

# FamilySupportStudy

A study of experiences, needs, and support requirements of families with enduring mental illness in Ireland.

**Yulia Kartalova-O'Doherty**  
**Donna Tedstone Doherty**  
**Dermot Walsh**

Improving health through research and information



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I would like to think that this interview, which I gave you voluntarily...that if one patient was to benefit from this interview, you would make an old man very happy.

Thank you for giving me a voice.

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## Executive summary

The most recent Irish policy document in the mental health area *A Vision for Change* (Department of Health and Children, 2006), recognises the role of family and friends in the care of persons with enduring mental illness. *A Vision for Change* highlights the need to include carers as active partners in the planning and delivery of mental health services, on a par with mental health professionals and service users.

This exploratory study confirms that carers and families often play an important role in the treatment and rehabilitation of persons with mental health problems. Most of the participants in this study remained the first resort of care at the onset of mental health problems of their relative, sought advice and access to treatment when their relative was unwell, provided care and support on discharge, and supported their relative with their rehabilitation or recovery. The caring, supporting, and proactive role of relatives in the treatment and rehabilitation of persons with mental health problems needs to be fully recognised and appreciated by all stakeholders in the mental health area. Support for families who can and wish to be involved in the treatment and care of service users needs to be provided.

### Aims of the study

- The aim of this study was to explore experiences, needs and support requirements of families with enduring mental illness in Ireland.
- The effects of enduring mental illness on the family, the adaptation of family members to the burden of mental health problems in the family, and the needs of different family members were investigated.
- The needs and support requirements of family members at different stages of their experience with enduring mental illness in the family were explored.
- The support resources available to the participants, their utilisation, and the future needs of families were investigated.
- The levels of satisfaction of study participants with the services and support offered to service users and to themselves and their families were explored.

### Methods

- A qualitative approach to data collection and data analysis was selected for this exploratory study.
- Semi-structured in-depth interviews were conducted and additional questionnaires were used in order to collect socio-demographic and other quantifiable information pertaining to study participants and persons with enduring mental illness.
- A combination of content analysis, ground theory, and statistical procedures was used for the analysis of the data.

### Study participants and their relatives

Although the study was based on a limited number of selective respondents, the authors have confidence in the generalisability of concepts and issues raised by this first in-depth exploratory study in the Irish context. The qualitative data emerging from the participants supported some previous international research and was indirectly validated by the findings of the *Vision for Change* (2006) published after the completion of data analysis for the current project.

Participants were recruited via Schizophrenia Ireland (SI), and the mental health services (MHS) of a Dublin catchment area. The overall response rate was 15.2%. A total of 38 family members of 33 persons with enduring mental illness residing in the city and county of Dublin volunteered to participate in this study. Most of the participants were members of SI and mothers; their average age was 61.3 years. The majority were retired, married, and residents of suburban areas. Nine fathers, three sisters, a brother, a wife, and a stepfather also participated in the study.

As reported by the interviewees, most of the 33 persons with mental health problems were sons of study participants, with an average age of 35 years, single, unemployed, and had been diagnosed with schizophrenia. Other kinship groups of service users included daughters, a husband, and a sister. According to the participants, four service users were married and three had children. Nearly one-third of service users were reported to be participating in either main-stream or sheltered employment, and a quarter were reported to be involved either in training or in main-stream education at the time of the study.

The duration of the participants' experience with mental health problems in the family ranged from 1.5 to 49 years. More than one-third of their relatives were residing at home with the study participants. The rest of the service users were residing in independent accommodation, in in-patient mental health services and in community residences at the time of the study. As reported by study participants, the majority of service users had medical cards and were in receipt of disability allowance.

The majority of SI members had private health insurance, whereas the majority of interviewees recruited via MHS had medical cards. A higher number of fathers, and other subgroups of relatives, such as a spouse, a brother, and a step-father, were recruited via MHS. Only SI participants reported that they were sharing the same accommodation with the service users at the time of the study, and that their relatives with mental health problems were participating in main-stream employment or education.

## **The perceived effects of mental illness on the family, family adaptation, and needs of different family members**

Most of the perceived negative effects of mental illness in the family were associated with the perceived disruptive behaviour of persons with mental health problems, which affected the social functioning of the family. In some cases, families became totally isolated from the community. Most of the participants in the study experienced separations or loss of contact with other family members. One of the perceived reasons for family isolation or disintegration was the stigma associated with mental illness, especially schizophrenia.

Several participants reported that their families adapted effectively to the mental illness, resulting in a change of outlook, or a rethinking of the idea of family. Some families adapted by accepting the illness of their relative as a part of their family life.

Information and knowledge about illness, its treatment and recovery was seen as a powerful coping tool by most of the participants. Knowledge about the illness and treatment helped to reduce the feelings of anxiety of family members, and allowed them to better fulfil their caring role. Information about recovery provided hope for the future of their relative, which was reported to have improved the participants' psychological well-being.

Most of the mothers and several fathers coped with the burden of mental illness by talking to other people. Support groups were viewed as serving a dual purpose of extending the social circle and getting information about the illness, symptoms and best ways of caring.

Participation in family support groups was perceived as emotionally threatening to fathers and siblings of persons with mental illness. Two sisters commented that there were no support groups available for their age group, which decreased their willingness to participate. Whereas female relatives valued the sharing of experiences in groups settings, male relatives seemed to benefit more from either individual or family settings. Several parents of persons with mental health problems who did not participate in family support groups considered individual or family counselling very effective.

### **Needs and support requirements of participants at different stages of their experience with enduring mental illness in the family**

Some stages of the experience with enduring mental illness in the family, elicited from the participants during the interviews, included the initial encounter with mental illness and treatment provision, getting a diagnosis, discharge, relapse or re-admission, acceptance of mental illness in the family, and the turning point towards rehabilitation or recovery.

Nearly half of the participants reported that the **initial encounter** with mental illness in the family had been the most difficult period of their experience. As recalled by the participants, the onset of mental health problems in the family occurred during the teenage years of their relative, and had been associated with some stressful events, physical health problems, or perceived substance abuse. Participants commented that it had been difficult for family members, primary health care, and even mental health professionals, to recognise the signs of mental health problems, as they had been mostly attributed to the difficulties of teenage years.

Most participants commented that there had been a lack of understanding, practical advice, or appropriate response at the time of their first contact for help. After a person was referred to in-patient treatment by primary care professionals, it was difficult to secure a place in an in-patient unit due to the complexity of admission procedures or lack of beds.

At the stage of the **first treatment provision**, all participants reported a lack of information from mental health services about the illness, treatment and prognosis. Several participants reported a perceived 'clash' between the confidentiality of information about the illness and treatment of their relative and the perceived natural right of family members to know what was wrong and what to expect. The majority of participants had anticipated that the relative would be discharged home to their care and had been willing to provide the best care for their relative.

Information about the **diagnosis** of persons with mental health problems was perceived by participants as essential for readjustment of their expectations and caring roles. However, the stage of learning the diagnosis was reported to be associated with shock and trauma. Several participants voiced a need for a gradual build-up of information about the illness and treatment before learning the diagnosis, and an individual appointment with mental health services for consultation at the time of learning the diagnosis. Voluntary counselling, provided by SI to some participants, was reported to be quite helpful and effective at the time of getting the diagnosis.

On **discharge**, a perceived lack of support services for the family and follow-up treatment for service users were reported by most participants. There was a pronounced need for an approachable and reachable family contact within the mental health services for help and advice. Participants reported that they had needed advice about the illness, treatment and the best way of caring at the time of discharge of service users to their home.

Several participants felt that their concerns had not been listened to by health professionals, either during the initial encounter or at **relapse**. They also felt they were in need of an ongoing personal contact and respect and sympathy from professional mental health services.

A stage described by the participants as **the turning point** was associated with the **improvement** in health and well-being of their relative, when their hopes and aspirations for the rehabilitation or recovery of their relative had increased.

Though examples of high-quality services were provided by some participants, most felt that the rehabilitation of their relative was not actively promoted by mental health services. Most participants perceived that service users had not been motivated by the mental health services to get on the road towards rehabilitation or recovery.

The lack of services and support at all stages was highlighted by most of the participants. All participants expressed the need for an approachable mental health services contact, a **key worker**, or a ‘mediator’ between families, service users, and mental health services.

Participants who perceived that the health and functioning of their relative had improved were optimistic about the future quality of life of their relative and themselves. Participants who reported that their relatives were using private mental health services at the time of the study, and resisting treatment offered by these services, were less optimistic about the recovery of their relatives, and about their own future quality of life.

### **Support resources available to the participants, their use, and the future needs of families**

One of the findings of this exploratory study was a lack of uniformity of services and supports provided to service users and their families across different catchment areas, public and private sectors, and individual in-patient and out-patient mental health services.

Voluntary support resources provided by SI, such as support groups, information, helpline, counselling, lectures and such like were viewed by all participants as the best, and sometimes the only, support resources available to families. Two educational programmes provided by mental health services were also viewed as helpful by those who were residing in the catchment areas of these services.

Some of the barriers to utilisation of available support resources were lack of information about the resources, lack of flexibility in the schedule of support groups and programmes, lack of support resources in the area, and limited operational hours of the emergency line. In some cases participants felt that they were at the stage of experience when they did not need formal support resources that much.

### **Perceived differences in the quality of services provided by private and public sectors**

Participants whose relatives had used both private and public mental health services felt that the untimely discharge due to the time limitations of the insurance cover and the lack of follow-up services on discharge were the major disadvantages of the private sector as opposed to public. Available and approachable psychiatric nurses were perceived by participants as one of the major benefits of public mental health services.

Major criticisms of the public mental health services, as emerging from the participants, were the 'run-down' state of in-patient buildings and the change of non-consultant hospital doctors every six months. Participants felt that it had been difficult for their relative to build up trust with each new professional, which may have negatively affected treatment.

### **The level of satisfaction of study participants with services and support offered to service users and to themselves and their families**

Participants whose relatives had medical cards, and who reported that the health or social functioning of their relative had improved over time, were more satisfied with the services and support provided to their relative, than those whose relatives did not have medical card, and whose health and functioning had not improved. Participants whose ill relative was female were more satisfied with services provided to their relative, than were participants whose ill relative was male.

Participants who reported that they had a specific contact person within mental health services whom they could turn to for help and advice were more satisfied with the quality of services and support provided to service users, than those who did not have such contact at the time of the study.

Participants who felt that their relative had good relationships with their psychiatrists reported higher levels of satisfaction with services and support provided to their relative.

Participants who were more satisfied with the services and support provided to their relatives, who reported that the health and functioning of their relative had improved, and whose relatives had medical cards, were more satisfied with the services and support provided to themselves and their families, than other groups of participants.

### **Recommendations**

Key recommendations from this exploratory study concentrate on family support at the onset of mental health problems, at various stages of mental health service provision and rehabilitation or recovery, family-tailored support services and general support resources, and directions for further research. A detailed list of recommendations and a framework for the provision of services and supports to families at different stages of their experience are presented in Chapter 10.

### **Family support at the onset of mental health problems**

1. Training and education of **primary health care practitioners** need to include recognition, early detection and appropriate responses to mental health problems. Communication between primary health care and mental health services should be improved in order to facilitate early intervention.
2. In order to assist early intervention, the public needs clear and accessible information on how and where to **access** professional mental health services. Mental health services need to provide such information in health clinics, general hospitals, schools and community facilities, and on the Internet.
3. **Information** about mental health, recognition and prevention of mental health problems, and tackling of the stigma associated with mental illness should be included in **teacher** training programmes and **school** curricula.

4. Information about existing **family support resources**, with a brief description of the types of services offered and associated contact details, needs to be made available in schools, health clinics, mental health services, general hospitals, community and civic offices, telephone directories and on the Internet. Such lists need to be **updated** at least once a year.

### Mental health service provision in partnership with families

5. At the time of the **first contact with mental health services** of their relatives, basic information should be offered to families about the available services, the time and manner of their operation, the time needed on average for arriving at diagnosis, and confidentiality issues. Concerned family members should be provided with a list of support resources available to the family, a brief description of the types of services offered and associated contact details.
6. **Family consultations** should be carried out by mental health services at the stage of identifying the nature of the illness, prior to **discharge**, and after **relapse or re-admission**. Such family consultations should be open to participation by service users and by their families who can and wish to become involved in treatment and care.
7. With the agreement of service users, during family consultations carers and relatives should be provided with information about the **diagnosis** or the general nature of mental illness, the **treatment and care plans**, including but not limited to prescribed **medication and its side-effects**.
8. Individual **needs** of family members and suitability of various **family support resources** should be discussed at family consultations, outlined in the care plan of service users, and reviewed on a regular basis.
9. A **key worker** should be assigned to each **service user** by the community mental health team, as outlined in *A Vision for Change*. In order to promote communication and partnership between stakeholders, it is recommended that such key worker will also be **available to the family** for advice and contact, with the consent of the service user.

### Rehabilitation or recovery of service users

10. All services, supports, and information provided to service users and their families at all stages of family experience with mental illness should be aimed at **rehabilitation or recovery**.
11. Persons with mental health problems who are on the waiting lists for public housing may need **guidance and support from mental health services** on how to avail of such accommodation. Communication between mental health services and local authorities should be improved.
12. Assessment of individual **occupational needs, skills, and abilities of service users** need to be carried out by social services in partnership with adult education authorities and rehabilitation teams, in order to facilitate 'place and train' modules suggested by *A Vision for Change*.

### Family-tailored support services

13. Family-tailored support services should include **family education, individual and family counselling, and family psycho-education**, involving service users and their family members. Such services should be developed in all catchment areas on the basis of the **needs** of service users and their families, highlighted during the **family consultations** and documented in the **care plans**.



14. More **individual-based and user-friendly** support services need to be developed and offered by mental health services for **parents, spouses, siblings, and children** of persons with mental health problems. Such programmes should be developed according to evidence-based best practice, piloted within an Irish context, and made available to families in all catchment areas.
15. **Cost-effectiveness and efficiency** of professional family support resources should be **evaluated** by mental health services. Outcome measures of such evaluation can include the satisfaction of service users, and their carers and families with the quality of support and services provided to families with mental illness.

### General family support resources

16. General family support resources include services of **voluntary organisations and community groups**. Adequate **funding** of existing family support resources need to be secured on a long-term basis to ensure continuation of their use by families with mental health problems.
17. More **mental health information centres**, available for information, advice, and counselling of service users and their families, could be developed by voluntary support resources, community groups, or mental health services. Such centres could be located in the premises used by voluntary organisations, community groups, or mental health services. The general public should have easy access to such centres.
18. Extension of working hours of **helplines** for persons experiencing mental health problems and their family members should be considered by voluntary organisations and community groups, in order to provide continuous support for families with mental health problems.
19. Development of new, and improvement of existing, mental health information centres, family support groups, and helplines should involve partnerships of service users and their families. This would provide additional **occupational and training opportunities** for recovering service users and promote **advocacy** for families with mental illness.

### Directions for further research

20. Research on the **experience and needs** of service users at various **stages** of their mental health problems should be carried out in order to provide further recommendations for improvement of support for service users and their families.
21. Research on **psychosocial factors** associated with the **onset** of mental illness should be carried out in order to identify and explore further factors involved in the onset or recurrence of mental health problems, and to tailor service provision to the individual recovery needs of service users.
22. Research on the **duration** between the **first contact for help** and **referral** to treatment, and between the **referral** and the **first treatment provision** need to be carried out in order to identify and explore further factors associated with duration of untreated illness, which may affect early intervention.
23. Research on the **processes and outcomes** of recovery need to be carried out, which would facilitate establishing measures of successful outcomes and effectiveness of treatment and care provision.
24. **Needs of service providers at various stages of service provision** should be explored and addressed in order to improve planning of service delivery as outlined in *A Vision for Change*.



# Chapter 1

Background to the  
study

## This study will explore the experiences, needs, and support requirements of relatives of persons with enduring mental illness in Ireland.

It will examine support resources already available to families and their utilisation, and determine what other supports are needed. The extent of satisfaction with services and support offered to persons with mental illness and to their families will also be analysed.

### 1.1 Introduction

The legal definition of an Irish family stems from the Constitution and includes married parents and their children (Constitution of Ireland, 1937). However the report of public consultation *Families and Family Life in Ireland* (Daly, 2004) carried out by the Department of Social and Family Affairs underlined that there was a need for developing a more inclusive definition of a family to reflect the changing nature of families in Ireland and elsewhere in the world. Such definition should include grandparents and children, foster parents and children, lone parents, partners as well as the same sex parents and children. There has been no new Irish legal definition of a family agreed upon by the government and the public. In this study, we used a broader definition of a family as used in clinical or counselling psychology (Patterson 1996). This definition includes one's family of origin (parents and siblings) and spouse and children (Rothausen, 1999), including step and foster parents and children.

Numerous studies have confirmed that families play an important role in the treatment and rehabilitation of their relatives with mental health problems. They often remain the first and last resort of care (Hanson & Rapp, 1992), especially in crises and emergencies. There is evidence suggesting that family support programmes can reduce relapse rates among persons with mental illness (Cassidy *et al.*, 2001) and help their rehabilitation in the community (Dixon *et al.*, 2001). In addition, relatives and carers of persons with mental illness are at greater risk of psychiatric morbidity (Yee & Schultz, 2000), and have more cases of infectious illness than the general population due to stress associated with the burden of mental illness (Stengard *et al.*, 2000). Both the physical and psychological well-being of families with mental illness constitute an important public health issue (Schene *et al.*, 1998).

As stated in the report on stakeholder consultation on quality in mental health services, *Quality in Mental Health – Your Views*, carried out by the Mental Health Commission in Ireland in 2004 (Mental Health Commission, 2005), the needs of families were closely connected with the quality of services provided to their family member. The most recent Irish policy document in the area of mental health, *A Vision for Change* (Department of Health and Children, 2006) recognises the role of family and friends in the care of persons with enduring mental illness.

*A Vision for Change* underlines the need for on-going partnership and open communication between all stakeholders involved in mental health, and points out that carers should be included as active partners in the planning and delivery of mental health services, on a par with mental health professionals and service users.

One of the recommendations of *A Vision for Change* is that 'services need to provide families and carers with support, information, and easily accessible help when needed.' (p.106). In order to meet such needs and support requirements in the most efficient and timely manner, it is necessary to explore the existing support resources, their limitations and developmental potential, most urgent needs and future support requirements of carers and families.

To date, no in-depth studies have been published in Ireland concerning specific experiences, needs, and support requirements of families with enduring mental illness. Experiences, needs and support requirements may vary among different groups of relatives of persons with mental health problems and between different diagnostic groups of persons with mental health difficulties, depending on the duration and severity of illness, family situation, housing condition, and the availability of services (see e.g. Marsh, 2001; Biegel *et al.*, 2004; Pickett-Schenk, 2003, Mental Health Commission, 2005).

This study was undertaken in order to provide information and guidelines for the development of mental health services, and pointers to tackling the stigma and social exclusion of families with mental health problems. It will provide an insight into the daily life of such families, their social and psychological well-being, and the role of the family in treatment and rehabilitation of persons with enduring mental health problems. In addition, the study will inform recommendations for service providers, policy-makers, and community groups concerning experiences, needs, and support requirements of families with enduring mental illness.

## 1.2 An overview of previous findings

### 1.2.1 Impact of mental illness on the family

The influence of mental illness on the family has been studied since the early 1950s. However service providers have seldom taken account of the expertise knowledge of the relatives and their potential therapeutic effects on the mentally ill person. The family has often been viewed as a contributor to mental health problems, rather than as an ally of service providers. Some family behaviours, such as criticism, hostility, and over-involvement, referred to as ‘expressed emotion’, were viewed as negative factors affecting the outcomes of treatment and care (Thorncroft & Szmukler, 2001). These views often led to a lack of communication and understanding between mental health professionals and relatives of mentally ill persons.

A study by Falloon and McGill (1985) found that the quality of caring relationships, rather than the emotional type of family communication, influenced the outcomes of treatment and rehabilitation of service users. Moreover, the main factor affecting successful outcomes may be the lack of a supportive and trusting relationship between carers and service users, and not the presence of hostility, over-involvement, or criticism in the family interaction patterns, referred to as ‘expressed emotion’ (Falloon & McGill, 1985).

Later studies have shown the positive influence of the family on treatment and rehabilitation, suggesting that family interventions can reduce relapse rates among persons with mental problems and help their rehabilitation in the community (Dixon *et al.*, 2000).

The impact of mental illness on the family has been thoroughly investigated. The term ‘burden on the family’ was used by Treudley (1946) as pertaining to the consequences for those in close contact with the mentally disturbed relative. The term was further subdivided into the objective burden, that is, specific financial, time and energy investments of the family connected with taking care of the sick relative, and the subjective burden, described as the emotional costs of the objective burden to individual family members in terms of their physical, social, and psychological well-being (Thorncroft & Szmukler, 2001).

The effects of objective and subjective burdens on family functioning and its individuals may be interrelated. Objective burden is associated with care-giving tasks, limitations of service provision, and social stigma (Marsh, 2001). The family may have to cope with different symptoms, harmful or socially unacceptable behaviours, and unhealthy daily living habits. Relatives invest much time and

energy in seeking help and negotiating with mental health professionals, social welfare agencies and legal representatives. They often bear the high financial cost of the illness, which in some cases leads to severe financial problems within the family, or even to impoverishment (Lefley, 2001). Normal life and career development of family members are often restricted or disrupted, which in extreme cases may cause family disintegration, social exclusion, or substance abuse. Social stigma often associated with mental illness may lead to isolation of the family and to the inability or unwillingness of family members to articulate their needs and support requirements.

The subjective burden of mental illness is inseparably connected with the objective burden in terms of its effect on the emotional and psychological well-being of individuals. Relatives often report such feelings as grief and loss (Marsh, 2001). A father described his grief as a constant mourning for his daughter, which never ended (Muhlbauer, 2002). Often relatives experience a sense of self-blame and guilt for the onset of the illness. Feelings of helplessness, inability to control the situation, and psychological distress are often described as constituents of the subjective family burden caused by a mental disorder in the family (Lefley, 2001).

Research on family burden yielded numerous instruments for measuring the extent of objective and subjective family burden and care-giver distress. Schene *et al.* (1994) reviewed 21 instruments used to assess care-giver burden in mental illness. However, there was no complete agreement among researchers with regard to the definition of objective and subjective burden of illness on the family and the concept of burden itself (Reine *et al.*, 2003).

Some researchers (Szmukler *et al.*, 1996) rejected the term 'burden' as pejorative, arguing that the dimensions of care-giving may have some positive as well as negative aspects. For example, more than 50% of 560 family members who participated in Chen and Greenberg's study (2004) reported that caring for a relative with mental illness helped them to clarify their priorities in life and enhanced their sense of inner strength and mastery. It may be beneficial for mental health professionals, social workers, and policy-makers to study and encourage constructive adaptation when working with families with mental illness.

### 1.2.2 Family adaptation to enduring mental illness

Several studies have shown that diagnosis, age, gender, family role, personality, coping effectiveness, values, and living arrangements can effect family adaptation to mental illness. Some individual variables can alleviate the family burden and facilitate family adaptation (Marsh, 2001). In other cases, complete disintegration or disengagement of the family from the ill relative can occur.

Families may disengage themselves from their ill relatives due to their feelings of hopelessness, victimisation, and misinterpretation of the symptoms as personality traits. Some families disconnect from their ill relatives due to the desire for self-preservation (Marsh, 2001), especially if the service user's behaviour is perceived as threatening. However, such families may still experience guilt for the termination of their relationship, and the void in the family persists. An individual family service plan, which may involve health professionals and social workers, may be helpful in such cases for improving of family relationships and providing more support to service users (Marsh, 2001).

An unhealthy family environment may also create problems for the mentally ill person. A person's mental health may deteriorate after contact with a family with substance abuse, violence, hostility, or over-involvement (Thorncroft & Szmukler, 2001). In such circumstances, the possibility of alternative community accommodation needs to be explored, and protective action is recommended by professional services (Marsh, 2001).

### 1.2.2.1 Individual variables influencing family adaptation to mental illness

Among several forms of enduring mental illness which influence the families quite severely are schizophrenia and major depressive, or mood disorders (Marsh, 2001). Most research has been concentrated on family experience of schizophrenia (Marsh, 2001). However, mood disorders can also have far-reaching consequences for families. Persons with major depression are more likely to be employed, married, and have children than those with schizophrenia. Support requirements of families with mood disorders may be different from those of families with schizophrenia. The general nature of mental illness should be taken into account in the analysis of family needs and in the design of family support programmes.

Persons with enduring mental health problems may have different levels of independent functioning, or psychosocial resistance to activities of daily living (Clifford *et al.*, 2003). The lower levels of independent functioning and motivation of persons with mental health problems may foster some activities of daily living, such as getting out of bed, changing clothes, taking medication, and socialising. Resistance to perform such basic living tasks may demand more time or energy of carers, and increase the burden on the family. The Psychological Resistance to Activities of Daily Living Index (PRADLI) (see Appendix 5) was found to have significant correlation with cognitive impairment and independent functioning of persons with mental health problems when used as a treatment outcome measure in long-term care (Clifford *et al.*, 2003). It may be useful to explore the influence of the perceived level of functioning of persons with enduring mental illness on their carers' degree of satisfaction with services and support provided to themselves and their relatives.

The age of persons and the duration of their illness may be important factors in the study of needs and support requirements of families with mental illness. In a study of care-givers in Finland, satisfaction of relatives with mental health services was positively correlated with the time since the onset of illness, as well as with the patient's age, suggesting that the functioning of service users may have improved with age (Stengard *et al.*, 2000).

Such demographic factors as gender, educational level, employment status, and residential status of the persons with mental illness and their relatives are important for the analysis of the experiences and support requirements of the families. The study by Chen and Greenberg (2004) found that higher levels of care-giving gain were associated with being female, having fewer years of education, being a relative, and living with the relative with mental illness.

Gender could be an important factor in adapting to the impact of mental illness on the family. Most studies suggest that the majority of family carers of adults with mental illness are women (Pickett-Schenk, 2003). Women are actively involved in day-to-day activities and provide greater emotional support to their ill relatives than men. As found by some studies (Lutzky & Knight, 1994), female carers are more likely to seek emotional support from others, whereas male carers are less likely to articulate their emotional problems in a group setting and tend to seek solutions on their own.

