making power, all organizational or professional members should give equally to the project (where possible).
- **For any similar projects which may emerge, it is recommended that more time should be dedicated to relationship building in the initial phases.** The partnership between professionals and family members in this project took a long time to establish itself fully. More time, although often tight on a pilot project
- **It is recommended that the steering group (as a whole), meet more often.** Some members found that meetings could be somewhat irregular and all members were rarely in attendance. While FRIENDS was a pilot project and it took time to establish a strong steering group, going forward it would be best to formalize the meeting procedure.

- **Without a project coordinator, it is recommended that formal procedures be established around communicating with all project participants.** It is suggested that the current steering group should meet to decide upon communication procedures, particularly for those without email addresses. Communication became a cause of concern for family members during the transition from project coordinator to more peer-led management.

8.4 Wellness Strand

- **It is recommended that wellness workshops be made available to family members caring for people with mental health difficulties.** Although wellness workshops and breaks were a significant cost on the project, all workshops were well attended and individuals benefited personally from their attendance. The workshops should include information on self-care and recovery and/or elements of stress relief and physical relaxation.
- **It is recommended that wellness workshops be made available to trained peer supporters.** Family members who are supporting others through peer support would benefit greatly from continued exposure to material, talks, workshops and exercises around self-care and recovery. Furthermore, workshops provide family members with an opportunity to socialize, support and learn from the experiences of other trained peer supporters.

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Appendix A – Consent Form

The FRIENDS project Evaluation.
Agora Research & Learning Alliance, Limerick.

FOCUS GROUP CONSENT FORM

Dear participant,

The purpose of the FRIENDS project evaluation is to examine the project's impact, to examine the experiences of people who have been involved and to assess and review the progress to date in achieving the original aims and outcomes. It is hoped that through this evaluation, we can learn from our experiences of FRIENDS and that some of this learning can be applied to future work and a model of best practice in terms of supporting relatives can be developed (FRIENDS, 2014).

Rest assured that all of our peer evaluators have been trained to a high standard in both ethics and confidentiality. All information provided by you will be treated in strictest confidence and will be used for this project only. No names or identifying information will be passed on or published. You have the right to withdraw from the project at any stage.

If you would still like to get involved please sign below, and we thank you in advance for your participation and co-operation:

Participant:

I give my consent to use any of the information I provide in the focus group for use in this evaluation of the FRIENDS project, 2014.

Signed: _____

Dated: _____

Appendix B - Focus Group Summary Form

The FRIENDS project Evaluation.
Agora Research & Learning Alliance, Limerick.

FOCUS GROUP SUMMARY FORM

Lead Facilitator Name: _____

Assistant Facilitator Name: _____

Type of Focus Group: _____

Date of Focus Group: _____

Location of Focus Group: _____

Time Focus Group Starts: _____

Time Focus Group Ends: _____

Names of Participants Present at Focus Group

Appendix C – FRIENDS Data Protection Contract

The FRIENDS project Evaluation. Agora Research & Learning Alliance, Limerick.

As a peer evaluator / transcriber for the FRIENDS project:

1. I will respect the confidentiality of all information gathered from participants in this research.
2. I will respect the confidentiality of information which constitutes “Sensitive Personal Data” as defined by the Data Protection Acts 1988 and 2003.
3. I will ensure that all documentation and audio tapes are held in a safe and secure manner and in the absolute strictest of confidence when in my possession.
4. I will return all records, papers, documents or other material relating to focus groups to FRIENDS staff upon completion of my role.
5. I will destroy all digital copies of focus group audio files from my personal computer immediately upon completion of my role as a peer evaluator and/or transcriber.
6. I will conduct myself in an ethical manner in my role as a peer evaluator / transcriber.

Signed: _____

Dated: _____