Female and male carers and relatives of persons with mental illness may have different needs and support requirements. For example, a study by Wackerbarth and Johnson (2002) showed that female carers for persons with Alzheimer's disease rated the need for interaction and support from others as more important than did male carers. Male carers, on the other hand, may value information about the illness, diagnosis, and symptoms more than female carers do, and are more likely to use the internet and other media resources for information.

In several studies, female carers reported more distress and depression associated with caring duties. Male carers may be less attentive to their emotions and may sometimes fail to recognize and report

stress (Lutzky & Knight, 1994). Studying individual coping mechanisms used by female and male carers may provide an insight on gender-specific needs and support requirements, and may provide direction for the development of family-tailored support services. Pickett-Schenk (2003) suggested that men could benefit from education and support programmes, especially if they emphasised the informational, rather than the social, focus. Promoting support programmes in specific male settings, such as sports events, fishing, and such like, may be more beneficial for male carers.

### 1.2.2.2 The effect of family roles on family adaptation

As shown by previous research, **parents**, and especially **mothers**, have been the major subjects of studies of family experience. They had the most contacts with service providers, and participated most frequently in family programmes (Marsh, 2001; Pickett-Schenk, 2003; Hanson & Rapp, 1992). Parents, and especially mothers, tend to spend more time caring for their children because of their family role. They may be more vocal in their support requirements than spouses, siblings, or children of persons with mental illness.

Themes recurring in the family experience of parents of mentally ill children are grief and loss, guilt and responsibility, disruption of family life and privacy, and marital problems. Another concern of parents as they age, is the future of their child after they are gone, especially with ongoing de-institutionalisation of the mentally ill population. They are worried about their child's housing, treatment, finances, and quality of life (Marsh, 2001; Pickett-Schenk, 2003; Hanson & Rapp, 1992).

The burden on **spouses and partners** of persons with mental illness can be quite substantial. Whereas parental programmes focus on continuity of care and support for their children, spouses may need more timely assistance in preventing financial ruin, protecting themselves and their children from potential disruptive or anti-social behaviour, and obtaining legal advice. Family consultation and individual and couple therapy could be more beneficial for spouses than support groups.

Recurrent themes in the experiences of **siblings** with mental illness in the family are grief and loss of their brother or sister, a feeling of being forgotten by their parents, guilt that they were spared by mental illness as opposed to their sister or brother, and the stigma associated with their career and relationships outside the family. There may also be benefits for their coping skills due to their perceived desire to appreciate 'normal life' and to help their ill relative. Marsh (2001) suggests the following support services to benefit siblings: home-based programmes; parenting classes for their parents; supported housing; and respite care during crisis for their ill relatives.

**Children** of mentally ill parents might be the most vulnerable group because of their developmental issues and the central role of parents in their lives. Offspring themes include grief and loss, difficulties of caring and lack of guidance and family support. Adult offspring sometimes admitted that they had been afraid to have children because of the perceived risk of developing mental illness themselves in the future. On the positive side, many offspring reported a strengthening of their coping skills and compassion toward others as a result of caring for their parent (Marsh *et al.*, 1996).

Marsh (2001) recommends provision of information and support appropriate to age and coping skills of various family members. Most adult siblings and children who were participants in the study by Marsh *et al.* (1996) found individual counselling very helpful.

### 1.2.3 Stages of family experience with enduring mental illness

Some studies have explored the process of enduring mental illness in the family holistically and have identified several stages of family adaptation to the situation. For example, Spaniol and Zipple (1994) divided the process of family development into four general phases: discovery/denial, recognition/acceptance, coping, and personal/political advocacy. A study by Karp and Tanarugsachock (2000) also identified four stages in the emotions of caring experience: before a diagnosis, getting a diagnosis, recognising the permanence of the mental illness and acceptance. Marsh (2001) describes a four-stage process of family adaptation to mental illness: the initial encounter, confrontation, resolution, and post-traumatic reactions. Many professionals recognise that the needs and tasks of the family may vary depending on the stage of mental illness. Stages of family experience with the enduring mental illness identified by several studies are reviewed below.

The **initial encounter** with mental illness can involve such feelings as shock, denial, and confusion. Participants in Muhlbauer's study (2002) reported feelings of concern, seeking assistance, and often having their concerns negated by some mental health professionals. Recognition that something was wrong with their relative eventually led to hospitalisation.

The stage of confrontation, or **getting a diagnosis**, may be characterised by emotional distress, problems in communicating with health care providers and financial concerns (Muhlbauer, 2002). As some participants in Muhlbauer's study reported, getting a diagnosis entailed the potential for treatment and recovery. The need to learn more about the illness, treatment, and symptoms was pronounced during this stage (Karp & Tanarugsachock, 2000).

The next stage identified by some studies was a **gradual recognition** that the illness could become enduring or even permanent. Sometimes other family members distanced themselves from the relative, fearful of losing their own identities (Karp & Tanarugsachock, 2000). At this stage, the relatives needed more explanation about the recurrent or enduring symptoms. Some of them reported dissatisfaction with community mental health services and turned to self-help groups for support. This phase often involved pronounced financial concern.

The next stage involved **acceptance** that the illness was permanent; at this stage, the need for being in control was not so pronounced any more. Expectations were readjusted, which resulted in decreased anger, increased tolerance, and better understanding of the illness. Although the feeling of grief and mourning still existed, the family could now concentrate more on their own lives. Some family members turned to advocacy groups or multi-family projects in order to improve the quality of service provision and the lives of other families with mental illness.

## 1.3 Support services and resources for families with mental illness, and their utilisation

### 1.3.1 Family support services and resources

During the last 20 years, five major types of family support services and resources have been designed in Europe and the US and assessed on the basis of their effectiveness for both mentally ill persons and their family members. These programmes were tailored to meet the three perceived major needs of families: information about the mental illness and its treatment, coping skills, and a support network and resources (Marsh, 2001). The most current five types of family support resources include family consultation, family education, family psycho-education, family counselling or psychotherapy, and support and advocacy groups (Marsh, 2001; Lefley, 2001).



**Family consultation** is widely used in the US and world-wide as a means of engaging the families in treatment and rehabilitation of their ill relative and helping them to identify and prioritise their needs. Consultations are especially beneficial at the onset of illness, but can also be helpful during crisis or relapse. During the consultation, families are offered professional advice on the diagnosis, treatment plan and medication of the relative, and on the future actions and goals of family members. The outcome of an effective consultation is family satisfaction with service provision to the relative with mental illness, as well increased competence in handling the situation. Other needs of families may also be addressed, such as the need for information about mental illness, acceptance of illness and alleviation of feelings of guilt and anger (Marsh, 2001).

**Educational programmes** focus largely on the needs of the ill relative and provide family members with information, understanding and support. They inform families about mental illness and its treatment, symptom management, crisis management, service provision and community resources. They also offer an opportunity for family members to share their experiences, network with other families, and in some cases to enhance coping skills. Studies of family education programmes have shown such benefits to the families as increasing understanding and acceptance of mental illness, shaping of expectations, and enhanced coping strategies (Marsh, 2001). Benefits for patients could be an improved family environment; better family support of treatment and rehabilitation; reduced risk of relapse; and improvements in service provision (Cassidy *et al.*, 2001; Lefley, 2001). Educational programmes can range from a one-day workshop to a 10-12 week course, and may also be available on the internet, on video, or in printed media.

**Family psycho-education** usually includes information about the mental illness and caring needs, but is more focused on family needs than on the needs of the ill relative (Marsh, 2001). Such programmes are usually longer in duration than educational ones and last from nine months to over a year. Interactive training includes problem solving, crisis intervention, coping skills, stress management, and cognitive behavioural therapy (CBT). Service users often participate in family psycho-education together with their families. Several studies have shown that psycho-education may reduce relapse, improve the ill person's functioning and increase family well-being (Lefley, 2001; Falloon, 2002).

**Individual counselling or psychotherapy** may be helpful to family members who prefer the privacy and confidentiality of individual sessions (Marsh, 2001). Also, as some studies have shown, mental illness may affect the psychological well-being of family members, thus making it more difficult for them to speak in a group setting and verbalise such feelings as grief, loss, guilt, or responsibility. Marsh and Dickens (1997) found that counselling could be especially beneficial to siblings and children of persons with mental illness. Couple therapy can also benefit spouses of persons with mental health problems and help them to overcome illness-related marital problems.

**Support and advocacy groups** have proven to be therapeutic to family members, and help to alleviate feelings of grief and guilt. They can also offer specific help to persons with mental health problems in terms of social support and job-finding (Thornicroft & Szmukler, 2001). As described by Marsh (2001), in the US family support and advocacy groups have three functions: group support and informal networking, access to a variety of educational programmes and advocacy, which includes anti-stigma initiatives and campaigns and encourages research and improvement of mental health services. Such groups can be beneficial for some family members who wish to go beyond their own family experience and advocate for a larger population of families with mental illness. Support and advocacy groups can offer settings for successful communication between professionals and families, and provide insights into family experiences and concerns for service providers, researchers, and the general public (Lefley, 2001).

### 1.3.2 A three-step model of working with families

In order to assess family needs and select the best suitable and efficient combination of support programmes for particular families and settings, Marsh (2001) suggests using a three-step model of working with families. **The first step** involves family consultation at the onset of illness, or at the stage of getting a diagnosis. Such family consultation can serve as a means of involving families in treatment and rehabilitation, assessment of their needs, informing them about available support resources, addressing their concerns for the family's future, and drafting a family service plan. In some cases such consultation may be sufficient for families; it can also be beneficial at times of other stages of family experience with mental illness if needed, such as at times of relapse or re-admission.

**The second step** involves amalgamation of existing community resources, such as voluntary support groups, and professional services, such as on-going consultations and educational or psycho-educational programmes, into the family service plan. As supported by empirical research, steps one and two are usually sufficient for most of the families (Marsh, 2001).

**The third step** may be needed for some families which continue to experience substantial psychological distress despite the supports provided during the first two stages. In such cases, individual, couple, or family therapy, or a combination of these, may be beneficial, depending on the specific family situation and individual needs of family members.

### 1.3.3 Barriers to utilisation of family support resources

Families may or may not avail of support services. A study by Biegel *et al.* (2004) found that participation in support groups depended on the cost-benefit ratio (benefits minus costs) and the ease of access. The main barriers to participation in family programmes were the lack of time, the lack of energy, and the lack of transportation to attend the meetings. The lack of respite care or day care options were reported among the barriers to participation in family programmes (Biegel *et al.*, 2004).

The authors suggested that non-members' assessments of benefits and costs could be based on inaccurate perceptions of, or information about such groups. In fact, some previous studies indicated that up to one-third of carers and families of lower socio-economic status had not heard about support groups for families (Biegel *et al.*, 2001).

It may be beneficial to request feedback from families on the reasons for their non-use of available support resources, in order to develop more efficient and responsive family support resources in the future (Marsh, 2001).

### 1.3.4 Satisfaction of families with the services and support provided to them and relatives

The satisfaction with psychiatric services of both users and their relatives has been increasingly used as a measure of outcome and quality of care (Stengard *et al.*, 2000). Whereas consumer satisfaction with mental health services has been evaluated by some studies (e.g. Druss *et al.*, 1999), little attention has been paid to the satisfaction of relatives and carers.

A study carried out in the US by MacDonald *et al.* (1990) reported that relatives were more dissatisfied with psychiatric services than patients, general practitioners, or social workers. They tended to have higher expectations of community psychiatric services, and complained about insufficient information and a lack of practical advice on how to deal with potential crises. Hanson and Rapp (1992) reported

that patients' families were particularly concerned with emotional support, aftercare services, responses to requests for information, and greater participation in the patients' care.

The survey *Breaking the silence* carried out by EUFAMI in 2001 among family representatives of five European countries, including Ireland, documented carers' views on the help provided during the first episode of psychosis. Between 22% and 44% of the carers were dissatisfied or very dissatisfied with the quality of care provided to their ill relative and to themselves. The two top priorities listed by carers were help for the patient, and their own need for advice on how to cope with problems and information on the diagnosis and treatment (De Haan *et al.*, 2001).

### 1.3.5 Family support services and resources in Ireland

In Ireland, there are several voluntary and national organisations providing support to families with mental illness. For example, Schizophrenia Ireland (SI) hosts family support groups, support courses and education courses for caring relatives in Ireland. There is also a counselling service for people with schizophrenia and their relatives offered in Dublin and in the midlands. Schizophrenia Ireland's helpline is open four hours per day, Monday to Friday, and provides information on schizophrenia. Trained volunteers and staff run the helpline. The website of Schizophrenia Ireland also provides information with regard to schizophrenia, its symptoms, treatment, and recovery.

Mental Health Ireland is a national voluntary organisation which promotes mental health and supports persons with mental illness and their families by providing an information service and advocacy. Mental Health Ireland consists of a network of mental health associations throughout Ireland, and is affiliated to Mental Health Europe and the World Federation for Mental Health.

Some mental health services also provide educational and support programmes for service users and their relatives. For example, several hospitals in Dublin run educational programmes for families with enduring mental illness. An information centre on mental health has opened at a hospital in Dublin in July 2006, providing a drop-in resource for service users, families and the general public.

### 1.3.6 Needs and support requirements of carers and families in Ireland

As stated in the report *Quality in Mental Health – Your Views* (Mental Health Commission, 2005), carers and families wanted improved co-operation with service providers, and follow-up and support of a person after the discharge from a hospital. They also needed more understanding, empathy and respect from mental health service providers.

A need for effective family support services at every stage of the person's illness and recovery process was underlined. Families highlighted the need for family counselling and family therapy, which could address their own stress and anxiety arising from the pressures of mental illness. They also needed access to respite services, a key worker for the family, access to a helpline during crises, and services of community psychiatric nurses. Better housing planning for the users of mental health services was needed in order to avoid the burden of the family associated with the need to provide care for their relative at home (Mental Health Commission, 2005).

The support requirements are best evaluated in the context of a specific family situation, duration and stages of mental illness. Whereas some of the needs can be met in a more immediate fashion, others may require extensive long-term planning and investment. Needs and support requirements may vary among different diagnostic groups of persons with mental illness, duration of illness, family situation, housing condition, availability of services in the area, and different stages of experience with enduring mental illness. In-depth interviews with families will provide insight into family-specific needs and support resources.



# Chapter 2

Aims and methods

The main aims of this study are to explore the experiences, needs, and support requirements of families with enduring mental illness in Ireland, and to provide recommendations for service providers, policy-makers, and community groups on further improvement and development of mental health services.

The study will aim to establish which support resources are already available to the families, their utilisation, and what other supports are needed.

## 2.1 Aims and objectives of the study

The specific objectives of the study are:

1. To investigate the experiences of family members of persons with enduring mental illness, the effects of mental illness on families, and family adaptation to the phenomenon of mental illness;
2. To explore the needs of subgroups of relatives such as parents, spouses, siblings, and offspring, and the effects of gender on needs and support requirements;
3. To analyse the experiences and support requirements of family members at different stages of the enduring mental illness of their relative;
4. To explore the support resources available to relatives, barriers to and facilitators of their utilisation, and the supports and resources needed;
5. To investigate the extent of satisfaction with services and support offered to persons with enduring mental illness and their families.

## 2.2 Methods

### 2.2.1. Study design: qualitative

Due to the lack of studies published in Ireland with regard to experiences, needs, and support requirements of families with enduring mental illness, there was a need for an exploratory, in-depth study in this area. A qualitative approach to data collection and data analysis was selected for the purposes of the study. Semi-structured in-depth interviews were viewed as the best tool for exploration of family-specific experiences, needs and support resources. Individual interviews were chosen in favour of focus groups for two main reasons:

- 1) in order to facilitate in-depth exploration of the experiences, needs and support requirements of different subgroups of relatives within the context of their individual families;
- 2) in order to minimise the potential threatening effect of stigma associated with mental illness, and to enable the participants to talk freely about their individual experiences and concerns in the privacy of confidential interviews as opposed to group settings.

In addition, questionnaires were used in order to collect socio-demographic and other quantitative information pertaining to study participants and persons with enduring mental illness. The Psychosocial Resistance to Activities of Daily Living Index (PRADLI) (see Appendix 5) was adapted for the study in order to explore the nature of daily caring tasks experienced by participants, and perceived levels of independent functioning of persons with mental health problems within the last 30 days prior to participation in the study.

### 2.2.2 Access to sample and ethical considerations

The inclusion criterion for participation in the study was having a relative with enduring mental illness of two or more years' duration, which required contact with mental health services at least twice within one year. Contacts with mental health services included admissions to in-patient psychiatric hospitals and units; use of out-patient psychiatric clinics; use of psychiatric day care hospitals and day centres; living in community residencies; contact with a psychiatrist or a psychiatric nurse; out-patient domiciliary visits; general hospital liaison services; psychiatric social workers; and psychologists employed by mental health services. The study excluded persons with a primary diagnosis of organic mental disorder, such as dementia and Alzheimer's disease, and mental disorder due to substance abuse. It was expected that relatives of persons with schizophrenia or major affective disorders would constitute the majority of the participants. However diagnosis was not part of the selection criteria due to the possible lack of information about diagnosis among various family members.

As the study was designed as exploratory, it was decided, where possible, to include parents, spouses, siblings, and adult offspring of persons with enduring mental illness in the study sample. This may help to address both the essential needs of all family members, as well as the specific needs and support requirements of various kinship groups.

The study included members of Schizophrenia Ireland (SI) residing in Dublin city and county, and relatives of mental health service (MHS) users of a catchment area in Dublin. As shown by some previous studies (see Pickett-Schenk *et al.*, 2000), members of family support associations may be of higher socio-economic status, and/or may have access to more resources than those not availing of support organisations. It was considered beneficial to contact relatives of persons using public mental health services in addition to the relatives who were members of SI.

The study was facilitated by Schizophrenia Ireland (SI) and mental health services (MHS) of a catchment area. A total of 250 information letters about the study (see Appendix 1) were distributed by SI and MHS representatives to family members matching the HRB inclusion criteria for the study described in the information letter. The information letter described the purposes of the study, invited to participate, and provided direct contact details of the researcher, such as telephone numbers, and postal and e-mail addresses. No personal identifying records of participants were provided to the HRB research team. Due to ethical considerations of confidentiality of participants, the selection procedures used by representatives of SI and MHS for the distribution of letters to potential participants were outside the control of the researchers and cannot be described in further detail.

Out of the total 250 information letters, 150 were distributed to SI members and 100 were mailed out to relatives of MHS users of a catchment area in Dublin. Fewer letters were mailed by MHS compared to SI because only one catchment area was serviced by MHS, whereas SI had access to its members across all catchment areas of Greater Dublin. Persons willing to participate contacted the researcher, and a convenient time and place for the interview were agreed by phone. Most of the interviews took place at the office of the Mental Health Research Division of the Health Research Board on Holles Street. Three participants were restricted in their travelling, and the researcher visited them in their homes.

International best practice (e.g. WHO Guidelines, 2000) pertaining to the conduct of ethical research in the social sciences served as a basis for the selection of methods and procedures for the present study.

Participants were assured that no personal identifying information was recorded, that the personal information that they disclosed was not available to other support group members or mental health representatives, and was used in the research report in a manner which would not allow identification of the respondents. In addition, participants were advised that all records of the interviews would be destroyed within 12 months of the publication of the report of the study.

The research proposal has undergone the peer-review process in the HRB, which included one internal and two external reviews. The study received ethical approval from the HRB Research Ethics Committee in June 2005. Ethical approval to proceed with the study was also given by the clinical director of MHS of the relevant catchment area.

### 2.2.3 Data collection

The interview schedule for this study was designed in order to explore holistically the influence of mental illness on the family and its individual members (see Appendix 6). The questions and issues included in the interview schedule were designed on the basis of findings of some previous research on experiences, needs, and support requirements of families with mental illness in the US, UK, Europe, and Ireland (see Chapter 1), informal discussions with relatives of persons with mental problems, meetings with representatives of family support groups and service providers, and observation of family support group meetings.

Prior to proper fieldwork, two pilot interviews were carried out with two members of SI. Minor adjustments were made to instruments and procedures, such as providing a clearer explanation of the Psychosocial Resistance to Activities of Daily Living Index (PRADLI) (Appendix 5). Also, an extra prompt was included in the interview schedule: 'What kind of support would you need most at the moment?' in order to identify and prioritise current needs of the family.

During the interview, the contents of the information letter were reviewed and discussed with the participants. Written consent was obtained from the respondents to indicate their willingness to participate in the study (see Appendix 2). Participants were informed that their participation was voluntary and confidential, and that they were free to withdraw at any time. The researcher also asked for their written permission for the interviewer to audiotape the interview and take additional notes during the interview. Participants were also informed that the tapes and notes pertaining to the interviews would be destroyed in 12 months after the publication of the study report. All participants provided their consent to the taping of the interviews.

After obtaining the written consent, the participants were asked to complete a demographic questionnaire which collected information on their age, gender, marital status, relation to the person with the enduring mental illness, education, employment status, occupation, hours of contact with the person with mental health problems per week, participation in family support or family education groups, and the extent of satisfaction with the quality of services and support offered to their family (see Appendix 3).

The participants were also asked to complete a questionnaire pertaining to the service-users, including age, gender, marital status, diagnosis (if known), duration of illness, education, employment, current residential status of the ill relative, use of mental health and support services, and the extent of their satisfaction with the services and support offered to the person with mental health problems (see Appendix 4).

In order to explore some elements of 'family burden', the physical capacity and psychological resistance of persons with mental illness to fulfil daily living tasks was included in the questionnaire. Psychosocial Resistance to Activities of Daily Living Inventory (PRADLI), used by Clifford *et al.* (2003) as a means of assessing long-time care needs and outcomes of mental health patients, was adapted for the study (see Appendix 5).

No personal information pertaining to either persons with enduring mental illness or their relatives was recorded.

The participants were asked open-ended questions about their experiences of the enduring mental illness in the family, encounters with mental health services, different stages of mental illness, and family support resources and their utilisation. (see Appendix 6).

The interview schedule was designed as an overall guide for data-elicitation. The interviewees covered some of the questions without any prompting. The order of the questions was also flexible depending on the general flow of the interview. The interviewer tried to ensure that all issues included in the schedule were covered during the interview. The interviews lasted between 45 and 120 minutes.

In total, 32 interviews with 30 families with mental illness were carried out. Most of the interviews (n=30, 93.8%) were carried out by the principal investigator. Two interviews carried out by the co-author of the study Donna Tedstone Doherty involved two additional members of the same families, namely, a daughter and a husband of two mothers of persons with mental health problems which were interviewed at the same time by the principal investigator. The two sets of scores of the PRADLI scale reported by the participants to the two interviewers were identical.

#### 2.2.4 Data analysis

A combination of qualitative and quantitative methods was used for data interpretation and presentation of the findings. The interview schedule provided an outline for content analysis of the narratives pertaining to the stages of experiences with mental illness, met and unmet needs and support requirements, barriers to utilisation of support resources, and some other issues mentioned in previous research and stakeholder consultations. Both deductive (from theoretical perspective based on the previous findings) and inductive (developed directly from the data) coding procedures were used. During the analysis, the researcher applied four criteria for rigor: credibility, confirmability, recurrent patterning, and saturation (Leininger, 1991). Credibility criteria refer to the truth and believability of narratives, usually supported by similar experiences reported by several interviewees. Confirmability refers to the evidence documented by previous studies which may underlie the phenomena reported by the participants. Recurrent patterning refers to repeated instances, or sequences over time, which could serve as a base for identifying stages of experience with a phenomenon recurring within similar contexts for different participants. Finally, saturation means that the coding process is carried out until additional data does not contribute to any further themes in the responses of the sample (Glaser & Strauss 1967; Pidgeon & Henwood, 1997).

Verbatim interview transcripts and field notes taken during the interviews were read several times by the researcher, and the themes considered credible, confirmable and recurrent were marked and coded. Memos were created on the basis of such instances, serving as building blocks for further analysis. Interview transcripts were divided into 22 broader categories pertaining to the topics prompted by the interview schedule, such as the initial encounter with mental illness, the first encounter with mental health services, discharge, relapse, influence of mental illness on the family, etc. Narratives pertaining to these topics were entered into Excel spreadsheets, together with some demographic characteristics of the interviewees, such as source of referral to the study, relation to



the ill relative, age, and gender. Tally sheets, or matrixes, were created in Word to account for themes recurrent in the narratives of different groups of participants.

In addition to the manual coding and creation of memos and tally sheets, SPSS Text Analysis for Surveys 1.0 was used in the creation and validation of code lists. In case of specific issues of needs and support requirements, deductive analysis and manual coding were found more efficient for data interpretation. However, for less predictable issues, such as advice to people in a similar situation, advice to the public and expectations of treatment and rehabilitation, SPSS Text Analysis for Surveys 1.0 was found to be a valuable inductive tool in the creation and validation of code lists and their interaction. Interpretation of codes, terms, and categories was drawn, and the data were coded until each category was saturated. All coding and data analysis was carried out by the principal investigator and validated by co-authors.

SPSS 14.0 was used for quantitative analysis of the reported demographic characteristics of the participants and their relatives, and perceived levels of functioning of persons with mental health problems. The extent of satisfaction with the quality of services offered to the persons with mental difficulties and to the families was analysed and compared among various demographic subgroups of relatives. Descriptive statistics, such as frequencies, were used to describe categorical data, whereas means and medians were used to describe continuous variables, such as age, duration of illness, and overall satisfaction with services and support. Multiple response sets and tables were used to describe and analyse services and support resources used.



## Chapter 3

Description of study  
participants and of  
persons with enduring  
mental illness

### 3.1 Description of study participants

An overall response rate of 20% was expected for the project, based on the minimum response rates of relatives of persons with mental health problems reported in some previous studies (see, e.g., Jubb & Slaney, 2002; Pickett-Schenk *et al.*, 2000). In total, 38 relatives of persons with enduring mental illness took part in the study, resulting in a 15.2% response rate, which was lower than the minimum reported by previous studies in the US and elsewhere. As mentioned in section 2.2.2., although the selection criteria were communicated by the researcher to the representatives of SI and MHC, the selection procedures used by these representatives for the distribution of letters to potential participants were outside direct control of the researchers and cannot be described or analysed in further detail. Reasons for non-participation were not available in this study and can only be speculated upon.

Some studies show that the persons who participate in family support groups may be more vocal and active than relatives who do not avail of family support programmes (see Biegel *et al.*, 2004). Indeed, 26 relatives (68.4%) were members of SI, which resulted in a response rate of 17% for the group of the sample recruited via SI. The group of 12 participants recruited via a catchment area of mental health services (MHS) represented a much lower 12% response rate. The researcher received three additional telephone calls from relatives of MHS users who were willing to participate in the study but could not make it within the deadlines of the project due to health or family problems. Thus, the total number of calls received by the researcher from relatives of MHS users was 15, resulting in a 15% response rate for MHS representatives, which was closer to that of the SI recruits (17%).

In total, 32 interviews with 38 relatives of persons with enduring mental illness were carried out. According to Morse (1999), 30–50 in-depth interviews are sufficient for exploratory qualitative research. The interviews lasted for between 45 minutes and two hours. All participants agreed to have their interviews audio taped. Two participants called the researcher after their interviews to add more information.

Thirty families with enduring mental illness were represented by the participants in the study. Eight couples (six married couples, and two mothers and two sisters of persons with mental illness) expressed their willingness to participate in the study. Each member of two couples (husband and wife, and mother and sister) agreed to be interviewed separately by the researchers in order to provide a more detailed picture of specific needs of different family members. Six other couples (five married couples, and one mother and sister) preferred to be interviewed together for mutual support. The interviewer asked the couples to provide their opinions in turn where possible. For the purposes of the study, output provided during joint interviews with six mothers and fathers and two mothers and daughters of persons with mental illness was analysed separately during further coding of the interviews.

In three families (10% of all families), there was more than one person with enduring mental illness. Information provided about different members of the same families was also analysed separately during further coding of the interviews.

The majority of participants were members of SI (n=26, 68.4%). Twelve (31.6%) participants were recruited via MHS. In order to achieve a more in-depth understanding of socio-demographic characteristics of the participants, a separate breakdown by the source of reference to the study is provided throughout this Chapter. As expected, mothers constituted the majority of the sample (60.5%) (Table 3.1).

**Table 3.1** Distribution of participants by their relationship to the person with enduring mental illness and by their source of referral to the study

Relationship to the person with mental illness	Source of referral to the study		
	SI Number (percentage of SI)	MHS Number (percentage of MHS)	Totals Number (percentage of total)
Mother	18 (69.2%)	5 (41.7%)	23 (60.5%)
Father	6 (23.1%)	3 (25.0%)	9 (23.7%)
Step-father	0 (0.0%)	1 (8.3%)	1 (2.6%)
Wife	0 (0.0%)	1 (8.3%)	1 (2.6%)
Sister	2 (7.7%)	1 (8.3%)	3 (7.9%)
Brother	0 (0.0%)	1 (8.3%)	1 (2.6%)
<b>Totals Number (percentage)</b>	<b>26 (100%)</b>	<b>12 (100%)</b>	<b>38 (100%)</b>

The percentage of mothers was higher among SI members (69.2%), than among those recruited via MHS (41.7%). As can be seen from Table 3.1, more subgroups of relatives, such as wife, brother, and step-father were represented in the MHS sample. Though some of the numbers of relatives were small, nearly all subgroups of relatives, except for the offspring, were represented in the sample. Some information with regard to the perceived needs and support requirements of offspring of persons with mental illness was provided during the interviews by other family members, and will be presented in Chapter 4.

As expected, females constituted the majority of the overall sample:  $n=27$  (71.1%), as compared to 11 (28.9%) male participants (Table 3.2). This general pattern was true of both groups of participants, with a higher percentage of male participants recruited via MHS (41.7% as opposed to 23.1% for SI recruits).

**Table 3.2** Gender of participants, by source of referral to the study

Interviewee gender	Source of referral to the study		
	SI Number (percentage of SI)	MHS Number (percentage of MHS)	Totals Number (percentage of total)
Female	20 (76.9%)	7 (58.3%)	27 (71.1%)
Male	6 (23.1%)	5 (41.7%)	11 (28.9%)
<b>Totals Number (percentage)</b>	<b>26 (100%)</b>	<b>12 (100%)</b>	<b>38 (100%)</b>

The ages of interviewees ranged from 20 years to 81 years (mean age 61.3). The average age of the participants recruited by MHS (66.9 years) was slightly higher than that of SI recruits (58.7 years) [U(26, 12) = 99.0,  $p = 0.073$ ].

The majority of the sample ( $n=22$ , 57.9%) were married or cohabiting (see Table 3.3). There were three single persons among the participants recruited via SI.

**Table 3.3** Marital status of participants, by source of referral to the study

Marital status of interviewees	Source of referral to the study		
	SI Number (percentage of SI)	MHS Number (percentage of MHS)	Totals Number (percentage of total)
Single	3 (11.5%)	0 (0.0%)	3 (7.9%)
Married/cohabiting	14 (53.8%)	8 (66.7%)	22 (57.9%)
Separated/divorced	6 (23.1%)	1 (8.3%)	7 (18.4%)
Widowed	3 (11.5%)	3 (25.0%)	6 (15.8%)
<b>Totals Number (percentage)</b>	<b>26 (100%)</b>	<b>12 (100%)</b>	<b>38 (100%)</b>

The level of formal education among the interviewees varied between some primary or completed primary school ( $n=4$ , 10.5%) and one or more university degrees ( $n=13$ , 34.2%). More members of SI had one or more university degrees ( $n=11$ , 42.3%), than the MHS group ( $n=2$ , 16.7%) (Table 3.4). Four (33.3%) participants recruited via MHS had no secondary education, whereas SI members had no such participants (Table 3.4).

**Table 3.4** Educational level of participants, by source of referral to the study

Educational level	Source of referral to the study		
	SI Number (percentage of SI)	MHS Number (percentage of MHS)	Totals Number (percentage of total)
Some primary/ completed primary school	0 (0.0%)	4 (33.3%)	4 (10.5%)
Some secondary/ completed secondary school	7 (26.9%)	2 (16.7%)	9 (23.7%)
Post-secondary/ certificate/diploma	8 (30.8%)	4 (33.3%)	12 (31.6%)
One or more university degrees	11 (42.3%)	2 (16.7%)	13 (34.2%)
<b>Totals Number (percentage)</b>	<b>26 (100%)</b>	<b>12 (100%)</b>	<b>38 (100%)</b>

Whereas nearly half of the SI group (n=12, 46.2%) were employed either full-time or part-time, no participants recruited by MHS were employees. Almost half (n=8, 47.4%) of the MHS group were retired (Table 3.5).

**Table 3.5** Employment status of participants, by source of referral to the study

Employment status	Source of referral to the participants		
	SI Number (percentage of SI)	MHS Number (percentage of MHS)	Totals Number (percentage of total)
Employed (full-time or part-time)	12 (46.2%)	0 (0.0%)	12 (31.6%)
Homemaker	3 (11.5%)	2 (16.7%)	5 (13.2%)
Retired	10 (38.5%)	8 (66.7%)	18 (47.4%)
Other	1 (3.8%)	2 (16.7%)	3 (7.9%)
<b>Totals Number (percentage)</b>	<b>26 (100%)</b>	<b>12 (100%)</b>	<b>38 (100%)</b>

Based on the current or former occupation reported by the participants, their socio-economic groups were established following Census 2002 classification. The highest number of participants (n=14, 38.9%) were in the non-manual socio-economic group. For the SI recruits, the second largest socio-economic group was that of managers and higher professionals (n=7, 28%), whereas for the MHS recruits the next representative group was lower professionals (n=3, 27.3%)

The majority of the sample classified the area where they lived as suburban (n=24, 63.2%), with the second largest category described as urban (n=9, 23.7%). Two people (5.3%) were living in town, and three (7.9%) classified there area as countryside.

Out of 14 (36.8%) holders of medical card, seven were recruited by SI (26.9%) and seven (58.3%) by MHS (see Table 3.6). The majority (n=27, 71.1%) of the sample had private medical insurance. Only one participant was in receipt of a carer's allowance at the time of the study. Four participants (two from SI and two from MHS) had both medical cards and medical insurance at the time of the interview (Table 3.6).

**Table 3.6** Distribution of medical card, private medical insurance, and carer allowance users, by source of referral to the study

Users of:	Source of referral to the study		
	SI Number (percentage of SI)	MHS Number (percentage of MHS)	Totals Number (percentage of total)
Medical Card	7 (26.9%)	7 (58.3%)	14 (36.8%)
Medical Insurance	20 (76.9%)	7 (58.3%)	27 (71.1%)
Carer's allowance	1 (3.8%)	0 (8.3%)	1 (2.6%)
<b>Totals Number (percentage)</b>	<b>28 (107.7%)</b>	<b>14 (116.7%)</b>	<b>42 (110.5%)</b>

The majority of the sample (26, 68.4%) reported their current participation in family support programmes/groups. Detailed analysis of such programmes will be presented in Chapter 7.

Most of participants recruited via SI (n=22, 84.6%) reported their participation in family support programmes. Only four interviewees referred to the study by MHS (33.3%) reported their participation in some family support groups.

## 3.2 Description of the persons with enduring mental illness

This section will present some information about the persons with mental health problems, as reported by the participants in the study. The overall sample of 38 participants provided information about their 33 relatives with enduring mental illness. In some cases two study participants were related to one person with mental illness, for example, a mother and father of a child with mental health problems, or a mother and sister of a person with mental health difficulties. In these cases, the mother was considered as the main responsible relative. The majority of the 33 persons with mental illness (n=23, 69.7%) were sons of study participants, with daughters being the next representative group (n=8, 24.2%). In addition, there was one ill husband (3.0%) represented by his wife, and one sister with enduring mental illness (3.0%) represented by her brother.

The majority (n=22, 66.7%) of persons with mental illness were relatives of participants recruited via SI (Table 3.7). The distribution of subgroups of relatives with mental illness was similar for both samples, with MHS recruits having two additional subgroups of husband and sister.

**Table 3.7** Relationship of persons with mental illness to main participants of the study by source of referral to the study

Relationship to the main participant	Source of referral of participants		
	SI Number (percentage of SI)	MHS Number (percentage of MHS)	Totals Number (percentage of total)
Son	15 (68.2%)	8 (72.7%)	23 (69.7%)
Daughter	7 (31.8%)	1 (9.1%)	8 (24.2%)
Husband	0 (0.0%)	1 (9.1%)	1 (3.0%)
Sister	0 (0.0%)	1 (9.1%)	1 (3.0%)
<b>Totals Number (percentage)</b>	<b>22 (100%)</b>	<b>11 (100%)</b>	<b>33 (100%)</b>

The majority (n=22, 72.7%) of 33 persons with mental illness were males, for both SI (n=15, 68.2%) and MHS (n=9, 81.8%) recruits.

The ages of persons with mental illness ranged from 18 to 70 years, with a mean age of 35.0 years (median=34.0 years). The average age of persons with mental illness reported by SI participants (mean age 31.8 years, median age 30.5 years, range 18–47 years) was significantly lower than the average age reported by MHS recruits (mean age 41.4 years, median age 40 years, range 24–70 years) [U (14.6, 21.7) = 69.0, p = 0.047].

The majority of persons with mental illness (n=27, 81.8%) were single. There were four (12.1%) married or cohabiting persons and two (6.1%) separated or divorced. The distribution of marital status was roughly similar for relatives of SI members and those of MHS users.

Three persons with mental health problems (9%) had children. Two of them were female (75%), and one was male (25%). Of the two females with children, one was single and one separated.

Educational level of persons with mental illness varied from primary school (n=1, 3.0%) to one or more university degrees (n=5, 15.2%). Nearly half of them (n=14, 42.4%) had spent some years in secondary school, or had completed secondary school, and 13 (39.4%) had a certificate or diploma. The percentage with one or more university degrees was higher among relatives of participants from SI (n=4, 18.2%), than among relatives of MHS recruits (n=1, 9.1%).

As reported by the participants in the study, more than half of the persons with mental illness (n=17, 51.5%) were unemployed. Seven persons (21.2%) were in training, and six (18.2%) were in either full-time or part-time gainful employment (Table 3.8). Only relatives of SI participants were in employment; none of relatives of MHS recruits were employed. The percentages of unemployed



persons were very similar for both groups in the sample: eleven (50%) relatives of SI participants and six (54.5%) relatives of MHS recruits (Table 3.8).

**Table 3.8** Employment status of persons with enduring mental illness at the time of the study, as reported by the participants, by source of referral to the study

Employment Status	Source of referral to the study		
	SI Number (percentage of SI)	MHS Number (percentage of MHS)	Totals Number (percentage of total)
Employed (full-time or part-time)	6 (27.3%)	0 (0.0%)	6 (18.2%)
Unemployed	11 (50.0%)	6 (54.5%)	17 (51.5%)
Retired	0 (0.0%)	1 (9.1%)	1 (3.0%)
Sheltered employment	0 (0.0%)	1 (9.1%)	1 (3.0%)
Study	1 (4.5%)	0 (0.0%)	1 (3.0%)
Training	4 (18.2%)	3 (27.3%)	7 (21.2%)
<b>Totals Number (percentage)</b>	<b>22 (100%)</b>	<b>11 (100%)</b>	<b>33 (100%)</b>

Based on current or previous occupation of persons with mental illness reported by the participants, socio-economic groups were established following Census 2002 classification. As reported by study participants, the highest percentage of persons with mental illness (n=14, 42.4%), were in the non-manual socio-economic group. This percentage was similar for both groups of relatives (see Table 3.9).

The reported percentage of persons with mental illness in the unknown/other group was relatively high for the overall group of relatives (n=7, 21.2%). There were no employers or managers among the persons with mental illness. However, three relatives of SI members (13.6%) were either higher or lower professionals, whereas none of relatives of MHS recruits fell into this category.

**Table 3.9** Socio-economic group of persons with mental illness, as reported by participants, by source of referral to the study

Socio-economic group	Source of referral to the study		
	SI Number (percentage of SI)	MHS Number (percentage of MHS)	Totals Number (percentage of total)
Higher/lower professionals	3 (13.6%)	0 (0.0%)	3 (9.1%)
Non-manual	9 (40.9)	5 (45.5%)	14 (42.4%)
Manual/Semi-/Unskilled	5 (22.7%)	4 (36.4%)	9 (27.3%)
Not applicable/unknown	5 (22.7%)	2 (18.2%)	7 (21.2%)
<b>Totals Number (percentage)</b>	<b>22 (100%)</b>	<b>11 (100%)</b>	<b>33 (100%)</b>

The highest percentage of persons with mental illness ( $n=12$ , 36.4%) resided at home with participants at the time of the study (Table 3.10). The rest of the persons with mental illness resided in independent accommodation ( $n=7$ , 21.2%), in an in-patient unit ( $n=7$ , 21.2%), or in a community residence ( $n=7$ , 21.2%).

All 12 of the persons with mental illness who resided at home with the study participants were relatives of SI members (54.5%). There were no relatives of MHS recruits residing at home with their relatives at the time of the study. More than half ( $n=6$ , 54.5%) of MHS service users were living in a community residence, whereas only one relative of a SI member (4.5% of the total sample) was living in a community residence (Table 3.10). The percentage of persons with enduring mental illness living in independent accommodation was much higher among those related to SI members ( $n=6$ , 27.3%) than among MHS service users ( $n=1$ , 9.1%). A higher percentage of MHS users ( $n=4$ , 36.4%) were in in-patient units at the time of the study than those related to SI members ( $n=3$ , 13.6%) (Table 3.10).

**Table 3.10** Place of residence of persons with mental illness at the time of the study, as reported by the participants, by source of referral to the study

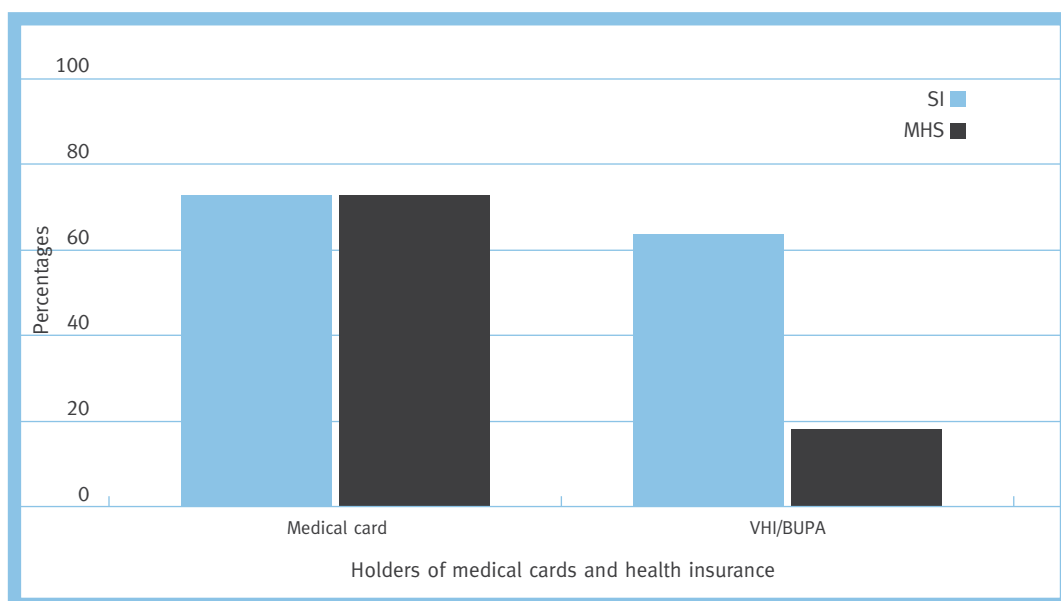
Place of residence	Source of referral to the study		
	SI Number (percentage of SI)	MHS Number (percentage of MHS)	Totals Number (percentage of total)
At home with participants	12 (54.5%)	0 (0.0%)	12 (36.4%)
In an independent accommodation	6 (27.3%)	1 (9.1%)	7 (21.2%)
In an in-patient unit	3 (13.6%)	4 (36.4%)	7 (21.2%)
In a community residence	1 (4.5%)	6 (54.5%)	7 (21.2%)
<b>Totals Number (percentage)</b>	<b>22 (100%)</b>	<b>11 (100%)</b>	<b>33 (100%)</b>

Of the seven community residents, the majority (n=5, 71.4%) lived in high-support accommodation; one (14.3%) lived in a medium support, and one (14.3%) in a low support residence.

The majority of the ill relatives of the respondents (n=24, 72.7%) had a medical card, and almost half of them (n=16, 48.5%) had VHI or BUPA insurance. The percentage of persons with mental illness who had a medical card was equal among the relatives of SI members (n=16, 72.7%), and among the service users of MHS (n=8, 72.7%).

The majority of relatives of SI recruits had medical insurance (n=14, 63.6%), as compared to only two relatives of MHS recruits (18.2%) (see Figure 3.1). This difference among the two groups was statistically significant [ $\chi^2(1) = 6.07, p = 0.014$ ].

Nine (27.3%) ill relatives had both a medical card and health insurance. The majority of such persons (n=8, 88.9%) were relatives of SI members. As reported by some participants, parents often put the names of their children on their own insurance. One relative of MHS recruit (0.03% of the total sample of persons with mental illness) was reported to have neither a medical card nor medical insurance.



**Figure 3.1** Percentage of holders of a medical card and private medical insurance among relatives of SI and MHS recruits, as reported by the participants, by source of referral to the study.

As reported by the study participants, the majority of persons with mental illness ( $n=21$ , 63.6%) were in receipt of disability allowances. This tendency was similar for both relatives of SI participants ( $n=16$ , 72.7%), and MHS recruits ( $n=5$ , 62.5%). Three participants (9.1%) recruited via MHS were not sure if their relatives were in receipt of this benefit.

As reported by the participants, the majority of the persons with mental illness ( $n=26$ , 78.8%) had been diagnosed with schizophrenia (Table 3.11). The percentage of persons with this diagnosis was the highest among both relatives of SI members ( $n=18$ , 81.8%), and MHS service users ( $n=8$ , 72.7%). Four persons (12.1%) had a diagnosis of bi-polar disorder. Three participants (9.1%) reported that they had yet to learn the diagnosis of their relative from the mental health services (Table 3.11).

**Table 3.11** Diagnosis of persons with mental illness, as reported by the participants, by source of referral to the study

Diagnosis	Source of referral to the study		
	SI Number (percentage of SI)	MHS Number (percentage of MHS)	Totals Number (percentage of total)
Schizophrenia	18 (81.8%)	8 (72.7%)	26 (78.8%)
Bi-polar disorder	3 (13.6%)	1 (9.1%)	4 (12.1%)
Not sure	1 (4.5%)	2 (18.2%)	3 (9.1%)
<b>Total Number (percentages)</b>	<b>22 (100%)</b>	<b>11 (100%)</b>	<b>33 (100%)</b>

There was no specific question in either a demographic questionnaire or in an interview schedule about substance misuse. However, 97.4% of the participants (all except one), volunteered information about perceived excessive use of alcohol or illegal drugs by their relatives. As reported by the participants, less than half of the persons with mental illness had at some stage used drugs or alcohol excessively (n=13, 40.6%). Percentages of those reported to have perceived additional problems with alcohol or drugs were similar for relatives of MHS recruits (40%) and relatives of SI participants (40.9%). More than half of the persons with mental illness (n=19, 59.4%) were not reported to have any problems with either alcohol or drugs.

The mean duration of illness among the persons with mental illness, calculated on the basis of demographic questionnaires and validated during the interviews with the participants, was 17.3 years (Table 3.12). The minimum duration was 1.5 years, which was slightly lower than the inclusion criterion of two years applied in this study. However, due to the fact that the relative of this participant had been diagnosed with schizophrenia, and had been admitted several times to an in-patient unit, the participant's experience with the mental illness of this person was considered valuable and was included in the analysis. The maximum duration of mental illness was reported as 49.0 years. (Table 3.12).

**Table 3.12** Reported approximate duration of mental illness of relatives of the participants at the time of the study, by source of referral to the study

Duration in years	Source of referral to the study		
	SI	MHS	Total sample
Mean	13.8*	24.4*	17.3
Median	11.5	21.0	17.0
Minimum	1.5	10.0	1.5
Maximum	32.0	49.0	49.0

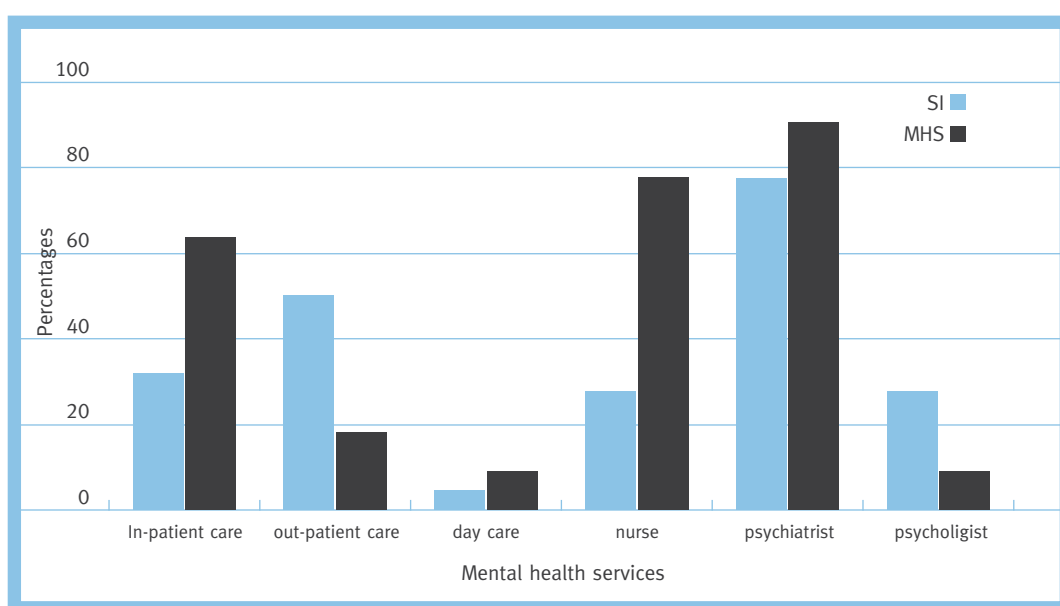
\*p < 0.05

As shown in Table 3.12, the reported average duration of illness was much lower among relatives of SI members (13.8 years), than among MHS service users (24.4 years). This difference in duration of illness between the two groups was statistically significant [U (14.1, 22.9) = 6.2, p = 0.013]. This could be explained by the fact that the average age of MHS service users (41.4 years, see Table 3.3) was significantly higher than that of relatives of SI recruits (31.8 years).

All participants reported that the persons with mental illness used several mental health services at least once a year. The services used by the persons with mental illness, as reported by study participants, were in-patient and out-patient care, day care, the services of psychiatric nurses, psychiatrists, and psychologists. None of the participants reported that their relatives used respite care. In addition, 12 (36.4%) persons with mental illness participated in various support programmes. The percentages of participants of support programmes were equal between MHS users (n=4, 36.4%) and relatives of SI members (n=8, 36.4%). The detailed list of support programmes used by persons with mental health difficulties is presented in Chapter 6.

The majority of persons with mental illness (n=27, 81.8%) used the services of psychiatrists (Figure 3.2). The reported percentage of persons who used the services of psychiatrists was slightly higher among MHS service users (n=10, 90.9%), than among relatives of SI recruits (n=17, 77.3%). More than half of MHS service users (n=7, 63.6%) used in-patient care at least once a year, compared to

relatives of SI members (n=7, 31.8%). Half of the persons with mental illness related to SI members (n=11, 50.0%) were reported to use out-patient care, whereas only two (18.2%) MHS service users used out-patient care. Most MHS users (n=8, 72.7%) availed of the services of a psychiatric nurse, as opposed to five (22.7%) relatives of SI members. However, a higher percentage of persons with mental illness related to SI members (n=5, 22.7%) used services of a psychologist at least once a year, as compared to MHS users (n=1, 9.1%).



**Figure 3.2** Use of mental health services at least once a year by persons with mental health problems, as reported by the participants, by source of referral to the study

### 3.3 Summary

To summarise, the majority of the sample was referred to the study by SI (68.4%). Most of the sample were mothers (60.5%), females (68.4%), of mean age 61.3 years, married or cohabiting, having one or more university degrees (34.2%), retired (47.4%), of non-manual socio-economic group (38.9%), living in suburban area (63.2%), holders of private medical insurance (71.1%), and members of some family support programmes (68.4%).

More diverse subgroups of relatives, such as spouse, brother and step-father, were represented by participants referred to the study by MHS. The percentage of males was slightly higher among the MHS (41.7%), than among SI group (26.9%). Mean age of MHS group (66.9) was slightly higher, than that of SI group (58.7). There were three single persons (11.5%) among the SI group, and none in the MHS group. More participants of SI group, than of the MHS recruits, had one or more university degrees (42.3% versus 16.7%). No MHS recruits were employees, as opposed to 47.4% of SI recruits. The majority (66.7%) of the MHS recruits were retired. There were more managers or higher professionals among the relatives recruited by SI (28.0% versus 9.1%). More than half of MHS group were holders of medical cards (58.3%), whereas the majority of SI group (76.9%) had private medical insurance. The majority (84.6%) of SI recruits were participating in various family support programmes at the time of the study. Only 33.3% of the participants recruited by MHS were availing of any family support programmes.

Overall, recruits of SI represented a younger, more socially and vocationally active population, of a higher socio-economic status and with a greater degree of participation in family support groups, compared to MHS recruits.

Most of the persons with enduring mental illness related to the interviewees were male (72.7%), sons of study participants (69.7%), with an average age of 35 years, single (81.8%), with at least some years of secondary education (42.4%), unemployed (51.5%), of non-manual socio-economic group (42.4%), living at home with participants (36.4%), holders of a medical card (72.7%), and recipients of a disability allowance (63.6%). Most of them had been diagnosed with schizophrenia (78.8%). As reported by study participants, more than half of the persons with mental illness had never been abusing alcohol and/or illegal drugs (59.4%). The reported average duration of illness was 49.0 years.

Four persons with mental health problems were married, and three had children. Most of the married persons (n=3, 75%), and most of the persons who had children (n=2, 75%) had been diagnosed with schizophrenia.

Based on the data from the interviews, service users of MHS were slightly, but significantly, older (mean age 41.4 years), than relatives of SI members (mean age 31.8 years). This may explain a significantly longer duration of illness in years reported for the MHS users, than that reported by relatives of SI members (mean 22.1 years compared to 13.3 years, respectively.)

A higher percentage of relatives of SI members than of MHS service users had one or more university degrees (18.2% versus 9.1%). None of the MHS service users were in gainful employment, as compared to 27.3% of relatives of SI members who were employed either full-time or part-time. More than half (54.5%) of relatives of SI members lived at home with the interviewees at the time of the study, whereas all the MHS service users lived away from family home. Therefore, the reported average number of hours of contact with persons with mental illness within the last 12 months was significantly higher among members of SI (52.9 hours per week) than that among relatives of MHS users (9.2 hours per week). More than half (54.5%) of MHS service users lived in a community residence with 24-hour nursing care.

The majority (63.6%) of relatives of SI members, as opposed to 18.2% of MHS users, had medical insurance. Most of the ill relatives of both SI members (72.7%) and MHS service users (62.5%) were receiving disability allowance.

When the diagnoses of the ill relative was reported, there were no significant differences found between the SI and MHS groups in the percentages of those diagnosed with schizophrenia, bipolar disorder, or having additional drug or alcohol abuse problems.

The majority (81.8%) of the persons with enduring mental illness used the services of psychiatrists. In addition, the majority of MHS service users also availed of the services of a psychiatric nurse (72.7%) and in-patient care (63.6%). A higher percentage of relatives of SI members (50% versus 18.2%) used out-patient care and the services of psychologists (22.7% versus 9.1%).

## Chapter 4

Perceived effects of  
mental illness on the  
family and family  
adaptation

“”

I think families are very good... at putting on a brave face, and when anybody asks how they are, they say ‘Oh I’m fine, I’m fine, everything is ok’, but it’s a face that everybody is putting on... I think there are issues there for everybody, and there are obviously different issues for different people.



This chapter will describe the reported influence of mental illness on the family as a whole, some elements of objective and subjective burden on the family emerging from quantitative and qualitative data, and family adaptation to the burden of illness.

The perceived effects of mental illness on individual members, and individual coping mechanisms used by different family members in order to adapt to the effects of mental illness on the family will be presented and analysed. Individual needs of different subgroups of relatives will be explored and presented.

## 4.1 Perceived effects of mental illness on the family, and family adaptation

### 4.1.1 Perceived contributing effect of the family to the mental illness of a family member

In several cases, when participants were asked about the influence of mental illness on the family, they reported that the family itself, due to some behavioural or genetic factors, might have contributed to the mental illness of a family member.

Two participants commented that the mental illness of one family member might have affected the mental health of another family member:

‘We are speaking of the elder son, but we had experience from the younger son... And we felt that the elder son was quite caring or defensive of the second, of the younger lad. He kind of felt a certain amount of sympathy for the younger lad, and at times you know we wondered, had he made himself feel quite ill out of sympathy, out of caring for the younger lad...’

‘He had depression, my husband was admitted to hospital... She was affected by his illness... she was so childish...’

Some fathers were criticised for being too cold and distant, or too strict and even violent towards their children or partners.

‘Her father has always been very cold and dictating...he talks at her, rather than to her... He was always too strict on children, I would call it violent now...He distanced himself from the children, always wanted to be in control...’

‘...generations of abusive relationships in the family...Male support was always missing...His grandfather behaved like that, his father behaved like that, he is behaving like that...he doesn’t use it all the time, this behaviour, it’s just when he’s under emotional stress.’

## 4.1.2 Elements of the objective burden of mental illness on the family

Some elements of the objective burden, as emerging from both quantitative and qualitative data, are presented in this section.

### 4.1.2.1 Average amount of direct contact time spent by the participants of the study with persons with mental health problems

In order to estimate the amount of time spent on caring for the person with mental health problems, all 38 participants of the study were asked to give an approximation of an average number of hours of contact per week with their ill relative in the last 12 months. The reported average number of hours of contact per week varied from 0.1 to 100 hours, with an average of 39.1 hours.

Out of all 38 participants in the study, mothers (n=23, 60.5%) had the highest average number of hours of contact per week with the person with mental illness in the last 12 months at 49.1 hours, followed by fathers (n=9, 23.7%), at 30.7 hours, and sisters (n=3, 7.9%), at 24.0 hours (Table 4.1).

**Table 4.1** Average number of hours of contact per week with a person with mental illness within the last twelve months, as reported by the participants of the study, by kinship group

Kinship group	Number (percentage of total sample)	Average hours per week	Minimum hours per week	Maximum hours per week
Mother	23 (60.5%)	49.1	0.25	100.0
Father	9 (23.7%)	30.7	3.0	100.0
Wife	1 (2.6%)	3.0	3.0	3.0
Sister	3 (7.9%)	24.0	0.1	42.0
Brother	1 (2.6%)	0.25	0.25	0.25
Step-father	1 (2.6%)	3.0	3.0	3.0
Total sample (percentage)	38 (100%)	39.1	0.1	100.0

Members of SI reported a significantly higher average number of hours per week spent in contact with their ill relative (52.9) than relatives of MHS service users (9.2) [ $t(33.8) = 5.8, p < .000$ ]. This can be explained by the fact that the majority of the relatives of SI members (54.5%) resided at home with the participants at the time of the study, whereas all the MHS services users related to the study participants resided elsewhere (in independent accommodation, in-patient units, or community residences).

Those participants who had a person with mental illness residing in their home had an average of 74.1 hours of contact hours per week with the person. When subjected to the Kruskal-Wallis non-

parametric test, this average number of hours of contact was significantly higher than that of the participants related to a person with mental illness residing in an in-patient unit, in independent accommodation, or in a community residence [ $X^2(3) = 19.5, p < .000$ ] (Table 4.2).

**Table 4.2** Average number of hours of contact per week with a person with mental illness within the last twelve months, as reported by the participants of the study, by place of residence of the person with mental illness

Place of residence of person with mental illness	Number (percentage of participants)	Average hours per week	Minimum hours per week	Maximum hours per week
At home with participants	14 (36.8%)	74.1***	30.0	100.0
In independent accommodation	8 (21.1%)	16.3	0.25	40.0
In in-patient unit	7 (18.4%)	20.9	0.1	56.0
In community residence	9 (23.7%)	18.9	1.0	48.0
Total sample (percentage)	38 (100%)	39.1	0.1	100.0

\*\*\*p < .000

In general, mothers who were members of SI and whose ill relative resided at home at the time of the study had the highest average number of hours of contact per week with the person with enduring mental illness. However, the theme of ‘time’ as pertaining to the ‘burden’ of mental illness on the family has not emerged from the qualitative data.

#### 4.1.2.2 Basic daily care-giving duties of study participants

In order to account for some elements of burden, associated with care-giving duties at the time of the study, a scale of Psychosocial Resistance to Activities of Daily Living Inventory (PRADLI) (Clifford *et al.*, 2003) was used to measure physical ability and motivation of persons with mental illness to perform daily basic living tasks such as getting in and out of bed, taking medication, and social and recreational participation (see Appendix 5).

As reported by the participants in the study, whereas most of the persons with enduring mental illness had virtually no physical impairments in performing basic daily living tasks, the majority (n=20, 60.6%) either displayed psychological resistance or needed some prompting in getting in and out of bed, dressing and changing clothes, taking showers, taking medication, exercising, and participating in social activities (Table 4.3). Ten persons (30.3%) were reported to be completely independent and motivated in performing basic living tasks, and in the case of three persons with mental illness (9.1%) the participants could not provide any information, as the person with mental illness was residing elsewhere at the time of the study.

Overall, as reported by study participants, persons with mental illness required minimum prompting on the part of their carers and were relatively independent and motivated. The mean total PRADLI

score reported by participants was not significantly different between MHS service users (48.2), and the persons with mental illness related to SI members (48.0).

Table 4.3 describes the ability and willingness of 20 persons with mental illness, reported by participants as somewhat resistant to basic daily living tasks, by tasks specified by the PRADLI scale of long-term care in mental illness (Clifford *et al.*, 2003). The total number of responses pertaining to resistance to activities of daily living was 120 (Table 4.3).

**Table 4.3** Ability and willingness of persons with mental health problems to perform basic daily living tasks, as reported by the study participants, by level of psychosocial resistance

Basic daily living tasks	Minimal assistance, resistant Number (percentage)	Minimal assistance, some cueing Number (percentage)	Independent, motivated Number (percentage)	Totals Number (percentage)
Eating as necessary to maintain appropriate weight	3 (15%)	3 (15%)	14 (70%)	20 (100%)
Dressing/changing clothes for a necessary reason	3 (15%)	8 (40%)	9 (45%)	20 (100%)
Going to the toilet when necessary	1 (5%)	0 (0.0%)	19 (95%)	20 (100%)
Ability and willingness to bathe appropriately	2 (10%)	6 (30%)	12 (60%)	20 (100%)
Ability and willingness to take prescribed medication	4 (20%)	6 (30%)	10 (50%)	20 (100%)
Restorative care, including walking, exercising	5 (25%)	7 (35%)	8 (40%)	20 (100%)
<b>Total number of responses (percentages of responses)</b>	<b>18 (15%)</b>	<b>30 (25%)</b>	<b>72 (60%)</b>	<b>120 (100%)</b>

Of the 20 persons who were reported to display some level of psychosocial resistance to performing basic daily living tasks, more than half (n=11, 55%) spent seven or more hours out of bed during the day. However, in nine cases (45%) the persons with mental illness were reported to spend more time in bed during the day, which was considered unhealthy by the participants.

'And Friday, Saturday, Sunday he just stays in bed. We will threaten him now and say if you are not out of bed in five minutes, we are phoning the hospital.'

The majority (n=16, 80%) of persons with mental illness did not participate in any social or recreational activities outside the family circle. As commented by most of the participants, the persons with mental illness found it hard to socialise and had very few, if any, friends, which was a concern for some of the participants:

'I hope he is mixing better, I hope he has friends, I hope he has somebody else other than me and my husband.'

Of the 20 persons who were reported to display psychosocial resistance to performing some basic daily living tasks, the majority were independent and motivated in their eating habits (n=14, 70%) and had no difficulties in going to the toilet when necessary (n=19, 95%). However, most persons (n=12, 60%) were either resistant, or needed some prompting, to do restorative tasks, such as exercising or walking, and more than half (n=11, 55%) were either resistant or needed to be reminded to change clothes.

As can be seen from Table 4.3, half of the persons (n=10, 50%) were reported to be either resistant or in need of some cueing in taking their prescribed medication. The theme of resisting medication also emerged from the comments of some participants:

‘But when she was taking her tablets you see she was a lovely girl, but she won’t, she doesn’t want to admit she needs them, no...’

Two participants reported that they had problems communicating with their relative, and that the relatives were resistant not only to taking medication, but to treatment in general, and did not ‘accept’ that they had mental health difficulties.

‘I would have liked to have found somebody that would have helped us ...taking control of the situation and built up a rapport with him and got round him to go for treatment, to take the medication, accept his position and assist us, or guide us on how to get round, you know, if they told us what way to talk to him, approach him, anything like that would have been most welcome.’

#### 4.1.2.3 Other elements of the objective burden

Most of the qualitative data emerging from the interviews regarding the influence of mental illness on the family in retrospect were associated with the emotional and social aspects of family functioning. Some of the elements of the objective burden, mentioned by participants, were inseparably connected with the subjective burden.

#### 4.1.2.4 Reported disruptive or socially offensive behaviour of persons with mental health problems

Some of the elements of the objective burden recurring in the interviews with the participants were associated with socially unacceptable, or disruptive, behaviour of the person, which affected the social functioning of the family.

‘She wouldn’t go into the bedroom upstairs, she took over the dining room so if somebody comes, sorry the bedroom is there and all her stuff...’

‘...all her...clothes, smoking, disruptive behaviour, she was very hyper...’

Some of the behaviours were perceived by the participants as threatening security of the house, its inhabitants or guests.

‘It’s a question of security as well, he is so absent-minded, he would leave the door open.’

In some cases, the participants had to summon external support in order to ‘protect’ themselves or other people from the offensive behaviour of their relatives:

'One particular night... he was annoying me and he was getting up and pacing the floor you know and I'd say would you ever sit down and he would never do it, he hit me in the eye .... I said to myself I am not putting up with this... and I rang up the guards.'

#### 4.1.2.5 Distraction from work or studies, and financial concerns of participants

It was reported that mental illness in the family had affected the jobs, careers, and financial well-being of some participants.

'I took off work, had to finish my classes earlier as was too distracted...It cut down on me financially, but I was just too upset...'

'...his relationships are not there, his career's not there, his finance's not there... to rent somewhere or buy a house, the emotional burden on us because we're worrying all the time about him, I mean we have to be able to finance him, he's not going to be able... can we afford to kind of keep him, you know, when we're struggling ourselves...'

#### 4.1.2.6 Negative atmosphere in the house

The 'negative atmosphere' in the family affected the ability and willingness of family members to have visits from friends or relatives, or to go out themselves:

'I never bring any friends to the house, because she's always around, there's usually a negative atmosphere at home, because she never talks to anybody, she'll sit there, or she'll frown or she'll scowl...'

'It has sundered the family, we can't even have the family Christmas together, a meal, anywhere out or in the house... To me Christmas is going to be a really traumatic time.'

One participant commented that even dogs in the house were affected by the mental illness of a family member and tried to avoid contact with the person:

'Oh when she'd come to the house you could see the hair standing up on the back of their necks, and they would get under the couch when she was there, wouldn't come out.'

#### 4.1.2.7 Stigma associated with mental illness

Participants mentioned the stigma associated with mental illness as one of the main reasons for curtailing their social lives, and for the complete or partial isolation of the family from its social network. From the point of view of some SI members whose relatives have been diagnosed with schizophrenia, the stigma in the society was more associated with schizophrenia, than with depression, as there was more public information available about depression.

'Depression and bi-polar are more recognised, there is more information...There is a stigma about schizophrenia.'

'I once mentioned to a friend, that it was more than depression, never saw this friend after that...There are a lot of myths, silly things in the paper...the information on schizophrenia should be on Prime Time.'

One participant felt that society and the government encourage such stigmatising because of the nature of the information provided in the media:

‘Society...punish patients and they punish the parents because... it will be on TV that this mental patient murdered this old lady, whatever...There is a bias there against a mental patient, at all levels... So the odds are loaded against the patient and they’re loaded against the parents, and ... there is nothing being done about it, nothing.’

Two participants mentioned that they never felt any stigma outside the family.

In some cases, extreme circumstances or the stigma connected with the mental illness had completely uprooted the family:

‘When he attacked this child, we had to move out of the area.’

One participant commented that his house was set on fire because of the bias towards mentally ill people. He was thinking of moving abroad because of the stigma:

‘I was hoping to move abroad because since my son had...this state of mental depression, it is known in the neighbourhood and people... set the house on fire here some years ago... As a matter of fact, it’s against the law, but there is no one has ever been charged with any sort of harassment or anything.’

### 4.1.3 The elements of the subjective burden on the family

Some of the elements of the subjective or emotional burden are described in this section. The elements of the subjective burden were closely related to the objective ones described in the Section 4.1.2.

#### 4.1.3.1 Worry, anxiety, ‘emotional blow’

The influence of mental illness on the family in general was often described as an emotional blow. Feelings caused by the illness of a loved one were described as constant worry, helplessness, anxiety and stress.

‘It’s like babysitting him all over again, constant worry.’

‘It created a high level of anxiety and stress.’

#### 4.1.3.2 Fear of the unknown, lack of outlook

According to some participants, ‘fear’ and ‘worry’ of family members were associated with the lack of information about the illness, symptoms, and what to expect in the near and distant future.

‘...it frightened my family, scared them very much. It was a new culture to this family and nobody explained anything to us.’

‘You wake up in the middle of the night... and your nerves are jangling, you’re kind of, oh what should we do? what will we do?...It’s the accommodation...’

#### 4.1.3.3 Confrontation and regret

Several participants mentioned that, if they had had some guidelines on how to communicate with the person with mental health problems, they could have avoided unnecessary confrontation:

'Like I've done terrible things to my son, I have to be honest with you, in the beginning because I thought he was acting the blaguard, taking drink and then taking tablets, and I had to sort of not allow him inside the house for a few days and things like that which I now regret. But how was I to distinguish between carry on and not carry on? ...and I had other family to think of and I had to try and make a stand...'

#### 4.1.3.4 Sadness, depression, trauma

Several participants described feelings of sadness, depression, and post-traumatic reactions created by the mental illness of their relative:

'It created a sort of sadness really that you never get over.'

'It was terribly emotional and dreadfully traumatic.'

#### 4.1.3.5 Grief and loss

The 'sadness' in some cases was associated with the feelings of grief, loss, and sympathy for the person who was gradually changing, or had rapidly changed, into a different person.

'It's upsetting...becoming a shell of who he used to be, because he's not what he used to be when he was younger.'

Some participants perceived that the quality of life of the person had deteriorated as a result of the mental illness:

'You see, say, young fellows his age in a little group anywhere, and they're enjoying themselves, I mean that is the hardest thing, you know, he's not there and he's not doing that...I mean he hasn't died or anything like that, but it is very hurtful. '

### 4.1.4 Family adaptation

This section will describe the effects of the mental illness on the family structure, and emotional adjustment of the family to mental illness.

#### 4.1.4.1 Family disintegration

All participants in the study reported some extent of disintegration of the family, and the shrinking of family 'nucleus'.

In extreme cases, a responsible or main carer was left in isolation after the complete disintegration of the family. Three mothers, two fathers, a wife and a brother reported that they had become completely isolated from the rest of the family due to their relative's mental illness.

'They just didn't want to know, I took the whole burden of it... It split the whole family apart...I am out on a limb altogether, he's an only child, I have nobody to discuss it in the house with. My family just opted out. '

'Well I would say that was around the time of my father's death and because it was an emotional time and the hurlers in the ditch as they call it, the side line players then started to come, they wanted this, that, and when it all fizzled out it was left to me just to carry on...Well even when my mother was there I was listed as the next of kin...the ball was in my park, even my brothers and sisters, I said to them listen, why wouldn't one of you people become next of kin, ah no sure we're not around.'



In some other cases, either parents, or one parent and one sibling, were left to care part-time or full-time for their ill relative, with other siblings or relatives leaving them to their own devices.

'It ruined it... I don't think my wife fully accepted the mental illness, I think she found it very difficult to forgive her daughter for the way she treated her, now I know she was at the receiving end.'

'I have a son, he hasn't been near us, he doesn't phone.'

One mother commented that she herself ended her relationship with her partner due to his inappropriate behaviour towards her son with enduring mental health problems:

'My partner started calling him names like Schizo and I just wouldn't have that, it was the end of it.'

Two spouses who participated in the study commented that they were left on their own by the rest of their relatives:

'It made everybody go, it's just been my husband and myself.'

In one case, the ill person himself was completely refusing to communicate with family members at the time of the study:

'He has rejected us, we haven't rejected him.'

#### 4.1.4.2 Constructive adaptation to mental illness

Despite the negative influence of mental illness on the family, and the partial or full isolation of study participants from their other relatives and friends, some participants seemed to constructively adapt to the illness of their relative, with or without support from other family members.

Some female participants fully accepted their responsibility for the care of their relative as inherent in their family role:

'I am very open about him, because he is my son and I am proud of him no matter what.'

Some participants reported that they accepted 'mental illness' as inherent in the personality of their relative, as opposed to something 'abnormal' or 'crazy':

'I don't look at it as mental illness as such, it's kind of an impairment, something a bit different from normal... You kind of need to accept his abnormality as normal.'

'I call it a behavioural emotional illness; I didn't see it as craziness... in artistic families you get this spectrum... there is a different enquiry here, and all drugs in the world are not going to change it.'

Two couples commented on the fundamental change in the whole outlook of the family and in their values:

'It changed the outlook of our family altogether... we were a family in need, whereas before we hadn't been a family in need... It altered my whole way of thinking about life or humanity, like there's no dividing line between the haves and have nots.'

'It made me rethink the whole family, everything was centered about him more or less.'

One participant commented that she was emotionally upset when trying to find a reason for the mental illness in the family. She was coping by accepting that mental illness may happen in any family for no reason:

‘Oh it was terrible, I cried, every night I cried and you know you go through all sorts of things, people will tell you, you know, when you have a child who has cancer or somebody in the family or your mother or whatever and you say why did it have to happen to her, you know. And this is how, I looked at my daughter and I said why did it have to happen, you know, why me, why her. It just happens, that’s the way life is, you know. It’s a roulette. Yeah, it’s a gamble, it’s like being in a casino, you know, and whatever comes up.’

One participant commented that some families ‘put on a brave face’ as a way of coping with mental illness and preferred to keep their needs and concerns private.

‘I think families are very good, well my family are, at putting on a brave face, and when anybody asks how they are they say ‘oh I’m fine, I’m fine, everything is ok’, but it’s a face that everybody is putting on... I think there are issues there for everybody, and there are obviously different issues for different people... An illness in the family affects everybody in a different way, but it affects everybody.’

## 4.2 Perceived effects of mental illness on individual family members

This section presents the perceived effects of mental illness on individual subgroups of relatives, such as parents, siblings, and children, of persons with enduring mental illness. The perceived effects of mental illness on male and female relatives as emerging from the interviews will also be described.

### 4.2.1 Perceived effects of mental health problems of children on their mothers

Some of the themes emerging from mothers of persons with mental health problems, and comments from other family members regarding the effects of mental illness in the family on mothers, are presented in this section.

#### 4.2.1.1 Loss and bereavement

Most of the mothers described the feelings of sadness, depression, and loss when a loved one was affected by mental illness. In some cases the feeling was compared to bereavement:

‘It’s like another bereavement, loss, they appear to be there physically, but they are not the same person.’

‘It’s very frustrating looking at somebody who has changed, there’s subtle ways... You think it’s life lost, the future gone, it’s very tragic, depressing.’

#### 4.2.1.2 Fear, distress, or abuse

Some mothers reported fear and general emotional distress caused by physical abuse from their children with mental health problems:

‘It’s frightening when your own son is threatening to kill you, it’s hard, it’s hard.’

A father mentioned that his wife had suffered physical abuse from her daughter with mental health problems, but had never mentioned it to him:

'I was going out to work, she was at home with her and she used to beat her...now I didn't know that, I am only really finding this out in the past few weeks.'

#### 4.2.1.3 Inability to care for a 'sick' child

A clash between a mother's perceived duty to help her child and her inability to do so also caused feelings of helplessness and frustration:

'For me as a mother you're supposed to be able to... your child is sick you're supposed to be able to make them better and I couldn't do that.'

'You want to protect him and help him...give him a hug...'

#### 4.2.1.4 Neglect of other children

Several mothers were concerned that they had 'neglected' their other children due to the mental illness of one of their children:

'It's a struggle to keep everybody balanced and not to allow it to touch heavily on their schooling.'

### 4.2.2 Perceived effects of mental health problems of children on their fathers

Selected themes emerging from fathers of persons with mental health problems, and comments from other family members regarding the effects of mental illness in the family on fathers, are described in this section.

#### 4.2.2.1 'Not qualified' to help a child

Perceived inability to perform their parental duty to help their child due to a lack of knowledge or qualifications were present in some fathers' interviews:

'The most difficult was when my daughter pleaded with me for help and I really didn't feel I was qualified to help her, and I thought hospital would have helped her... She went missing all night, but I had the little fellow to mind so I couldn't even go out looking for her.'

#### 4.2.2.2 Anxiety, lack of solutions, traumatic

Fathers reported feelings of anxiety and an inability to relax due to the enduring nature of the illness of their offspring:

'I have become anxious, find it hard to relax, it seems to be in the back of your mind all the time.'

For some fathers, the most difficult thing about the mental illness of their son or daughter seemed to be the fact that it was ongoing, and that there was no solution to the problem in the future:

'I don't see a resolution to it, it's traumatic, and it's ongoing.'

#### 4.2.2.3 Perceived damaged image of the family due to the stigma

Fathers, even more so than mothers, seemed to be very sensitive to the perceived stigma associated with their child's illness:

'I didn't talk to anybody about it, just the family.'

One of the mothers commented that it might have been more difficult for her husband than for herself to talk to other people about their child's mental illness, because of his extreme sensitivity to the effects of the stigma:

'My husband would have kept inside a lot more than me... There's an image thing as well, they might feel less of a man or something if they've produced a child with schizophrenia.'

### 4.2.3 The effects of mental illness on sisters of persons with mental health problems

The following section presents some themes emerging from study participants who were sisters of persons with mental health problems.

#### 4.2.3.1 Perceived lack of solutions and practical advice

The theme of absence of solutions to the 'problem' was recurrent in sisters' discourse, similar to fathers':

'It's not like a problem you can work out, there's no solutions.'

Two of the three sisters who participated in the study reported that it was difficult for them to understand what was happening, and that they would have appreciated some information and 'practical advice' on how to deal with their sibling's illness:

'Just to get some practical advice, how to approach him, how to understand why he does X, Y, Z, just daily coaching skills.'

#### 4.2.3.2 Fear that the illness is hereditary

Sisters spoke of fear and worry that the illness was hereditary and might be passed on to their children:

'There is also a worry for my kids, it is hereditary, you know.'

#### 4.2.3.3 Concerns for the future of a sibling

Sorrow or grief about the future of their siblings emerged from the qualitative data:

'And also, he's my big brother, do you know, he's one of my best friends, you want him to have a normal life and be able to marry and have kids, and it's going to affect him having a proper life.'

#### 4.2.4 Perceived effects of mental illness on siblings of persons with mental health problems, reported by other study participants

Several participants of the study volunteered their comments on how mental illness in the family affected siblings of persons with mental health problems.

Several parents perceived that the mental illness might have emotionally affected siblings more than themselves, due to the belief that mental health problems were hereditary:

‘Maybe it’s more frightening for them than it is for the parents, because I don’t have it at my age and I probably won’t get it but they don’t know is it going to hit them.’

Several parents mentioned that their other children suffered from feelings of loss of their sister or brother:

‘She would remember her being a young girl, somebody to play with...She is definitely on the way back.’

A mother commented that her other son had told her that he ‘did not have a brother’ anymore due to the mental illness of his sibling.

Parents of siblings informed the researcher that the brothers and sisters of persons with mental illness suffered socially from the mental illness in the family.

‘They won’t bring their friends in the house.’

Four participants reported that their other children were still angry or annoyed with their siblings with mental health problems, and could not forgive them for their disruptive behaviour during crises.

‘My son finds it difficult to forgive her.’

#### 4.2.5 Perceived effects of the mental illness of a parent on their children

No participants in this study were children of persons with mental illness. However, four participants who were parents of persons with mental illness provided information on their grandchildren, who were children of persons with mental illness. As emerged from the analysis of the data volunteered by the participants, three persons with mental illness had children.

##### 4.2.5.1 Perceived ‘confusion’ of children

Two participants commented that, due to the mental illness of their children, they were taking an active part in the rearing of their grandchildren. One participant commented that one of her grandchildren perceived her as his mother:

‘...he thinks I am his Mummy.’

One participant commented that his grandchild felt that his grandparents’ house was his home:

‘He felt our house was his home, he was reared in this house.’

#### 4.2.5.2 Perceived worry and concern of children

As reported by a participant, a child of a person with mental illness was worried when his mother was sick:

'They are very fond of her, love her to bits...Her son gets upset when she is not around, he'd say what's wrong with her?'

#### 4.2.5.3 Perceived fear

Two participants commented that their grandchildren were frightened by their parents' behaviour in crises:

'...and she'd painted all her face black and the poor thing screamed, he was so frightened when he saw his mother...'

One participant reported that her grandchild was afraid of getting her parent's 'sickness':

'She said "I think I'm getting paranoid, I think I've got mom's sickness"... I said well what makes you think that, she said "because I can hear somebody whispering."'

#### 4.2.5.4 Perceived blame

One participant commented that his grandchild thought that he was 'to blame' for some changes in his parent's life, such as moving house:

'In his child's mind his mother had left home because of him, so I'm hoping some of the counselling he will get will assure him that none of this is his fault.'

#### 4.2.5.5 Perceived influence of children on persons with mental health problems

Two participants commented that child-rearing duties had a positive influence on a person with mental health problems by giving him more responsibility:

'With a child now, you know, he is a bit responsible and that, but when the child was younger, he was quite nervous with the child, you know, but now he can manage him better, he loves the child.'

### 4.3 Individual coping mechanisms of family members

This section will present individual coping mechanisms used by mothers, fathers, sisters, and offspring of persons with mental health difficulties, as emerging from the interviews with study participants.

#### 4.3.1 Coping mechanisms used by mothers

The majority of mothers (n=22, 96%) provided information on their individual coping mechanisms that helped them to somehow offset the negative effects of the mental illness of their child on their psychological well-being.

#### 4.3.1.1 Caring as part of a family duty

Two mothers commented that they considered caring for their ill relative as inherent in their family duty:

‘It was difficult, very difficult... I don’t know how I coped to be honest with you but I did and the kids needed somebody to look after them, I was the only one, I didn’t want them ending up in foster homes, only because they’re my grandchildren, you know, and they’re so sweet really. And that was basically it really, I just ploughed through it...’

‘I want to make myself as strong as possible, which is why I am doing what I’m doing, so that they won’t be saying “Poor mom, it’s hard on poor mom...”’

#### 4.3.1.2 Coping by talking

Eight mothers commented that they coped by talking to other people, such as family, friends, and various support groups. Meeting other SI members through family support groups was seen as very effective, as they had similar experience with mental illness of their relative:

‘You meet others who have gone through the same...’

‘And it’s actually a huge relief when you can sit and talk to people and they understand exactly what you’re talking about, you know, when I can sit in my group and say well my son hit me over the head with a baseball bat. And somebody goes well mine actually hit me with a frying pan, and it’s just so accepting.’

Human contact, sympathy and caring were viewed by some mothers as very important in helping them to cope:

‘Kindness, just really feeling that people cared about your son or daughter, and would go to the bother of asking you how is he and really be interested in your answer.’

One mother joined a support group for parents of drug misusers in order to have some ‘social contact’. A mother of a person with mental health problems talked to a social worker:

‘I called on her just to talk the whole situation through.’

Talking to other people seemed to serve a dual purpose: as a means of extending one’s social circle to some new friends with whom one could share experiences and worries, and as a means of getting information about the mental illness, its course, and its treatment:

‘I joined SI, met other people with the same problems, met good friends... Now I have lots of books at home.’

#### 4.3.1.3 Information and knowledge

Information and knowledge were seen by mothers as powerful coping tools. In addition to such sources of information as family, friends, and members of support groups, mothers reported using books, leaflets and CDs provided by SI. Several mothers mentioned conferences, newspapers, lectures, TV and radio as sources of information about the mental illness, treatment and recovery.

'I coped by talking about his illness, information, learning..., conferences... I think knowledge brings you sort of power really and strength, certainly helps you to keep going, involvement, you know that sort of thing.'

Several participants mentioned that there should have been more information provided to relatives of persons with mental illness in a timely manner. Information about mental illness was not perceived as being easily available to families:

'I think there definitely should be something that we should, as a family, go to. We don't have to be individually seen. Because we're not sick people, we just want somebody, or psychologists or counsellors or whatever, somebody that will talk to us and explain to us what what's happening and which we didn't get, we didn't get any of that information till much, much later and a lot of it I asked for myself. And a lot of it I found out about on the Internet and by reading books and seeing movies on television and things like that, you know.'

One participant commented that one had to be aware of what support resources were available in order to use them:

'So the help was there, but one had to be very much on the ball.'

#### 4.3.1.4 Openness and advocacy

Several mothers commented that public availability of information and open discussion of mental illness were seen by them as positive changes in recent years and helped them cope better.

'I am delighted with this new programme for schools.'

One participant recalled a talk on the radio given by a psychiatrist who had himself been affected by mental illness:

'I just heard him on the radio... and he was wonderful talking about it, very humane, intelligent man.'

#### 4.3.1.5 Studying

Two mothers mentioned that studying and educational courses somehow helped them to cope with the mental illness of their children:

'I went on VEC course.'

'Not great, but I always did things like studying, I did a course of women's studies.'

#### 4.3.1.6 Use of counselling and mental health services

Five mothers used counselling provided by SI, and family therapy offered by the MHS.

One participant voluntarily signed herself in to an in-patient psychiatric unit to have some private space and get her emotional balance stabilised:

'I ended up signing myself in for ten days because I needed a safe space, away from home, away from the situation, so that I could regroup, so that I could rest, have somebody make a few meals for me...So once I could get out of the emotional situation, go for therapy and get a normal balance, then I could prioritise. '



#### 4.3.1.7 Doing more household chores

Some participants ‘switched off’ by doing more household chores, or ‘going on automatic’ in times of crisis:

‘I’d start cleaning or polishing, or gardening...he’s calmed down and I’ve calmed down.’

‘Part of me switches and I just go on automatic...My life changes when she becomes unwell, your life revolves around it.’

#### 4.3.1.8 Physical activities and relaxation techniques

Physical activities and sports were also used by some mothers as a means of coping with the subjective burden of mental illness in the family. Sports and relaxation activities mentioned by SI members were Reiki, tennis, walking, yoga, and exercising at a gym.

Taking one day at a time was also reported by two mothers as a powerful strategy to overcome difficulties:

‘But then, I suppose you learn to live with it, and take each day as it comes.’

‘I repeated this rhyme, “Yesterday is history, tomorrow is mystery...” You learn to live in the moment.’

#### 4.3.1.9 Support from other family members

Participants mentioned husbands and children who helped them to cope:

‘...my husband, we work together.’

‘ They were involved when he got diagnosed...We are a team.’

#### 4.3.1.10 Religion

One mother mentioned that her religion was helping her to cope with mental illness in the family.

### 4.3.2 Coping mechanisms used by fathers

All fathers (n=9) provided information on how they coped with the negative effects of their child’s illness on their own psychological well-being.

#### 4.3.2.1 Coping by talking

Three fathers (33%) commented on the positive effect of talking to people about mental illness. These participants also found SI support groups very helpful for sharing similar experiences and listening to other people talking:

‘In the sense that you meet others who have gone through the same, they are going through the same experiences or have gone through the same experiences that you are going through you know.’

'Not just providing information but coming down and talking through it and listening to them talking through things.'

#### 4.3.2.2 Individual counselling

Two fathers found counselling effective for relieving their emotional burden:

'I remember asking one lady who was counselling me, "When will I be able to talk about my daughter without being upset?" and she said "If that happens it will happen," so there was hope there, I knew it would happen.'

'I feel I have benefited from the counselling, I really have found it helpful, ...I got a lot of emotional help, and they pointed out to me that I'd been bottling an awful lot of emotions over the last four years.'

#### 4.3.2.3 Being in control of the situation

Three fathers commented that they had to somehow take control of the situation in order to relieve their emotional burden, and try to find some practical solutions as opposed to talking through their own feelings:

'And this has been a difficult one because there weren't easy solutions to it, but I muddled through, and I was looking up websites on the different medications and drugs she was on, so I was doing my own sort of on-line research, and was keeping up to speed on the medications and often questioning the efficacy of some of these products and the dangers, it nearly got to the point where I was writing the prescriptions for my daughter, I was a second counsellor, a psychiatrist advisor, when I'd go in to the meetings, but I needed to do that, to have some sense of control over the situation. I couldn't just sit there, twisting my hands, saying to the psychiatrist "what's going to happen". I had to know as much as he knew... I clearly needed help (laughing)... I think what keeps me going is just trying to solve it, arguing with the services and trying to get them to do what I think they should be doing.'

This participant commented that some kind of reassurance from mental health services that they have the situation under control would have helped him to 'relax':

'As I say, a distraught parent shouldn't have to be arguing with services. I mean I was really upset on both of those occasions and nobody met me half way and said "You relax, we'll take it from here".'

#### 4.3.2.4 Physical activities

Three fathers who were members of SI (33%) commented that they used physical activities such as walking and sports as a means of coping with the emotional burden of the mental illness.

#### 4.3.2.5 Positive personality traits of persons with mental health problems

Two fathers commented on the positive character traits of their children with mental illness which helped the fathers to cope better with influence of mental illness on the family:

'He is a schizophrenic but he has a nice personality.'

'And he has also a very good heart, he would give you the shirt off his back... he's good natured.'

#### 4.3.2.6 Religion

One father commented that religion was his only means of coping, and that it gave him some hope for the future:

‘Pray to my God, hope that things get better, that was the only thing.’

#### 4.3.2.7 Medication

One father mentioned use of medication as a means of coping with insomnia, in addition to other coping mechanisms:

‘I don’t know, you just plod on, I got involved with a...charitable organisation, I do hill walking, I have some friends I go cycling with, not as much as I used to... Medication I think as well, I’ve taken lots of Zanax, I had trouble sleeping, I try to avoid taking them too often.’

#### 4.3.2.8 Avoiding discussions of mental health problems

One father commented that he preferred not to talk to anybody outside the family about his son’s mental health problems.

#### 4.3.2.9 Comments on coping mechanisms of fathers, provided by mothers

Three mothers from SI provided additional information about how their husbands, who did not participate in the study, were emotionally affected by talking about their children’s mental illness either in support groups or in counselling sessions. All three participants admitted that neither group discussions nor counselling had helped their husbands, and in some cases had even contributed to their psychological distress:

‘Well, he did go a couple of times, up to the meeting I go to, but he doesn’t go now. I think he just got too emotionally upset... I’m not saying he wouldn’t go again but it didn’t seem to do him any good, so I thought there’s no use having two of them being depressed.’

All three participants commented that their husbands preferred to keep more inside, that they were less inclined to talk about their feelings than women.

‘Women are different, I’m not sure how we’re different but I don’t know what would encourage them to come along... At a meeting its usually the women who’ll ask... the men don’t discuss with each other anyway, about any illness, they won’t sort of chat to each other, but about sport or about... Anything else but their feelings.’

One participant commented that her husband did not want to accept that he needed support to cope with the effects of his son’s mental illness:

‘I think my husband definitely needed support, he’s a typical man, he’s not on for accepting the support or going for it... he was so increasingly depressed, he was withdrawing and I eventually persuaded him to go to the GP who gave him the name of somebody to go to who I don’t think was a great help to him to be fair... but then you see this is where I feel your own motivation is important, I don’t feel he had the motivation.’

### 4.3.3 Coping mechanisms used by sisters

All three sisters who participated in the study provided information about their coping mechanisms.

#### 4.3.3.1 'Blocking it out'

Two sisters who lived together with their ill relative commented that they tried to 'block out' their worries and feelings, and not to think about the illness too much.

'It is just trying to block it out, there's nothing, it's just very depressing so I try not to express it... You can't, it's not like it will blow over, you know, I just try to block it out and try not to think about it as much.'

One sister commented that she tried to stay away from her ill relative as much as possible, and was hoping to go abroad as soon as she finished her studies.

#### 4.3.3.2 Studies and work

Studies and work were found to be their best distractions from the effects of the illness on the family:

'How did I cope, I don't know... it was like you didn't have any option, but just to continue, keep going and I had Leaving Cert ahead of me so it was just focus on study.'

#### 4.3.3.3 Coping by talking

Two sisters commented that they also coped by talking to the family and a small circle of friends:

'I always just spoke to my mom about it, and the two of us would try and figure things out, or we'd counsel each other...'

#### 4.3.3.4 Barriers to participations in counselling and support groups

One sister commented that she did not perceive counselling as helpful:

'I never wanted to go counselling, I didn't feel comfortable going in and talking to a stranger.'

One sister did not find SI support groups very helpful due to the fact that there was nobody of her age in the groups:

'Yeah, Schizophrenia Ireland has been very good, I was going to some of those meetings, but I even find that they're all way, way older than I am, some of them are lovely and you know they're so kind and helpful, but you know there is nobody in my age group, they're all elderly and then I just think if there was something at their level, a sisters and brothers section.'

The timing of group meetings was also mentioned as a barrier to attendance, as the groups were not available during the weekends when they had more spare time from work or studies.

#### 4.3.3.5 Additional comments on coping mechanisms of sisters, provided by other study participants

Twelve participants volunteered additional comments about how sisters of persons with enduring mental illness who did not participate in the study coped with the effects of mental illness on the family.

As perceived by participants, sisters of persons with mental illness were trying to avoid the person with mental illness, and ‘would not like to know’ much about the illness because it was too ‘upsetting’ for them.

‘She’s avoiding getting too sucked in, which I understand because they have their own lives.’

‘And they don’t always want to listen sure they don’t. It’s easier for them.’

One participant commented that a sister of a person with mental illness did not want to participate in family therapy.

As reported by the participants, some sisters openly confronted their siblings with mental health difficulties as they could not admit that they were ill:

‘The girls are inclined to say that they get too much sympathy or they were let away with too much murder, you know, that is kind of the attitude of the girls towards them.’

One mother recalled advice that she had provided to a sister of a person with mental illness on the importance of avoiding confrontation, being supportive, and not treating the ill person’s anger as a criticism directed towards the speaker:

‘She got very annoyed and said “Oh God you always talk about stupid rubbish, will you stop for God’s sake, I’m fed up with it.” Now I wouldn’t do that, I would be more, I’d humour her... and I said to her afterwards “Maybe can you be a little bit more sensitive... Look, you know her situation, you’re only exacerbating, you’re making it worse, why are you doing that... You should be always supportive, you know, she needs to be on an... equilibrium all the time, you know, de-emotionalised kind of, so you don’t disturb her”... She said “Well I read somewhere... that mental people should be treated like anybody else.” I said “That’s different... If you’re angry with people you get very upset and they don’t understand... Even if she’s angry with you, you have to understand that she will get angry with you sometimes and she will say things sometimes to you but it doesn’t mean she’s attacking you or criticising you, it’s coming from a different place, you know.” But it’s very hard, it’s very hard to explain.’

Three participants commented that their daughters were effectively coping with mental illness in the family and were involved in their siblings’ treatment and rehabilitation.

#### 4.3.4 Coping mechanisms used by brothers

There was one brother participant in the study. The participant commented that his wife’s support helped him to cope with the effects of his sister’s illness.

The participant also commented that, due to the family circumstances, he had no option but to provide care for his sister:

‘Well life is funny, life is not straightforward, I’d be twice as happy if she was back in Canada and happy as Larry, but that’s not going to happen... unfortunately it’s the life and time of the things.’

#### 4.3.4.1 Additional comments on coping mechanisms of brothers, provided by other study participants

Fifteen participants volunteered additional information about coping mechanisms of brothers of persons with mental illness.

Eight participants reported that brothers of persons with mental illness avoided their siblings and were reluctant to seek any support or information about the illness:

'That brother wouldn't really, I'd say, have any sort of an in-depth knowledge about mental illness and wouldn't want to have it either, just illness and hospitals no, would sort of upset him.'

'I told him... if there was any sort of meeting and I think there was a conference at some point, that if he was home and was able to go I thought it would benefit him. Now that hasn't happened. So I think he still has nervousness about being home... I think he'd be reluctant, to be honest.'

Two mothers commented that their sons were involved in caring for their siblings with mental health problems:

'He seems to communicate with him more, maybe because they're brothers you know.'

'He was very involved when he was diagnosed.'

Some mothers felt that brothers of persons with mental illness needed some kind of contact for advice or information:

'I'd say it would be useful if they had some group that they could contact if necessary...my little son went to one of the meetings but he's not going regularly. But they would need someone that they could contact if the need arose...I'd find it would be more advice rather than anything else.'

One mother commented that support groups might be too threatening to siblings as they have to speak up about things they are not sure about, or get too emotionally involved with their siblings' illness:

'I didn't want to talk too much about it because I thought the best thing would be to lead them into it as gently as I could so they sit into it and then I'd start coming out a little bit and saying things, but because they have to live their lives, they have families and they're young...And then there's people that want to know what's wrong and I'd say I don't know what's wrong for definite... It's not a question of just saying something, putting a label on it because the label takes a long time to come.'

One participant suggested that some sort of counselling would have been beneficial to brothers of persons with mental illness in order to relieve their emotional burden:

'It affects him deeply, I think he could benefit from, and I don't know whether it's, perhaps bereavement counselling, or psychotherapy, he needs to deal with a lot of emotions that are inside him.'

### 4.3.5 Perceived needs of children

Two grandparents who participated in the study commented that they provided some kind of informal counselling to a grandchild whose parent had a mental illness.

‘...and I said “Do you know what, hysteria plays a big part in that, you’re feeling a slight hysteria.” So I explained to her that she was probably so worried that she was getting the symptoms, a lot of the symptoms she was just after.’

‘So I am counselling him myself in my own amateurish way.’

Both participants expressed the need for the children to have professional counselling offered to them:

‘But she’s fine, I mean she’s fine and she’s not fine, she goes up and down like a yoyo and they were very, very depressed, they really should have been seeing people.’

Participants commented on what supports their grandchildren might need in the future.

‘He’ll have to be educated on the way up. I mean what do you tell an eleven or twelve year old, that your mother is mentally imperfect, do you tell them that... How does he feel, how is that going to make him feel, that his mother is different than anybody else’s, it’s going to be difficult on his self-esteem and whatever... It’ll be a difficult thing for him but hopefully he’ll have the awareness and intelligence, you know, to take it all on board, but they don’t always, you’d be surprised, you think they’re very intelligent would be aware and very supportive and, like, they’re not always.’

One participant hoped that the future counselling offered to his grandson by the MHS would be helpful. He was satisfied that the programme was designed for a specific age group of children from similar backgrounds, and was geared to their level of understanding of the family situation:

‘So he’ll be on a ten-week programme, once a week, but there’ll only be some other little boys and little girls, the same age, they mix them very appropriately, and all of them will be from similar backgrounds, a parent who maybe has had a mental illness, so when they’re talking to the kids it will only be in that limited remit of “So your Mammy was sitting very quietly and she wouldn’t talk to you...” and they will explain what she was going through, and he certainly needs some of that because he is, as I say, he is a bright little fellow, but even recently it was brought home to me that, its amazing how a child can have a view of the world that we don’t have.’

Two grandparents felt that the family environment was very stable both for the person with mental health problems and for his child, because of the support and inclusion provided by his wife and her extended family:

‘He’s in a stable environment, and his wife’s extended family are very good as well, you know, they include him in holidays and Christmas and all sorts of things.’

### 4.3.6 Coping mechanisms of a spouse

There was one wife of a person with mental health problems who participated in the study. The participant accepted her role as the main carer of her husband as part of her family duty:

‘I mean you can walk away but I would never walk away from him, he is my husband.’

She commented however that she had not been able to accept her husband's illness for a long time and had not coped as well as she could have:

'Oh very very bad, I often screamed at him because I'd get so frustrated, trying to get through to him, you know what I mean, I couldn't get through to him and he would get agitated.'

Although the participant did not get any information about her husband's mental illness from the hospital, she had read books and watched television programmes on schizophrenia:

'Not really, no. But I do, how I know about it is I've often read about it and look at programmes on television, there was a programme on one time.'

Though the participant received support from her relatives and from the MHS, she also mentioned a lack of understanding and empathy towards her as the wife of a person with mental illness:

'I don't think they understand it, they feel sorry for him but they don't feel sorry for me...There's nothing about how I feel, as I told you my relatives are very kind. But nobody, never say how do you feel, that's the worst part of it you know...Even the hospital, you'd never hear anybody saying, oh it must be very difficult for you Mrs...'

However, her positive outlook, being active and not 'stopping and thinking' about life with her husband helped her to cope. The participant's only worry was her husband's health:

'The other day I went upstairs and cleaned all the top of the house... I am very, very positive in my outlook because if I had to stop and think of my life with him the way things are, I probably would end up in hospital myself but I'm not that kind of person... I'm positive and I'm happy in my day you know, except for my whole concern is he's on my mind all the time because I worry about him.'

## 4.4 Perceived and emerging needs of individual family members

Table 4.4 presents the experiences, coping mechanisms and needs of mothers, fathers, sisters, brothers, offspring and a wife, as emerging from the interviews, and further analysis of the data. As suggested by the data on experiences and coping mechanisms used by different subgroups of relatives in order to offset the negative effects of mental illness on the family, all subgroups of relatives could have benefited from some counselling and family therapy, provided either individually or in a family setting.

Mothers expressed the need for some contact, or mediator between the person with mental illness and family members, so that they could contribute to treatment of their relative. Most of the female participants viewed social contact and sympathy as helpful.

Information about mental illness, treatment and rehabilitation was viewed as beneficial by mothers and fathers who participated in the study. Sisters of persons with mental illness required more specific advice about current symptoms and day-to-day coaching on how to handle disruptive behaviour of their sibling.

Advocacy and openness about mental illness was seen as beneficial by female participants in the study. Male relatives of persons with mental illness, such as fathers or brothers, needed to accept and express their emotions, and might have feared that public sharing of experiences could damage



the image of the ill person and of the family. Fathers found individual therapy a helpful way of 'unbottling' their emotions.

Some fathers needed to have some kind of control over the situation in general, and over the treatment of their relatives in particular. They wanted reassurance from the services that their children were given the best available medication and treatment, and needed to be actively involved in the care of their relative.

As perceived by the participants of the study, children of persons with mental illness needed gradual help to understand the illness and behaviour of their parents, geared to their age group and specific family background. Group counselling was suggested as one of the helpful tools for offspring. A stable environment of a two-parent, supportive family was viewed as beneficial to alleviate the negative influence of the mental illness of a parent on their offspring.

Whereas female relatives valued the sharing of experience in group settings, male relatives seemed to benefit more from individual or family settings. The male carers coped by trying to find information on their own, and used many sources of available information in order to 'educate themselves' about the illness. In some cases, counselling was perceived by participants as threatening the emotional balance of male relatives of persons with mental illness.

**Table 4.4** Influence of mental illness on individual family members, their coping mechanisms and emerging needs, based on qualitative data from the interviews

Subgroups of relatives	Perceived effects of mental illness on the relative of the person with mental illness	Coping mechanisms	Emerging needs
<i>Mothers</i>	<ul style="list-style-type: none"> <li>• ‘Grief’, ‘loss’ of a child</li> <li>• Inability to help and protect the child, perceived as inherent in the role of a mother</li> <li>• Inability to handle disruptive behaviour or aggression of the child</li> <li>• Fear about the child’s self-harm and harm to others, insecurity</li> <li>• Worry about the child’s future and well-being</li> <li>• Isolation, lack of ‘social contact’ as a result of family disintegration or stigma</li> <li>• Worry about psychological well-being of other relatives</li> <li>• Taking on parental duties towards grandchildren</li> </ul>	<ul style="list-style-type: none"> <li>• Acceptance of their responsibility to care for their sick child as inherent in the mother’s role</li> <li>• Active involvement in their child’s treatment and rehabilitation</li> <li>• Acceptance of their responsibility to care for their sick child as their duty to other family members</li> <li>• Talking to other people about mental illness and sharing individual experiences as a means of relieving the emotional burden</li> <li>• Extending the reduced social contact by means of participation in support groups</li> <li>• Seeking information and advice on the child’s behaviour from people in the same situation</li> <li>• Seeking information and advice from books, leaflets, the Internet, and mass media</li> <li>• Treating the mental illness of their child as any other illness, or as a part of the family life in general</li> <li>• Being open about the illness, advocacy, participation in conferences</li> <li>• Studying, working</li> <li>• Doing more household chores</li> <li>• Reiki, yoga, walking, an other physical activities</li> <li>• Taking ‘one day at a time’</li> <li>• Religion</li> <li>• Seeking professional counselling, family therapy, medication</li> <li>• Use of in-patient services as a respite from the emotional burden</li> </ul>	<ul style="list-style-type: none"> <li>• Individual/group counselling or family therapy</li> <li>• Support groups for parents</li> <li>• Information about the illness, symptoms, and advice and training on handling disruptive behaviour</li> <li>• Information on treatment and rehabilitation of persons with mental illness</li> <li>• Mediator or human contact between the person with mental illness and the rest of the family</li> <li>• Social contact, empathy, acceptance</li> <li>• Recognition of an active role in the treatment and rehabilitation of their child</li> <li>• Information about housing, supports for themselves and their relative, wills and trusts</li> <li>• Openness and public advocacy regarding persons with mental illness and their relatives</li> </ul>

**Table 4.4** Influence of mental illness on individual family members, their coping mechanisms and emerging needs, based on qualitative data from the interviews

Subgroups of relatives	Perceived effects of mental illness on the relative of the person with mental illness	Coping mechanisms	Emerging needs
<i>Fathers</i>	<ul style="list-style-type: none"> <li>• Inability to help and protect the child perceived as inherent in the role of a father</li> <li>• Ongoing, enduring nature of mental health difficulties</li> <li>• Difficulties in finding solutions</li> <li>• Anxiety, inability to relax</li> <li>• Perceived lack of control of the situation</li> <li>• Inability to control emotional and traumatic experiences</li> <li>• Fear of perceived stigma</li> <li>• Inability to 'let go' and hand over control to others involved</li> <li>• Taking on parental duties towards grandchildren</li> </ul>	<ul style="list-style-type: none"> <li>• Talking to other people about mental illness and sharing individual experiences as a means of relieving the emotional burden</li> <li>• Treating mental illness of their child as any other illness, or as a part of the family life in general</li> <li>• Extending the reduced social contact by means of participation in support groups</li> <li>• Seeking information and advice on the child's behaviour from people in the same situation</li> <li>• Seeking information and advice from books, leaflets, internet, and mass media</li> <li>• Use of counselling and family therapy</li> <li>• Trying to find practical solutions to the problems</li> <li>• Taking control of the situation through active involvement in the child's treatment and rehabilitation</li> <li>• Arguing with the services about the best treatment for their relative</li> <li>• Valuing the positive character traits in their child</li> <li>• Walking, other physical activities</li> <li>• Religion</li> <li>• Reducing social contact to relatives only, being secretive about the illness and/or diagnosis</li> <li>• 'Hiding' their emotions, avoiding situations which may trigger their emotions, such as support groups or counselling</li> <li>• Medication</li> <li>• Resorting to external help in household duties</li> </ul>	<ul style="list-style-type: none"> <li>• Information about the illness, symptoms, treatment and rehabilitation of the child</li> <li>• Reassurance on the part of services that treatment and rehabilitation of the child is under control</li> <li>• Individual counselling or family therapy</li> <li>• Accepting and expressing their emotions</li> <li>• Trusting that sharing experiences would not damage the image of the ill person or the family</li> <li>• Accepting that mental illness is part of the family life</li> </ul>

**Table 4.4** Influence of mental illness on individual family members, their coping mechanisms and emerging needs, based on qualitative data from the interviews

Subgroups of relatives	Perceived effects of mental illness on the relative of the person with mental illness	Coping mechanisms	Emerging needs
<i>Sisters</i>	<ul style="list-style-type: none"> <li>• Difficulties in finding solutions</li> <li>• Grief, loss of a sibling</li> <li>• Worry about the sibling's future and well-being</li> <li>• Inability to handle disruptive behaviour or aggression of the sibling</li> <li>• Fear about the sibling's harm to others, insecurity</li> <li>• Worry about the well-being of a parent caring for the sibling</li> <li>• Perceived stigma in society about mental illness and schizophrenia</li> <li>• Worry that the illness is hereditary and can be passed down to their future children</li> <li>• Social isolation, lack of social contact</li> <li>• Anger towards the sibling</li> <li>• Inability to forgive and accept their sibling's mental health difficulties</li> <li>• Unwillingness to share the same accommodation with the sibling</li> </ul>	<ul style="list-style-type: none"> <li>• Talking to family and friends about their sibling's mental health problems</li> <li>• 'Informing themselves' about the illness through reading and on-line research</li> <li>• Taking part in caring for their sibling in the house</li> <li>• Visiting their sibling in an in-patient unit or in a community residence</li> <li>• Open confrontation with the ill person</li> <li>• Avoiding contact with the ill person</li> <li>• Avoiding thinking about the illness, 'blocking it out'</li> <li>• Studies, work</li> <li>• Leaving the family home, travelling</li> <li>• Avoiding external counselling and discussion of the family problems outside a limited circle of family and friends</li> </ul>	<ul style="list-style-type: none"> <li>• Practical advice on how to handle the sibling's disruptive behaviour, information about symptoms, behaviour and coaching on day-to-day skills of caring</li> <li>• Available contact for advice and information on symptoms and caring after the ill relative</li> <li>• Support groups for siblings, geared for similar age groups and family situations, at flexible hours</li> <li>• Individual counselling and family therapy</li> </ul>

**Table 4.4** Influence of mental illness on individual family members, their coping mechanisms and emerging needs, based on qualitative data from the interviews

Subgroups of relatives	Perceived effects of mental illness on the relative of the person with mental illness	Coping mechanisms	Emerging needs
<i>Brothers</i>	<ul style="list-style-type: none"> <li>• Grief, loss of a sibling</li> <li>• Anger towards the sibling</li> <li>• Inability to forgive and accept their sibling's mental health difficulties</li> <li>• Unwillingness to share the same accommodation with the sibling</li> <li>• Fear about the sibling's harm to others, insecurity</li> <li>• Worry about the well-being of a parent caring for the sibling</li> </ul>	<ul style="list-style-type: none"> <li>• Avoiding external counselling and discussion of the family problems outside a limited circle of family and friends</li> <li>• Open confrontation with the ill person</li> <li>• Avoiding contact with the ill person</li> <li>• Avoiding thinking about the illness, 'blocking it out'</li> <li>• Studies, work</li> <li>• Leaving the family home, travelling</li> </ul>	<ul style="list-style-type: none"> <li>• Individual counselling and family therapy</li> <li>• Accepting and expressing their emotions'</li> <li>• Trusting that sharing experiences would not damage the image of the ill person or of the family</li> <li>• Accepting that mental illness is part of the family life</li> </ul>
<i>Children</i>	<ul style="list-style-type: none"> <li>• Worry about the parent's health and well-being</li> <li>• Fear of the parent's unusual behaviour, insecurity</li> <li>• Confusion about the family situation</li> <li>• Fear that they are getting the 'sickness' of the parent</li> </ul>	<ul style="list-style-type: none"> <li>• Asking questions about the parent's illness to their grandparents</li> <li>• Treating their grandparents and parents, and their grandparents accommodation as their home</li> <li>• Informal counselling from their grandparents</li> <li>• Professional counselling from the services of their parent</li> </ul>	<ul style="list-style-type: none"> <li>• Professional counselling for groups of offspring of similar age and background</li> </ul>

## 4.5 Summary

Mothers whose children with mental health difficulties lived at home had the highest average number of hours of weekly contact with the person with mental illness within the 12 months prior to the study, followed by fathers and sisters of persons with mental illness. However, the theme of the amount of time spent on caring for the persons with mental illness did not emerge from the interviews with study participants.

As reported by participants, most of the persons with mental illness had no physical impairments preventing them from fulfilling basic daily living tasks in the last 30 days prior to the study. However, the majority were either resistant or needed extra cueing to get in and out of bed, dress and change clothes as necessary, and to take medication, exercise, and participate in social activities outside the family circle. In addition, several study participants commented that their relatives did not want to accept that they were unwell and were resistant to any kind of treatment or medication.

Most of the elements of the objective burden of caring for persons with mental health problems were associated with the person's disruptive or socially unacceptable behaviour, which crippled the social functioning of the family both inside and outside the house. Moreover, some behaviour of persons with mental health difficulties posed a threat to the security of the house and its inhabitants or guests. Some participants commented that if they had some practical advice on how to handle such behaviour in times of crisis, the situation could have been handled better and some of the disruption could have been avoided.

The social life of families was curtailed, and in some cases families became totally isolated from any human contact outside the family. One of the reasons behind the family isolation was the perceived stigma, associated with any kind of mental illness, and with schizophrenia in particular.

The participants commented that the mass media sometimes added to the stigma by reporting distorted or exaggerated information about the risk posed to society by persons with mental health problems. Participants believed that the stigma of mental illness would be lessened if the media presented more accurate information. Some participants advocated informing the public about mental health problems from early childhood by designing special programmes for schools.

The elements of the subjective or emotional burden on families were represented by the themes of worry, fear, anxiety, helplessness, grief and sadness, emerging from the interviews with the participants in the study. The grief was associated with the change in the relative as a result of the illness, and the loss of hope for the future quality of life of the ill relative. The themes pertaining to the emotional burden on the family were inseparably connected with the elements of the objective burden.

Most of the participants experienced either complete or partial family disintegration as a result of the mental illness of a family member, resulting in separations or loss of contact with other family members. Seven participants reported their complete isolation from the rest of the family. The rest of the participants had some support from their families. However, some offspring 'did not want to know' about their brother's or sister's illness and preferred to avoid any contact with their families.

Some of the participants reported that their families effectively adapted to the illness of their relative by changing their outlook, or 'rethinking' the concept of 'family'. Some families adapted by accepting the illness of their relative as an inherent and normal phenomenon of their family and, in some cases, of their life in general.

Most of the mothers and some fathers coped with the burden of mental illness by talking to other people, both inside and outside the family circle. Support groups were viewed as effectively serving a dual purpose of extending the social circle that had been reduced by the mental illness in the family, and getting information about the illness, symptoms, and best ways of handling the behaviour of the ill person at times of crisis. In addition, meeting people who had shared similar experiences with the person with mental illness and whose health or well-being had improved, induced hope in the participants that both their relative and themselves might feel better in the future.

Information and knowledge about the illness and its treatment, and the potential for recovery was a powerful coping tool for most of the participants of the study. Knowledge about the illness and symptoms helped to reduce the feelings of worry and anxiety associated with the strange or unacceptable behaviour of their relative, and helped them to fulfil their caring role. Information about treatment, medication and recovery provided some hope for the future of their loved one, and therefore improved the participants' psychological well-being.

Participation in support groups was perceived as somewhat threatening by several fathers and siblings of persons with mental illness. As reported by participants, fathers and brothers sometimes got too emotionally upset when listening to other group members sharing their feelings, and were reluctant to talk about the mental illness of their relative in a group setting. Some sisters also commented that there were no support groups available for their age groups, which decreased their willingness to participate.

Some fathers coped by trying to solve the 'problem' of mental illness in the family by doing their own research on the illness, and getting actively involved in the treatment of their child. They felt the need to control the situation and ensure that their child had the best treatment and medication available through the mental health services. In some cases, this led to arguments with the services about the choice of treatment and medication, especially when fathers did not receive reassurance from the services that the treatment of their child was under control.

As perceived by the participants of the study, children of persons with mental illness needed assistance in understanding their parent's illness and behaviour, geared to their age groups and specific family backgrounds.

Whereas female relatives valued sharing of experience in group settings, male relatives seemed to benefit more from either individual or family settings. Also, a gradual, step-by-step awareness-raising about mental illness was suggested by the participants for fathers, brothers, and sons of persons with mental illness.

## Chapter 5

Needs and support requirements of participants at different stages of their experience of enduring mental illness in the family

“”

The beginning was the most difficult... It's shattering, when you're first told, when he was acting oddly and you didn't know, you think you're the only person in the world with this illness and what will you do, where will you go...



This chapter will describe the different stages of participants' experiences of mental illness in the family, treatment of their relatives, and their needs and support requirements during these stages.

The presentation of results will follow the stages outlined by the interview schedule, describing the initial encounter with mental illness prior to the treatment provision by the mental health services; the first encounter with treatment provision; discharge; relapse; and perceived most difficult stages of participants' experiences with enduring mental illness. Additional stages of family experience of mental health problems, as emerging from the qualitative data, will be identified and presented.

## 5.1 The initial encounter with mental illness in the family

This section will describe the experiences of relatives of persons with enduring mental health problems at the onset of signs of illness, and first contacts for help prior to the first treatment provision to persons with mental illness by mental health services.

### 5.1.1 Duration of illness, hours of contact, and age at the onset of illness

As reported in Chapter 3, the approximate duration of the mental health problems of the participants' relatives ranged from 1.5 to 49 years (mean 17.3 years). The reported average number of hours of contact with the ill relative (mean 38.9 hours) significantly decreased over time ( $r = -0.363$ ,  $n = 33$ ,  $p = 0.038$ ), with participants whose relatives' illnesses were of longer duration reporting fewer hours per week spent with the person with mental health problems.

On the basis of the reported age of the persons with mental health problems, duration of illness, and additional information provided in the interviews, the approximate age at the appearance of the first signs of mental health problems, or the onset of illness, was calculated. The reported age at appearance of the first signs of mental illness ranged from seven to 31 years (mean 17.6 years, median 17.0 years). Fifty per cent of participants ( $n=19$ ) reported that persons with mental illness were about 17 years old when the participants had first noticed signs of mental health problems. The majority of the persons with mental illness ( $n=22$ , 66.6%) had been living at home with the participants and had been in their early or late teens at the onset of their mental health problems, which may explain the higher average number of hours per week spent with the person with mental health problems at the initial stage of illness, as opposed to later years.

The analysis based on the data provided by the participants in the demographic questionnaire did not indicate that such factors as diagnosis, gender, relationship to the ill person, area of residence, education and marital status of either the participants or their relatives, and source of reference of the participants to the study had any significant influence on the reported age at the first signs of mental health problems.

### 5.1.2 Noticing change in a relative

More than half of the participants in the study (n=20, 52.6%) commented there had been a gradual, rather than an 'overnight' change in their relatives' behaviour, which could have been attributed to the difficulties of teenage years or to some personality traits of the person, rather than to the 'mental illness'. Therefore, mental health problems had been difficult to spot:

'I honestly think that the families are the last to notice, you know, because it's all little by little...There wasn't a massive big change, there was gradual...'

Three participants in the study commented that the person with mental health problems changed 'overnight', without any noticeable previous signs of mental health problems:

'Her behaviour became very strange one night, she started complaining that she had pains in the stomach, and before that she had got these long kind of dreads put into her hair and she was acting very, very strangely.'

'He was in college, and in great mood, driving the car and had a great time and saw a girl there he was quite fond of, and all that sort of stuff, you know... It came on about twelve o'clock. "They're coming for me..." Out of the blue.'

Six participants commented that their relative had been quite intelligent and creative since their childhood years:

'She was extremely creative and musical and she just kept to herself.'

'It's a real strange thing that you know you have a mixture of intelligent, good-looking kid and then this other side that can't cope.'

These participants commented that their relatives had been quite shy and sensitive since their school years, had problems with their self-esteem, and often seemed to be 'in their own world':

'Well, when he was in school he was kind of into himself and shy and didn't participate a lot in social things. It was though he was in another world sometimes.'

'Possibly because she was the eldest, she sort of in a way had controlling aspects to her personality... She was always very sensitive... I think we all tiptoed around her quite a bit.'

Participants felt that, although it was very difficult for them to notice any signs of mental health problems and to admit that their relative needed some professional help, information about mental health could have helped them to assist their relative in getting some professional or home help:

'I don't know, the train is coming down the track probably and I don't know whether you avoid it but it probably could be handled better, the people would know, would be able to get on because it just doesn't only affect the person, it actually affects the family.'

'Oh we didn't look for any support, because we didn't know what was wrong with him, and we just thought maybe it was a phase he was going through...If we had had advice then it probably would have been much better.'

Two participants had joined SI during the build up of signs of mental health problems, and found the information and counselling they received very helpful. Some participants who were SI members

at the time of the study thought that they should have joined SI straight away in order to get information on the illness, on how to handle disruptive behaviour, and on how to get professional help for their relatives:

'I should have joined SI immediately.'

#### 5.1.2.1 Social relationships, academic performance, and bullying at school

More than half of the persons with mental health problems (n=18, 54.5%) started to develop problems with social relationships in their first years of secondary school, and their academic performance had gradually deteriorated:

'It goes back quite a long time... And as far back as I can remember, he's been quite different from the other children, but especially in secondary school... He found it difficult to make friends, oh he would talk to them but he wouldn't maintain friendships, he wouldn't be ringing anybody and they wouldn't be ringing him, and he found it difficult to apply himself in school and his results started to get gradually worse.'

Four participants mentioned that their relatives might have developed mental health problems after they had been bullied at school:

'It started when she was about 14, 15, she was being bullied at school.'

Some participants of the study mentioned that they had not known about the bullying at school until much later, when the person with mental health problems started to get professional help and admitted that they had been bullied at school:

'It came out when he was 22 that he had been bullied at school...And he was a gentle quiet boy, I didn't know that he was being bullied, in those days they didn't talk about it, even today they are very slow to tell, but at that stage it was not discussed on the radio or anything, I'm going back 13 years...And the fact that he was my eldest son, this is important too, I didn't want him to be made out to be a mammy's boy, you know.'

#### 5.1.2.2 Stress and mental health problems

Four participants commented that their children had become noticeably 'unwell' around the time of studying for their Leaving Certificate because of stress:

'Well I think he had problems all through his life really, from the time he was very young, but as he got into teenage years it manifested itself in a completely different way, and after his Leaving Certificate he seemed very unwell and stressed.'

One mother commented that prior to the onset of mental health problems, her son had gone abroad as a volunteer. Stress and the shock of 'seeing atrocious things' when doing voluntary work might have affected his mental health afterwards when he came back to Ireland:

'Because we wondered was it traumatic stress ... At the height of trouble, he went as a volunteer... and he had seen atrocious things, and the terror...you know, he wasn't medically trained...'

A wife commented that her husband often had his 'breakdowns' before Christmas:

'The pressure of Christmas was too much for him, and then he used to have little problems in his job.'

### 5.1.2.3 Perceived alcohol and drug abuse at the onset of mental illness

Six participants spoke about perceived alcohol or drug abuse by their relative at the time of the onset of mental health problems.

'It happened I think when she was about twelve, she changed overnight, very suddenly, became very secretive, did everything in extremes, if she drank alcohol, she drank a lot and when she took drugs she took a lot.'

Several participants felt that their relatives resorted to alcohol or drugs to self-medicate at the times of stress:

'He's very intelligent...He was very mathematically good but in terms of emotions... and very poor relationships. He wasn't a regular drinker, but if he was going out he'd like to get himself drunk before he could socialise with people, you know.'

'When you look back at it now, it was a gradual build up of different things happening...Originally, that's where it started for us, taking all sorts of notice of his body and things like that... Then he couldn't get up to work and started missing out on work, he was sleeping all day at work... He started coming in drunk then, falling through the door... I think he was trying to cope by drinking.'

Some participants commented that self-medication with alcohol or drugs could have triggered mental health problems in their relative:

'He was sending us e-mails and making very threatening phone calls... He was demanding large amounts of money... So we went to see him and he wouldn't see us... And we met one of the fellows there and he said that he seemed to be very wound up about the exams and thought he wasn't going to pass, so he started on the cannabis... and that kind of triggered...'

'A friend of his committed suicide. He said to me, "Mum, I am drinking, I want you to know I'm drinking, I am not getting over his death."'

A sister reported that her brother had epilepsy since he was 13 years of age, and the family had always been aware that he could be aggressive from time to time. However, when he became older he developed problems with alcohol, became more disruptive and was admitted to a psychiatric hospital:

'Well we always knew he had epilepsy when he was 13, so we'd grown up with him being...ill with his epilepsy and he could become quite aggressive with us and with his other siblings. As he got older then he started to drink and socialise so that didn't help. In his early twenties we became afraid of him because he used to get aggressive... from what I can remember he had started a fight on the bus coming home and they took him into hospital then.'

### 5.1.2.4 Sexual abuse and abusive relationships

Two participants felt that the illness 'manifested itself' because of sexual abuse during childhood years:

'Well it manifested because she herself was sexually assaulted when she was a young girl... And we had her in counselling from the time she was 12, we paid for private counselling, but she was quite disturbed by it, and became quite difficult into her teens.'

A father commented that when his wife had taken their daughter to the Rape Crisis Centre, there had not been any support or sympathy offered to the mother, and he had found the staff ‘icy’ when he spoke to them on the telephone:

‘She found them aloof, quite cold to her, our daughter was taken away into a room and my wife was left quite upset crying sitting in the room... I phoned once, when they were there, and it was icy, I mean it was a few years ago, but they certainly didn’t seem to welcome men ringing the place, you know, so I found them very dismissive, and I found them unhelpful.’

One participant commented that abusive relationships with her daughter’s ex-husband may have triggered the mental illness:

‘I don’t know whether as a result of what was happening to her, or that it was something contributing to what happened to her, I haven’t a clue, I can’t tell you because I don’t think anybody will ever know which was the horse before the cart or the cart before the horse, but the marriage failed... and she came out of the marriage very, very stressed.’

#### 5.1.2.5 Problems with physical health at the time of the onset of illness

Seven participants mentioned that the gradual build up of signs of mental health problems was accompanied by sleep disturbances in their relatives:

‘He was talking to himself and then developing on from that, there was staying up at night.’

‘Well basically he wanted to stay in bed during the day. And he would become very alert maybe at half three, four o’clock in the morning. With the result the following day he would be tired and he would have to stay in bed until three or four o’clock.’

Four participants recalled that some physical problems occurred at the same time as the signs of emotional problems. Physical health problems mentioned by participants included stomach problems, flu, acne, and thyroid deficiency. Whereas the person with mental health problems had been getting help for physical illness, some participants complained that their mental health problems were not spotted by medical professionals:

‘My mum died and she was very close to her and my husband and I separated, so she started developing all sorts of problems, we were at the doctor every week, you know stomach problems, everything... So nobody picked up that it was obviously at an emotional or a deeper level, one doctor said I think we’ll refer her, there has to be something else.’

‘And he was sleeping on the floor and having difficulty at school, blood tests have been taken and he developed a thyroid deficiency, for two years... But the physical area don’t deal with the mental area, it’s separate, never the twain do meet.’

### 5.1.3 ‘Breakdown’ of persons with mental health problems

As reported by participants, the gradual build up of signs of mental health problems was followed by a ‘breakdown’, whereby the relative started getting ‘on edge’, hearing voices, getting disruptive, or attempting self-harm. It was usually at this crisis stage that the family finally admitted that something was wrong and started seeking professional help:

'He was working at that stage, and he didn't get up and go to work. And he got very psychotic but I didn't know what is was and he got terribly violent and terribly, terribly ill really and I found it very difficult to get help.'

'You see we were putting it all down to teenage stuff, so it could have been a couple of months, we were just saying yeah it's teenage stuff, but we were not sure what it was... Until he started jumping on my car and saying all kinds of mad things, that was kind of when we knew, it wasn't just teenage stuff anymore but there was something different going on with him.'

#### 5.1.4 First contact in seeking help

Participants mentioned their first contact in seeking help during the 'breakdown' in the case of 28 out of 33 persons with mental health problems (84.8%). Of these 28 cases, more than half of the first contacts in seeking help were GPs (n=17, 60.7%). Other contacts included psychologists (n=4, 14.3%), an ambulance called for physical health emergency (n=3, 10.7%), private psychiatrists (n=2, 7.1%), public psychiatric hospital (n=1, 3.6%) and prison (n=1, 3.6%).

'He was in prison... And when I'd go visit him, I knew he shouldn't be there, that he was just in another world, you know. So I got in touch with a doctor and they took him out of prison, and they put him into another place, it was a hospital.'

Two participants reported that a private psychiatrist had been their first contact in seeking help. In five cases out of 33 (15.2%) information about the first contact in seeking help was not provided, either because the relative had resided elsewhere during the onset of mental illness, or the participants did not remember.

Of the reported cases of 28 first contacts in seeking help, the majority of persons with mental health problems (n=21, 75.0%) had voluntarily sought help for the first time from GPs, psychologists, psychiatrists, a general hospital, and a public psychiatric hospital, sometimes with additional cueing from their concerned family members. In seven cases (25.0%) participants had contacted GPs, psychiatrists and police in the absence of their ill relative. Of the reported seven cases, six persons with mental health problems had not been on speaking terms with their family members at the time of the build up of illness, and had not wished to seek help:

'He wouldn't go to the doctor for me... So the doctor came to see him, and when he heard that the doctor was coming, when I opened the door to let the doctor in, he went out the back way...'

##### 5.1.4.1 Recognising mental health problems

As commented by participants, sometimes persons with mental health problems behaved differently with other people than they did with their family. Participants felt that it had been difficult for educators, primary health care services, or mental health professionals to find that there was 'something wrong' with their relatives:

'And when you went to schools, teachers said "ah there's nothing wrong with him", you know. There was, but he's a pleasant person, he would kind of do a display so there's nothing wrong.'

'She went to see a psychiatrist but she's very good at interviews, she can get jobs, she's not able to keep them but she's good at interviews... And obviously she wasn't truthful with the psychiatrist and she would want to give a good image of herself and then his conclusion was that she wasn't mentally ill but she was immature... and then when she had her breakdown about four months later she was described by the psychiatrist as a very seriously ill girl.'

Two participants commented that, had it not been for their previous experience with the person's mental health problems, their son would not have been admitted to the hospital, as neither the police nor doctors on call could see any signs of mental health problems at the time of admission:

'Our doctor phoned us and said "These cops are just looking at me, they don't think there's anything wrong with this guy". But he said "I'm signing him anyway," and he said "It might be better if you go down to the doctors in hospital before he gets there". So we went down and spoke to the doctors and told them what had been happening, and the doctors told us afterwards that if we hadn't actually arrived and told them what had happened they would have let him go. He was just so plausible and so presentable.'

Some of the participants commented that GPs attributed their relative's behavioural problems either to the difficulties of the teenage years or to family problems during the first contact for help:

'Well originally... she was staying in her room and listening to music, pulling back the curtains, and then I went to my GP and looked for his advice. I was told lots of teenagers do that, they all do that. But I said no, it was more than that, and I really was not given any solutions.'

'I noticed that he was paying an awful lot of attention to the mirror, looking at himself in the mirror, now he's a good-looking man, and when we brought him to our local GP, he actually OK'd it for him to have a nose job at one stage, which I couldn't believe, because I could see that it wasn't a nose job he needed, it was something deeper than that.'

One participant commented that when their son was displaying 'difficult' behaviour, they first contacted the school, but there had been no help. After that the parents went to the GP, who sent them to the psychotherapist in order to improve their parenting skills. However, when the parents followed the advice received during their psychotherapy sessions, their son's behavioural problems became more aggravated:

'Well when he was in his teens he became very difficult at home, he'd fly off the handle, become very angry and start to throw things around... So we wondered what the matter was, and because he was in his teens... we were a bit at a loss. And we contacted the school and they weren't finding anything the matter with him, so we thought maybe then that it was our parenting was causing the problems. So we went to our GP and he sent us to a psychotherapist and we went to the psychotherapist a number of times and he was more or less telling us how to treat teenagers. Which when we acted on that, our son became very upset altogether... '

Some health professionals provided treatment for depression or stress-related problems until persons with mental health problems had a 'break-down' or told the family that they had been hearing voices:

'We had him to the doctor beforehand, we had to attend the GP before that but when he got that breakdown... then we knew that there was something seriously wrong...But before that it was sort of treated as depression.'

'He did say to me "But I'm hearing voices from the computer and television..." So that concerned me a lot, before this episode we actually arranged him to see a psychologist because I thought his problems were all stress related, and the psychologist was seeing him once a week and charging him but he really didn't realise that he actually had a mental health problem, until I rang him and said that he'd been hearing voices, then he referred him to the psychiatrist.'

Three participants of the study recalled that it had been somewhat easier for them to recognize the signs of the illness as they had had previous experience with mental health problems with another family member:

‘Because I had been through the mental illness with my daughter I recognized the signs and suddenly, little things, alarm bells started going off in my head. But there wasn’t anything I could do, because he was 26, so I kind of watched and waited and I did speak to my daughter’s psychiatrist a couple of times.’

‘She got very depressed initially...Because of the experience I had with my husband, I knew.’

One participant commented that she had been reading about schizophrenia during her son’s build up of signs, which helped her to recognise mental health problems and made it easier to seek help:

‘Well he was maybe in his teens, he had difficulties in making friends, losing contact with people, all the usual things that you read in the handbook of the symptoms of schizophrenia, he was showing... In his college days he found it hard to keep studying and he started losing his friends and becoming aggressive and going for long walks and coming back with strange ideas and that kind of thing... But he became more and more distressed as time went on, so I went to see a psychiatrist to say “Look my son is showing all these symptoms and I wonder is it schizophrenia because I’d been reading about it”, I think in my mind I must have realized... But he did go over the edge within a fortnight or so, I went to the psychiatrist because he was obviously really on edge.’

## 5.5.5 Perceived barriers to accessing mental health services

### 5.1.5.1 Reluctance of persons with mental health problems to seek treatment

Three mothers had spoken to psychiatrists prior to the ‘break down’ of their children. They were advised that, unless their child went to seek help voluntary, they would have to wait until he or she got ‘on edge’ in order to get them to in-patient services:

‘So I went to psychiatrist before he was admitted, and it was only a fortnight before...and she said all you can do is wait until he becomes a danger to himself or to yourself and starts doing unusual things... And within a fortnight, I must have taken some action into my hands by telling him that he was very ill and that he needed to go to hospital and that why wouldn’t he come, I got very cross with him and I think that’s what made him go over the edge.’

‘I rang the psychiatrist twice and I said “You know, I’m going to have to take off work again, I’m finding it very hard to cope...” And he said “There’s only one way you’ll... get a psychiatric bed for a patient in hospital, if they are physically violent”. So that was the end of it, just forget about it, he said “Do you know the whole thing is to get people back into the community, and she’s gentle”... Ad she is, you know, she has a gentle personality, but she’s a devil to live with.’

Four participants whose relatives were living in their homes and using services of private psychiatrists at the time of the study reported that no support or backup was offered to the family. The only advice on how to seek help in the time of crisis was provided by SI.

‘So she disappeared for a week... And it was after that that my mum got in touch with SI, some of the counsellors there suggested that if she ever does that again, actually call your GP in advance and say “Look we’re having this problem”...So like we had never, that was a brilliant idea, so like if it ever happens again, I think that’s probably what we’ll do...The only advice that we had been given from psychiatrist was it’s up to her, she’s an adult, she has to be the one to go.’



### 5.1.5.2 Getting help out of office hours

One participant commented that it was difficult to get their relative admitted to a hospital during the weekend. The GP agreed to help the family outside his working hours, and helped to arrange the person's admission during the night, though hospitals were reluctant to admit the person:

'Sunday lunchtime, how do you find a GP... As I was driving by his surgery I saw my GP's car, the poor man had been trying to catch up on his sleep when I arrived... The GP was in touch with one hospital who basically didn't want to take him in, and then he got on to another and they didn't want anything to do with him either, and the GP said "Look you have to take him", he kept saying "You'll just have to give this guy a bed and that's it."'

Another participant found it hard to get timely out-patient help for her son from private psychiatrists at the time of the crisis because it occurred during the summer when a lot of psychiatrists were on holidays:

'And I phoned seven psychiatrists, this was in July, and they were all either on holiday or just about to go on holiday or they'd just returned with a long waiting list. Basically, I couldn't get him into out-patients at all as an immediate thing, I mean it could be two months down the line but things were so bad, you know, you couldn't wait for two months.'

### 5.1.5.3 Perceived alcohol abuse at the time of seeking help

One participant reported that his daughter had voluntarily gone to the public hospital to get help but had not been admitted as she had been under the influence of alcohol at the time. However, this had not been explained either to the person seeking help or to her parent:

'But she was drunk, and they told me afterwards that they don't deal with people who are drunk... Now had I known the next day when she sobered up, I could have brought her back again, but I didn't know that, I thought they were just not dealing with her, so there was a problem there that I think they should have explained the policy to her. She was really panicking with her condition, and she knew herself she was getting out of control... So we left it, and I dealt with her for a week trying to sober her up, I phoned around and I said the public mental health services won't take her, I assume it was just full or busy, but the explanation would have helped me... I rang a private hospital, she had BUPA cover, and again they were busy, but I finally convinced this woman that she really was ill and needed help, so they took her in.'

### 5.1.5.4 Perceived inconveniences of catchment areas

Five participants commented that they could not get their relatives into the hospital or unit of their choice because of the catchment area of their address:

'And anyway to cut a long story short they recommended we got a place for her in this hospital. I actually didn't want her to go there but they said I had no choice because that was my catchment area... It would have been handier to go up to town, but never mind anyway.'

'So we got in touch with the psychiatrist, and he said, "Oh he needs to go to another psychiatric clinic". Which is the local psychiatric clinic in our catchment area. So my son never did see that psychiatrist we spoke to.'

A father commented that he could not get two of his sons into the same in-patient service because only one of them had an address in Dublin:

'We had him admitted, he'd gone off himself, but they wouldn't take his brother because he wasn't in the catchment area.'

One mother commented that she brought her son to private services as she had not realised that he could have gone to public services as he had an address in Dublin:

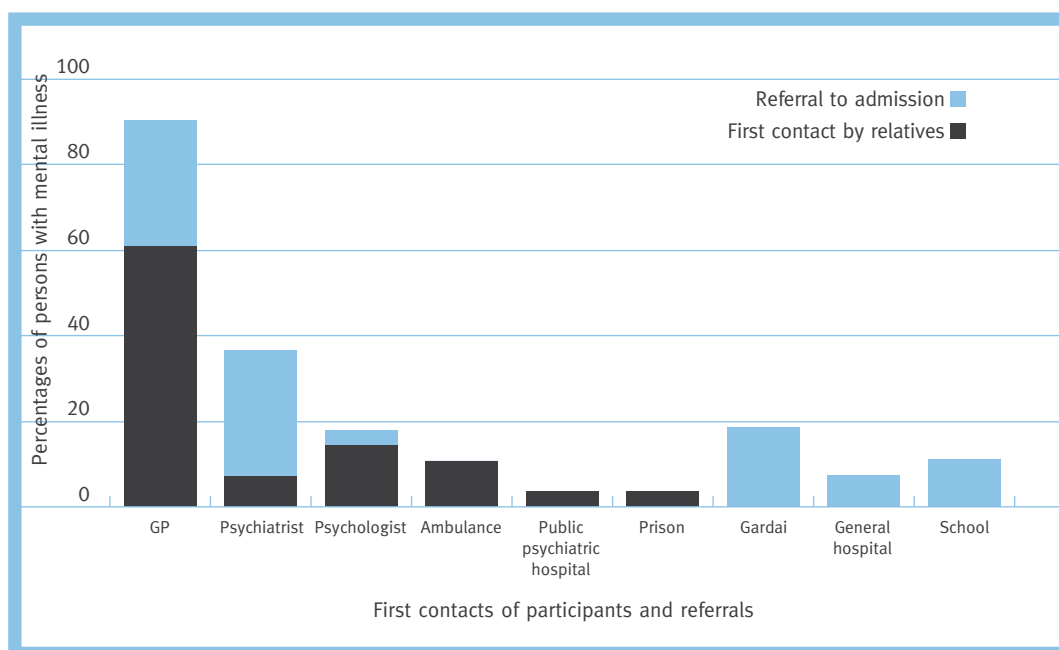
‘Well it was private you see, although he had an address in Dublin and I think he could have gone public I didn’t realize the system but he was admitted under a private psychiatrist. Now I didn’t know this for a little while and then they started talking about VHI, now I must have had some premonition because I had put him on VHI that year. Which was a complete mercy... But then when I realized that he could have gone public, you know, and I started realizing that we had cut ourselves off from the sort of support that we would have had had he been public.’

One participant commented that she found it very difficult to get help for her son on time because he was not yet sixteen at the time of his ‘breakdown’:

‘And after that I phoned the police and the ambulance and he ended up in hospital for the night. And let home the next day...Very little support to be honest, now I mean when he was taken into hospital, the first thing we knew that they had to look to the health board to get funding for it, and there was big talk about it because he was only fifteen, he wasn’t yet sixteen and do you know you need to be sixteen to go into a psychiatric hospital. And there was all kind of stuff and they didn’t want him in an adult hospital and then when the funding came through, he was to go to the hospital.’

### 5.1.6 Referrals to in-patient mental health services

Figure 5.1 shows the first contact of the participants in seeking help during the ‘breakdown’ of their relatives, and the percentages of referrals to in-patient hospitals or units made at the time of the first contact for help. As can be seen from Figure 5.1, referrals for first admissions to in-patient mental health services, as reported by study participants, were made by GPs, psychiatrists, psychologists, gardai, schools and a general hospital.



**Figure 5.1** Percentages of first contact of participants and referrals for admission to in-patient hospitals and units

### 5.1.6.1 GP as a source of referral to treatment

Out of the total of 17 persons with mental health problems, whose families turned to their GPs for help, six (35.3%) were referred by the GPs for admission to public or private hospitals. In the majority of cases (n= 11, 64.7%), when participants contacted GPs for help, this did not lead to admission of their relative to an in-patient unit or hospital.

Several participants reported that GPs either persuaded or committed their relative to go to a public or private hospital, or referred them to a psychiatrist. The experience and skills of such GPs, and their personal contact with the relatives, were highly valued by the participants:

‘So I rang a GP who I knew and told him the story and he came out and my son didn’t wish to see him at all but he then agreed, and the GP talked to him and he said “I think you need to see another doctor as well as me”, and my son said “Like who?” and he said “A psychiatrist”, and my son went berserk really... I then went to make a cup of tea and when I came back somehow the GP had persuaded him to go to up to hospital immediately.’

‘Then she went to her local GP and he was very good, I think it was probably because of the area, I think he was used to meeting people who had social, psychological, psychiatric problems, and he rang me up and said “I’m your daughter’s GP, I am concerned for her mental health”, and that was the first time we heard “mental health”, and I said “Can I come and see you?” and he said “Certainly.”’

Some parents commented that there was a lack of information, sympathy, and response from primary services during their initial encounter with the mental health problems of their relative:

‘We got no support, nobody talked us into anything and that in itself not helping the situation, by not getting the proper level of understanding and passing it onto the parents of these people... We had no sympathy, we had nobody.’

‘I feel neglected because of my ignorance, and my GP’s lack of, what’s the word, response to my call for help.’

Sympathy and personal support provided by some GPs to participants at the time of their initial encounter were highly valued, even more so than their knowledge about mental illness. One participant commented that a lot of GPs would not want to deal with the ‘hassle’ of mental illness:

‘Well I had the GP who I went to, because this GP is known to have some sympathy towards mental illness, in a way that a lot of GPs don’t, to be fair, a lot of GPs don’t want to have the hassle of somebody with mental illness. Now he would have had more sympathy, not a huge amount of knowledge, but at least he’d be somebody who wouldn’t shut the door on me, he would allow me to come in and talk about it, and he would certainly say “We’ll make an appointment for him to go and see the psychiatrist, and we do have an option that we can go to the psychiatrist.”’

Some GPs helped participants to find information about SI services:

‘GP and I then looked up the telephone directory under schizophrenia and found SI, and rang them, and then I had a counselling session with a lady there from SI which was helpful.’

### 5.1.6.2 Committals

More than half of 31 persons with mental health problems who were reported to have been admitted to in-patient units or hospitals (n=19, 61.3%), for the first time had been admitted voluntarily. More than one third of reported first admissions were non-voluntary (n=12, 38.7%).

Two participants commented that they had to ‘trick’ the person with mental health problems into being admitted to in-patient mental health services:

‘Although we tricked him in a way because the doctor told him on the phone that if he didn’t go voluntarily, he’d have to go down and see somebody, and if he didn’t he’d come and take him down. So he went with him and on the way he demanded cash, we gave him four hundred euro and he agreed to go down, but formally he voluntarily went in.’

‘The first admission was involuntary, I forced her and in fact in the car, I was driving and I pretended I was going for a drive until she realized the direction I was taking and she wanted to jump out of the car so I had to try and drive with one hand and hold the door with the other.’

Participants commented that if they could not get help from their GPs, or persuade their relatives to voluntarily go to a hospital, they had to opt for involuntary admissions:

‘I forget if his doctor ever sent him, his GP, I remember once I sent him in because we had called the doctor and the doctor had said he could do nothing, at this time he had spent two days just looking at the television with no picture, completely in a trance so we were kind of getting worried about it, so I signed him in that time.’

Two participants used counselling and advice from SI on how to deal with the relative and what steps to take in order to get help for the relative and themselves:

‘We had gone to counselling, because we were, how were we going to handle this, what way should we deal with him, and they advised us to go and see somebody in SI. So we went to SI, and met a very excellent counsellor there who spent about an hour with us and she said “There’s only one answer, he should be in hospital, he’s possibly got schizophrenia, he needs to be committed”...And then, coincidentally, he got quite aggressive, and he was threatening me, and wanted to cut himself, and we had already started to talk to our GP to see how would we get him committed, where would we put him, things like that. ‘

Information about the illness and mental health services made it psychologically easier for one participant to commit her son to hospital:

‘Basically a good humoured, gentle kind of fellow really, it’s hard to talk about it but he had his final breakdown, he tried to get at me and he was going to kill me and I got the police... and he was hospitalised then. I signed the committal form and I had no problem with that because at least you were going to have a diagnosis of some kind. ‘

One participant reported that she found it impossible to get timely professional help for both her son and herself at the stage of his ‘breakdown’. The participant had to get her son arrested in order to get some help, which negatively affected both her son and herself:

‘I went to my GP, and he was concerned but at the same time my son wouldn’t go to the doctor. And I tried to get him into public, and I tried to get him into private, and in the middle of the interview he’d go home on the bus. I knew there was something very radically wrong with him and it got progressively worse, and he broke the all the doors down, and broke all the windows, and then he started to punch me a bit... I couldn’t get him to hospital. I called doctors on call, I called GPs, I asked them to come up. I called several nights, called the Gardai. In the end I had to leave the house, I tried every avenue I could on the medical side and nobody would do anything. My family kind of didn’t help either... So in the end I had him arrested, which is a terrible guilt trip for me at the moment ... We withdrew the charges, so he hasn’t any record or anything, but he was very badly affected by it.’

Five participants commented that it had taken them a lot of hassle and arguing with the services to get some professional help for their relative:

‘So we just coped with it the best we could, and bullied them into taking her in, and that sort of thing, so it’s not ideal way to deal with a crisis in your family, that you have to argue with authorities to get some help, you know, I think there’s a huge missing bit.’

‘And finally he was admitted, after a lot of trouble and hassle he was admitted to hospital, so it was following years of problems... Probably, before his diagnosis, I would say he was probably very unwell for a good twelve months, if not longer.’

Participants felt that there was a lack of formal support for both the persons with mental health problems and their carers at the initial stage of illness:

‘I really think there is a huge lack of support services in place, at that stage, when somebody is descending into mental illness, and they are displaying the initial symptoms, when parents or other siblings of family members are trying to deal with it...I think that’s a huge missing bit when there’s a crisis like that, I think there really should be a professional service that comes in, and says like “You relax, we’ll take it”, that wasn’t there.’

‘They’re so hard to reach, they’re so hard to get a hold of when there is an emergency.’

## 5.2 The first encounter with treatment provision to a relative

According to participants, the majority of the 33 persons with mental health problems (n=31, 93.9%) had used in-patient psychiatric services at least once. Two persons with mental health problems had never used in-patient mental health services. They were living at home with participants who were SI members, and had been treated by private psychiatrists prior to and during the time of the study.

Most of the reported first admissions had been to public mental health services (n=21, 67.7%), with eight admissions to private hospitals (25.8%), and two admissions (6.5%) to the Central Mental Hospital.

### 5.2.1 Reported duration of untreated illness

All the participants were asked if they could remember how long their relative had been unwell before they got any kind of treatment or professional help. Participants provided the approximate length of time since the onset of illness until treatment for 26 relatives (78.8%) in years, months, weeks, or days, which were then recalculated in years for further analysis.

The approximate duration of untreated mental illness, as reported by participants, ranged from one day to ten years. The average number of years of reported untreated illness was 1.97 years, with the median duration being one year. Fifty per cent of relatives were reported to have been ill for at least one year before getting any professional help. There were no significant differences in the reported approximate duration of untreated illness between the SI and MHS groups of participants. No significant differences in the reported average duration of untreated illness were observed between groups of participants and their relatives by gender, diagnoses (if known), place of residence of the relative, employment status, marital status, socio-economic groups, and other socio-demographic characteristics.

There was a significant negative relationship between the average reported age at the onset of illness (17.6 years), and the average duration of untreated illness (1.97 years). Relatives who were reported to have been younger during the onset of mental health problems were also reported to have a longer period of untreated illness ( $r=-4.12$ ,  $n=26$ ,  $p = .037$ ).

### 5.2.2 Participants' first impressions of in-patient mental health services

Four participants whose relatives had first been admitted to a public psychiatric hospital commented that their first impression of the building and the staff was very low due to the 'rundown' state of the hospital:

'It is an old hospital, it's very run down and I think staff are demoralised, that's the impression I have now and it's just bad... I was so frightened of it, I wouldn't put a dog into it, from my experience of it, it was horrendous.'

'I can't see through the windows, there were dirty tissues on the floor, there were butts and cigarette ash and this is the visitors' parlour... you wouldn't put a derelict person, you wouldn't put a homeless person... into a place like that. This is not human... Totally depressing... Hospital is, not staff, the conditions are very poor... How is anyone supposed to stay healthy? The day I went to visit, two patients had absconded.'

Five participants whose relatives had been admitted to a public hospital further commented that, although their first impression of the building was not great, the staff provided excellent care to their ill relative, despite the lack of resources:

'It's a horrible place to be in and whatever, but once you're inside, the nurses are nice and they're helpful.'

'If half the hospitals in Dublin were half as good, it would be a better place to be, there's nothing wrong with it, you get a first class service there, they deserve a medal really and truly... These people are very dedicated people, I've seen them in action so I have no doubt... When I used to go up there first I was very apprehensive because I didn't know.'

A father commented that the bureaucratic side of first admission was a 'farce':

'And I was read the riot act by a doctor who was caught up between private medicine and public medicine, and instead of being hospitalised for three days, one of the days it was five minutes, it was five to midnight when he went in, that counts as one day, he was in the next day for three or four hours, it was twenty-four hours, and the following day about eight or nine hours... It was a farce. I couldn't dream of going through that again.'

Three participants commented that they had been devastated to see their relative in in-patient mental health services at the time of first admission:

'So I took him up and he was saying all the way he would see somebody there and talk with them but he wasn't staying and they saw him and they advised admission immediately and thank God he agreed to do it, and he was taken into the locked ward and he was devastated and I was devastated...'

'So I went to see him and I thought it was an awful different world altogether, he was very agitated and he was with strange people, and some of them were well and some of them were not well...'

### 5.2.3 Information and support provided to participants during the first admission

Most of the participants had been disappointed with the support provided to them and their families during the first admission of their relative. The main concerns voiced by such participants were lack of information from the doctors and nurses regarding service provision to their relative, lack of involvement of families in treatment of their relatives, lack of advice to the family on how to 'behave' with the person, lack of sympathy and 'human contact', and lack of support resources for families or information about availability and suitability of such resources.

Participants commented that they were very upset and felt disoriented about what to do and needed some personal, 'human' contact from the services. One mother commented that she felt she was becoming ill herself and should have been informed about the illness and involved in treatment from a 'health economics point of view':

'I just felt terribly in the dark, and it was a terrible, terrible time, this lack of support because I had no family support... And my argument was that I felt I was becoming mentally ill myself at the time with all I have described to you. My argument was that if I became ill or if I didn't know how to react with him in a helpful way and he became ill again and it cost the system, never mind the caring, would be far greater, you know, it was just logical from a caring point of view and from a health economics point of view that the family should be involved.'

Most of the participants whose relatives had been admitted to in-patient services commented that the information or supports were not easily available, unless they made efforts themselves to find the information:

'I went looking for it myself, I went looking for the information, because nothing was given to me, like I wasn't told about Schizophrenia Ireland.'

One participant commented that he was given some advice on the admission of his relative to a hospital, which he tried to follow from then on. However, the participant felt that it was difficult to follow all of it, as there was no community nurse available in the area:

'And he told me that any conversation with my son would put him back, and he told me you plead or bribe and treat but you don't confront, and that's what I've done... Now also you don't tell him to do anything, you wait, he's the worst person in the world to ask or get him to do anything... And this is done by the community nurse, but there's no community nurse in the area at all... He'd prefer someone to come in and talk to him but there's no one to come in and talk to him.'

All participants were anxious to get information about their relatives' treatment, diagnosis and prognosis. Six participants recalled that they had been frustrated as no information had been provided by mental health services for long periods of time following admission, and there had been no sympathy or personal contact offered to the family:

'We waited one month and could not get to see the doctor... We were so frustrated, we were going to lose this child who was so frightened, and it was a very bad time for us, and the door swung open and the doctor said to us, "What is all the fuss about, would you make such a fuss if his leg was broken?" And we said "But you can see a leg broken."... Arrogant, and no sympathy.'

'We got nothing, we heard nothing from the hospital or the professor and after a couple of months we made further enquiries.'

Participants felt that some kind of individual meeting or consultation should have been arranged at the time of the first admission, to explain to the family what was going to happen, what to expect, and what was the plan of action:

'When we went into the mental institution, we had nobody to say "Well this is what's going to happen", or "What we're doing is..." or what the plan was... Somebody to come, some qualified person that had so many years of experience of this problem, to come and arrange to talk to his mother and myself at least, if not all the family, you know. This didn't happen. This didn't happen.'

It was only after further enquiries or reading about mental illness themselves that some participants realised that it took a long time to get a diagnosis, and if a patient had been admitted voluntarily that there was a confidentiality issue which made it difficult for the services to release specific information about the illness and treatment to his or her relatives. However, as reported by some participants, this was not explained to them during the first admission, and there was little support or advice provided to the family by mental health services:

'I think psychiatrists are unwilling to diagnose schizophrenia, they say it takes about eighteen months to two years because it's seemingly an umbrella term and no two people suffer the same. So they're reluctant to put a tag on patients, perhaps rightly so. Well that was my first encounter so I didn't know what to expect and I couldn't pass any judgement at the time but I got no support whatsoever, there was no support there for carers, it wasn't suggested to me that I should go to a parents' group or anything else. I remember one nurse saying to me, describing my daughter, "She's a time bomb waiting to go off..." Now I knew she was, but for a nurse to say this to a parent and offer no support...'

'Our experience with the public health system was very good, but the difference was he was committed and therefore they were able to talk to us. In other words if in this country a person is committed they're no longer responsible and therefore the doctors are responsible and the doctors can do whatever is necessary...So that's why this time when he went back voluntarily, we had very little contact with the doctors.'

Five participants commented that, although there was not much support offered to them from services, the nurses were very helpful and provided some information to relatives:

'Not a lot from services, what I had to find I had to do it myself, now her psychiatrist was excellent and she had a very good relationship with him. But in the hospital you know if you want, some nurses were very good and they would tell you the information.'

Participants spoke highly of services where they had been informed about their relatives' medication and care:

'I was kept abreast of her medication, and what they were doing. Her psychiatrist said to me, I thought this was great, she said she wouldn't stop looking for some form of medication that would give her some quality of life. To hear that, it was fantastic, because it gave me hope, and I knew her psychiatrist and her team were interested in giving her some quality of life, so that was great... If they were changing her medication they'd let me know, they also told me the side-effects of particular medication and so on.'

#### 5.2.4 Confidentiality issues

Seven participants perceived the issue of confidentiality of information about the illness and treatment of persons with mental health problems as 'difficult' for them as carers:

'I think this issue of confidentiality is very, very difficult. I can understand where they're coming from, I could tell they were always holding back from me, giving me the information that I felt I needed because



they felt it was being disloyal to my son and I think this is a difficult problem as to how much, because for me I just needed everything I could get to understand this and to know what to do.'

Seven participants had anticipated during the first admission that they were going to be the main carers of their children after their discharge from the hospital, and therefore they had the right to know how to provide the best care and contribute to treatment of their child, and how not to interfere with the treatment:

'I was immediately told he is an adult, his responsibility, nothing to do with you. And I couldn't credit it, it was basically, you know, go away because we're teaching him how to become responsible, which is perfectly in order, and he had to learn how to cope himself, but my point from the very beginning was that he was going to return to his home, and this was going to be his main place of support, and I needed to know what was going on and I needed to know the best way of helping.'

The need for redefining of their caring role after the experiences with the first psychotic episode emerged from three participants of the study. They felt that their knowledge of how to care for their relative had not been sufficient anymore and that they needed some advice on how to 'behave' with persons with mental health problems:

'When he was psychotic the things he had said to me destroyed the way I felt about caring for somebody, you see. I didn't know what to do now, I didn't know how much to be there and how much not to be there, and how much to offer and how much not to offer, and how much to do for him and how much not to do for him.'

### 5.2.5 Information about diagnosis

Participants felt that information about the diagnosis was very important because it made them readjust their expectations about the future and accept illness:

'Just to tell me what to expect because unless you know something about it you don't know what questions to ask.'

In cases when diagnosis of schizophrenia had been provided, the participants were advised by some mental health services not to expect too much in the future, or that the person with mental health problems 'may never leave the hospital again':

'They did diagnose schizophrenia, two of them told us that he was not harm to himself and to others, and that generally speaking not to expect too much and have no expectations.'

'We went to the psychiatrist in the clinic... and he said he may never leave the hospital again. And of course we were totally shattered as you can imagine.'

In several cases participants were not given information about the diagnosis from in-patient services and learnt about it from other sources.

'Fortunately the psychotherapist had mentioned the word, so immediately we wanted to know something about schizophrenia... We weren't given the diagnosis, now we were fortunate that we'd been told "schizophrenia" by the psychotherapist'.

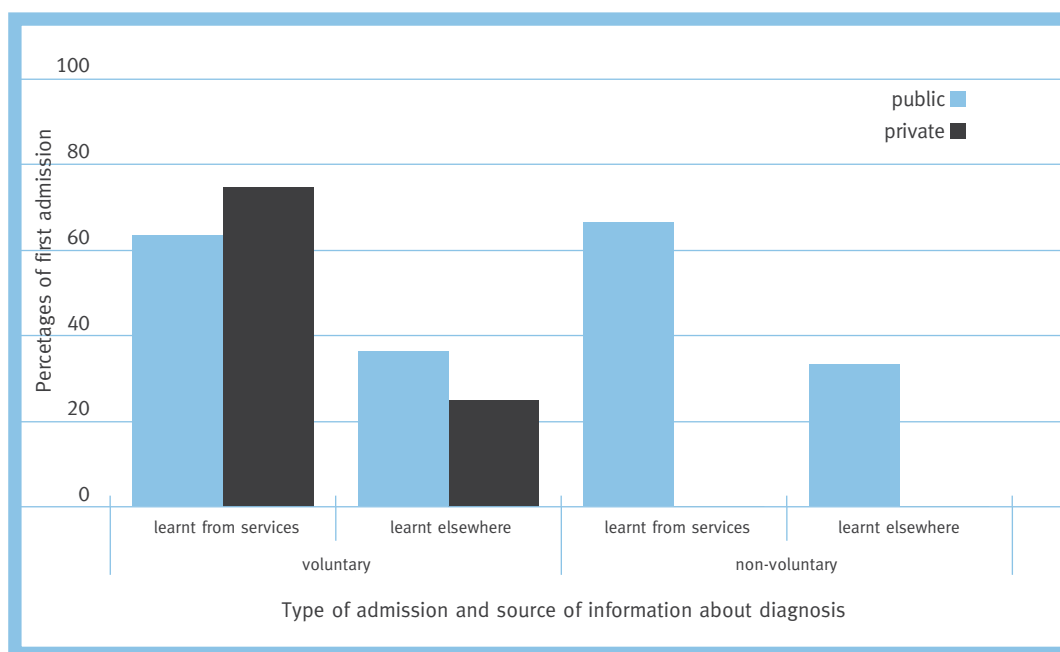
Three participants learned about the illness and medication from the person with mental illness themselves, rather than from the mental health services:

‘But my daughter is also very good herself, she’s very open and she asks questions, so I learnt a lot from her, she would tell me the medication she was on and then I would try and find out about it.’

‘We actually haven’t been given a diagnosis yet and this is seven years down the line... He actually saw it on his chart and he said to me “Have I got schizophrenia?” So this is how we found out.’

In the majority of the 33 cases (n=24, 72.7%), participants learnt the diagnosis of their relative from mental health services (in-patient or private psychiatrists). In three cases (9.1%) the persons with mental health problem told their relatives about the diagnosis themselves, in two cases (6.1%) participants first heard the diagnosis from their GP, in one case (3.0%) from their relative’s social worker. In two cases (6.1%) participants had read about the illness and made conclusions about the diagnosis themselves, and in one case (3.0%) diagnosis had not yet been given to the family, despite the fact that the person had been using in-patient mental health services for seven years.

Of 21 persons with mental health problems whose family members had learned the diagnosis from in-patient services, 13 (61.9%) had been admitted voluntarily, and eight (38.1%) non-voluntarily. In cases of non-voluntary admission to public hospitals, in-patient services had informed the relatives about the diagnosis of service users. In the 13 cases of voluntary admission, the relatives were also informed about the diagnosis by in-patient mental health services (see Figure 5.2).



**Figure 5.2** Percentages of first admissions to in-patient services, by type of admission and by source of information about diagnosis, as reported by the participants of the study

As can be seen from Figure 5.2, there was no clear relationships between either the type of admission (voluntary or non-voluntary), or the type of in-patient services (private or public), and provision of information about the diagnosis to the participants.

### 5.2.5.1 Manner of getting information about diagnosis

Though all the participants commented that they had been anxious to know what was going on with their relative, getting the diagnosis of schizophrenia from mental health services had been associated with a shock, 'blow', and traumatic reactions:

'The reality of having to face up to this, that she had schizophrenia, it was like a death.'

'And I was obviously gob smacked, you can imagine what it was like, and my husband wouldn't take it on board, he didn't want to know, he said the psychiatrists don't know what they're talking about.'

Four participants commented that the information about diagnosis had been delivered to them in an inappropriate way. Two of the participants felt that the information about the diagnosis should not have been given on the phone:

'He rang out of the blue, I was in the middle of working... And I couldn't even get privacy, and I was on a mobile phone and the line was bad and I just thought it could have been handled better.... Apart from the way the diagnosis was handled, I found him quite good, easy to talk to, very approachable, an absolute lovely man, but it was just the way the diagnosis was handled, and then no follow up.'

'He was seen by the psychiatrist, I remember that day, and I said "What did the psychiatrist say?", "Oh, he said I have schizophrenia, mild schizophrenia, what's that?" So I got an awful shock, I had heard of schizophrenia... He said "He's ringing you this evening." So the psychiatrist rang me at home and said "Well, I told your son he has mild schizophrenia, and of course there's no such thing as mild schizophrenia." I didn't like his attitude, and I felt it was very inappropriate that he should discuss it over the phone.'

Two participants commented that a gradual build up of information from mental health services about the process of arriving at a diagnosis might be helpful for a relative in order to prepare oneself for the diagnosis, as well as personal contact and support from the services at the time of getting the diagnosis:

'I think we should have had a gradual build up to it, have been kept informed for those 12 days so that it wouldn't have come as such a bombshell, I could have prepared myself, if he had said to me on the Wednesday, "Look I will ring you on Friday, I may have some unpleasant news for you", I could have geared myself for that, I could have asked off work for an hour to come home, you know... Looking back on that if they had kept us in contact every few days, if they could have said "We're doing this and it's building up to this or the signs are that..."'

'Now maybe if I had been told this at the beginning it would have shocked me to death whereas I was led into it gradually and I just sat into it. But I feel in the beginning that people shouldn't operate this type of illness or where it could go on their own without families being able to communicate or people being able to ring up and say "Well, what's happening today..."'

Participants felt that there should have been some kind of individual appointment made for the family in order to explain about the illness and its consequences for the family, and practical advice on how to deal with specific situations:

'And once I was given the diagnosis then I was just basically told, "That's it, this was the diagnosis, and we're going to try different medications, and see how we go along, and stabilise him", and that was it, really I think what would have helped was some support from the hospital when the diagnosis was given, if the doctor had said "Look we have somebody here in the hospital whom you can make an appointment to see, and they will explain to you about the illness, what will I do, how it might affect the relatives and the rest of your family." I think that would have been a fantastic help, well somebody within the environment,

public or private, to enlighten the family, and maybe say “This is the research, this is what to expect, this is how you can help, this is how to deal with particular situations, or try to deal with them.”

Three mothers noted that they had received a lot of written information about schizophrenia, and it was too ‘drastic’, and upset them even more because of the stigma associated with the word ‘schizophrenia’. The importance of personal contact and moral support was highlighted by these mothers:

‘Yes, they did give me information about schizophrenia and all that, and the different types of schizophrenia, you read about it and all, it’s so drastic, you know what I mean, I think there is a stigma there, you know, there is... Like it’s just ... a mental illness, it’s not anything different than depression to me, you know. Very bad depression to me you know.’

‘Even if they had a booklet, well I did get booklets, but still maybe a booklet and then to come and talk to somebody. That would be helpful.’

Three participants felt that counselling for carers, or even for the whole family, would have been helpful at the stage of learning the diagnosis:

‘I mean when you get a diagnosis that is so serious, you are so devastated, well I certainly was, you can’t think straight, and you are trying to muddle through and cope with this diagnosis that you’ve been given, and that’s why I come back to the fact that if there was somebody there who could explain something to you, give you the information all the time, at the beginning, and say there is, you know, a support network here, to help you and the family, not just the person with mental illness, I think this would be a tremendous help’.

‘I think straight away there should have been family counselling, if a counsellor came into the house and we all sat down and had counselling, I think that was the need, straight away, in the beginning, I think it would have been extremely helpful.’

Three participants commented that they attended an ‘information course’ for parents, offered by the mental health services in their catchment area, and found it helpful:

‘Well there was an information course going that they ran, and we did attend it, my husband and I did attend, for parents.’

### **5.2.6 Participants’ perceptions of private versus public services at the time of their first encounter with treatment provision**

Of the total eight participants whose relatives had been first admitted to a private hospital, five also had later experiences with public mental health services.

Of eight participants whose relatives had been first admitted to a private hospital, six felt that they had not been properly informed about their relatives’ treatment because they were using private as opposed to public services:

‘It was this great sense of “If he’d been under 18...” Because he was a private patient there wasn’t the structure to help me’.

Two participants commented that private services were run like a business, or a hotel, where neither the patients nor their relatives were provided enough individual attention and care:

‘So my experience of the private mental health services in this country is not good. My daughter I’m sure would have benefited greatly from a much earlier intervention, and I certainly wouldn’t have had to bring her up to the private health, which was a disaster. They just drugged her, she was lying on the bed drugged most of the day, and her condition deteriorated, and they had her on twelve tablets at one stage, different medications, it was an incredible mix of tablets... Very little, very little, and that’s my first encounter. Pleasant people, but it’s like a hotel, I mean it’s really like a hotel up there.’

‘On his first admission, I went in very regular, every day, if not every second day, and I felt it was run like a business, I didn’t feel that there was anybody that I could, any particular nurse or anybody that I struck up a relationship with, that I could phone and say how I felt.’

**Seven participants felt that there was more support provided to both the families and the persons with mental health problems by the public sector than by the private.**

‘I think had I been a public patient I might have got more support. I think that the psychiatric nurse comes to your home and I think there are meetings in the hospital when I think the parents, the family, can be involved. Now I’m not entirely sure what the situation is now but at the time I kept saying I need this, I need that, and they said oh well because you’re private, you know... I did manage to talk with the social worker for that period... but I think she was feeling that this was kind of a favour on her part, it wasn’t really her role to talk to me as I was a mother of a private patient.’

**One participant commented that, although there seemed to be slightly more support for families from public mental health services, there was still not enough offered for families in either sector:**

‘That’s where we became in touch with the services, before that we were doing our own thing, I’m talking about seeing the doctor privately, there was no back up services there at all. So if we had gone into the system probably earlier I think it would have been better for everybody because maybe the system would have better services and better support. Now we’re learning that there isn’t much of a difference... I was brought into a room and there were about twelve people there and I was asked to explain about my son and I wasn’t expecting that really.’

**The main problem of the public services, as reported by the participants whose relatives had been admitted to public hospitals, was the change of registrars, which could negatively affect treatment of persons with mental health problems:**

‘The unfortunate part about that was, she started off and bonded with the person she was put in charge and then they had to move on, because every six months they had to change. And then she had to start off again and build up a relationship with the next person and they moved on, so each time it was very difficult.’

‘I’m trying to think which psychiatrist, because they used to change them so much, they’d change them nearly every six months.’

**Two persons with mental health problems who had never been admitted to in-patient services had been attending private psychiatrists. Participants commented that they were ‘shut out’ of the treatment of their relative and were not given any information other than diagnosis and medication. They had not been given any advice about how to ‘approach’ the relative, or where to find support for themselves:**

‘And she has stayed with him and that’s not to say that he wasn’t good, he prescribed medication and he did say psychotic episodes, schizophrenic tendencies, spoke to me on the first day, but told me he didn’t want to see me again because she was an adult and it was up to her to take control of her illness... His job was to deal with her only, and my job was to make her go to him, so that was it. This is purely a chemical

imbalance, there is only one thing for her and that is these tablets to bring up the dopamine levels... And there is no other way that she could be helped, end of story, and that was it.'

'There was no such thing as co-operation between the family and him. He was the boss, and no discussion about anything.'

One participant reported that the person stopped taking the tablets and started to disappear from the house. The psychiatrist did not offer any advice on how to deal with the situation, other than to make the relative take medication:

'But I rang him and told him, and he did say to me that he did notice recently, he knew that she hadn't been taking her full dose... But he thought that there was a new tablet not that might help and when she came back to encourage her to come to him, but I did and she hasn't gone in, she said she didn't need tablets.'

## 5.3 Discharge

Participants of the study provided information about the discharge of 29 of 33 (87.9%) relatives after the first admission. Two relatives had never been admitted to in-patient mental health services, were living at home with participants and had been using the services of private psychiatrists. In the other two cases the relatives were not sure where or when the person had been first discharged.

### 5.3.1 Place of discharge

The majority of the 29 service users who first used in-patient services (n=22, 75.9%) had been discharged home to their relatives after the first admission. Five persons had been discharged to an independent accommodation, and two had been discharged to community residencies.

The percentages of the 22 persons who had been discharged home after the first admission were roughly equal between those who had been first admitted to the public in-patient services (n=17, 77.3%), and private in-patient services (n=5, 71.4%). Two persons who had been discharged to community residencies had been first admitted to public in-patient services.

### 5.3.2 Information on discharge

All the participants whose relatives had been discharged home from in-patient services commented that there had not been enough information provided to them on discharge of their relative. The participants either received a telephone call a day or two prior to discharge to be informed that their relative was going home, or got the information from services while they were visiting their relative in a hospital or unit:

'He was discharged back to me, into my care. It was by phone. I was out of the country when he was discharged. He went to his grandfather's.'

'Absolutely nothing, no information was given to me or his mother... They called me and they would say "He's being discharged this evening at five o'clock."'

In two cases in-patient services did not advise participants that persons with mental health problems had been discharged:

‘Well we used to go up every night to see her, at least five times a week if not seven, and I said to my wife “She’s going to be in here a while, she’s not well at all”, and the next morning the door bell rang and there my daughter was at the door, the hospital never even phoned to say she was being discharged or anything, and we had no contact with the hospital whatsoever.’

‘Well actually he was discharged and they didn’t tell me or my GP... And in fact he disappeared for a day or two, and my son’s friend...found out where he was living, he had got a bed-sitter... So my husband and I were very upset and we knew that he wouldn’t come home because he thought we were an enemy, especially me because I had committed him, I suppose that’s why, I’m not absolutely sure.’

In two cases, persons with mental health problems insisted on going home themselves, though the services had not planned to discharge them yet:

‘She told me “I have to come home”, so I brought her, lock, stock, and barrel.’

‘I thought there was a better way of breaking the news to me, it was a bombshell, and especially at work, but he said to me that my son had more or less put the gun to his head and said “Look, I’m going, contact my parents and I’m going...” So the psychiatrist maintained that he had no other option, they had to ring me at work or else my son was going to walk.’

### 5.3.3 Discharge from private in-patient services

Two participants whose relatives had used private in-patient services commented that their relatives had been discharged when they had still been unwell at time when their VHI or BUPA insurance coverage was over. They reported that no further arrangements for continuing treatment had been made by private services:

‘But the problem with the private sector is that they know well in advance, particularly with VHI, when the VHI is going to finish, and I think that they should make arrangements when somebody has a serious psychiatric condition, to get you into the public services, but that didn’t happen... Yea, he was just discharged home, with no support, no help, no suggestions, and he was extremely ill.’

‘She would be sent home, just in the middle of treatment, and no apologies... her money had run out... And at this stage she was hearing voices and was quite distracted, and she couldn’t function, and her poor little son was trying to talk to her, but she wasn’t with any of us, she was sitting in some other place, listening to these voices who were telling her she was worthless and she should kill herself... and all this kind of thing.’

### 5.3.4 Advice provided by mental health services on discharge

The advice that most of the participants got from the services on discharge of their relative into their care included to make sure that service users took their medication, to contact services when something ‘went wrong’, to encourage their relatives to go for out-patient treatment, and to contact SI. The participants felt that they should have been given advice on how to provide better care for the relative at home.

‘Just to make sure he takes medication and he’ll never be in there again.’

‘Very little, I would say no advice in regard to whether you discuss the psychosis or you disregard it, whether you talk to him naturally and as normal as you always had... The only real advice we were given, to bring him back to the health centres, you know, to follow his appointments.’

All participants of the study whose relatives had been discharged to their homes commented that, though they had received some information on medication and treatment of their relative, it had not been sufficient for them to provide care for their relative at home. They needed some practical advice on how to handle difficult situations and crises, how to communicate with their relative, and what to do in case of emergency.

‘Well advice on his every day ordinary living.’

‘Well it would have been helpful to know what to expect, or how to deal with situations, or maybe relatives should give a list of situations that they find themselves in and they could be answered maybe just like as samples. Maybe just the effect of some situations and just to deal them... It would be a little bit helpful, you know, when she’s in the house with the rest of the family’.

Most of the participants commented that they had to ask for information and advice themselves; it was not forthcoming from the services:

‘I had to ask all the questions. I had to ask you know what was the long-term prognosis, what exactly would we do, how do we handle him, were we to be firm, were we to give in at certain points, were we to be sympathetic... I thought, like is he going to be a danger to himself or to us, everything, I had to ask everything... I found the whole thing very pessimistic and the only advice he gave us was to join SI and that was it.’

### 5.3.5 Lack of contact with mental health services on discharge

Two participants commented that they had not been given any emergency contact details with mental health services on discharge of their relatives to their care. SI was the only contact available to the participants:

‘We weren’t given any contact details.’

‘I mean at the time when I got most worried I rang SI and they referred me back to the last doctor in hospital and there was no way I could even get in contact with him.’

### 5.3.6 Follow-up from mental health services on discharge

Participants felt that there should have been more ‘follow-up’ from the services after the discharge of their relative on an on-going basis, and not only in cases of emergency:

‘Well on discharge you’d like to know that there was more, the system was going to contact him again, that it wasn’t just going to, if we hadn’t have gone near them they wouldn’t go near us... I think that’s what it amounts to for most people, it’s a fire brigade sort of job, unless the fire is on...’

‘I think if we had had a contact maybe every two, three, four days, something like that.’

One participant commented that the social worker refused to deal with the relative:

‘And the psychiatric social worker more or less refused to deal with my daughter because she wouldn’t obey, but I said “Sure if she was obeying she wouldn’t need you, it’s the nature of illness”... She had no empathy whatsoever with us.’



One participant commented that for a while after her discharge her daughter had seen a psychologist, but the mental health services could not get funding for either a psychologist or a social worker later.

'She had a psychologist at that time, she lost him afterwards as they couldn't afford to pay a psychologist, couldn't get funding for it, and the social worker...'

### 5.3.7 Perceived lack of suitable accommodation for relatives on discharge

Three participants expressed an opinion that their relatives should not have stayed with the family on discharge, because of negative effects on both the family and on themselves. They felt that it was very difficult for persons with mental health problems to recover in the same situation where they had been at the time of their admission to in-patient services:

'Somebody with schizophrenia would agree that living at home with close relatives is not in their best interest, that they have to really live more independently, where they'll get a more genuine reaction. I mean they can't come to terms with their illness in a sheltered environment, like at home with their close relatives. And the only way they'll adjust to society is by taking responsibility for living on their own.'

'Everybody has agreed that we move him not to come back to our house, he needs to be by himself, so we're trying to organize that from the hospital, get accommodation.'

Two participants commented that, though the hospital had referred their relatives to a hostel on discharge, they had been sent home to wait for a place in the hostel. One participant reported that she had been unwell herself at the time of her son's discharge, and experienced 'emotional manipulation' on the part of the services so that they could discharge him home while he was waiting for a place in the hostel:

'...and this was the point in which I myself would have been seen as having a break down... and yet the approach of the registrar, "Do you not love your son?" An emotional manipulation definitely was used, which is totally and absolutely unacceptable because you need to be in the whole of your health, you know, not to be hit, and I was emotionally vulnerable... I refused to take my son home, because I wasn't well, it was a sheer physical impossibility, so, the gap between hospital and hostel...'

Two participants commented that there was a need for an 'in-between', 'half-way house' where the person with mental health problems could stay with some support or supervision after discharge, prior to independent or sheltered living:

'It's great closing hospitals, great idea to close these big mental hospitals but there must be something else, there must be an in-between, where he could maybe go, not locked up, a facility where they'd be supervised by a doctor or nurse, but the doctor said to me 'give us a shout if anything goes wrong', and we are the doctor and the nurse on 158 a week.'

'If he had gone gradually from hospital to the higher support, but there was no higher support hostel... And so they weren't equipped to actually deal with him... So he went from hospital to... low support which was a massive, too big a jump... because he'd missed out on school, all the emotional places around, you know, finding his feet, he was in too deep water, so he needed a shallower pool to jump out into.'

In two cases, in-patient services had arranged for a person with mental health problems to stay in independent accommodation on discharge, but eventually they moved back to their parents due to the perceived lack of support or suitable accommodation:

'...he rented a bed-sit... And he got terribly lonely and we said well you better come home for a short while until you get sorted out. So he came back home but he stayed indefinitely then.'

'At that time there was a very good psychiatric nurse and social worker, and they tried to find somewhere for them... and eventually they got some sort of little flat... and we got rental allowance from social welfare... And she got somebody else in who took a complete advantage of her... I was taking their advice that it's better for her to be independent, so we tried to get another flat... and then it became too expensive to rent anywhere that wasn't a hovel... At this stage the rest of my family had moved out, so I said well why have her living in a hovel and I have empty rooms... So she came back home, and she's still home, and that's a good few years now.'

## 5.4 Relapse

All the participants informed the researcher that their relatives had several relapses of mental health problems. Participants provided specific information on the relapse of 19 (57.6%) persons with mental health problems.

The themes associated with the first relapse, emerging from the participants, were very similar to the ones associated with the initial encounter, namely, stress due to study or work difficulties, difficulties of social interaction, pressures of relocation, or family arguments:

'We were moving to a house, and I honestly think the pressure of that, anything like that would bring it on... So from that on, on and off every third or fourth year he would have a breakdown and go to hospital.'

'She'd always have a cut off point usually which wasn't very long, and after that she'd you know usually spiral into depression or whatever... Like she started a course and she left because she couldn't stand the teacher, she couldn't stand the people on the course...And that's why she left her work, she couldn't get on with people, as I said before like she doesn't have social skills.'

Some of the persons with mental health problems resorted to drugs or alcohol again during their relapse:

'This was a complete breakdown and again what was happening was he'd gone back on cannabis, and as soon as he hadn't got it available, he came down off it with an extremely psychotic episode... '

Participants felt that they needed more support from the mental health services at the time of relapse, both in terms of advice and action. They needed an approachable contact in case of emergency or reappearance of the signs of illness of their relative:

'I'd love to have somebody to keep an eye on her but I don't know who to approach, who's approachable...'

### 5.4.1 Stopping to take medication

According to participants, at least five relatives stopped taking their medication prior to their first relapse, despite their families' 'cueing' to take their medication.

'We bought him an apartment two years later, probably too soon... Because he stopped his medication this year, he had started saying "Ah I feel grand I'm going to drop my medication", and he did and he'd another breakdown.'

In some cases the reason for stopping medication was the side-effects:

'And he went the first time and got the injection, but he didn't get the second one, and after about four weeks he couldn't study, he thought he could get through this without the medication... But medication was

making him sleep twelve hours a day so it was hard for him to study... And of course he got very frustrated and he was getting aggressive because the medication had gone out of the system.'

'One of the side effects of these tablets was putting on weight. So then we had the extremes of eating to beat the band and then not eating at all, so there was that swing also.'

#### 5.4.2 Perceived suicidal intentions and suicide attempts during relapse

In two cases participants had suspected that their relative might have had suicidal intentions at the time of relapse, but got no 'action' from the services:

'I went to turn the mattress, underneath were packets of paracetamol...I said to the consultant, "I am afraid of suicide..." and he said, "Well, you know the statistics." And I said to him, "I have no business being here. All my son is, he is statistics to you, and he is my lovely son!"'

In four cases, relapse was associated with a suicide attempt by the person with mental health problems:

'I got a phone call from a hospital to say that he'd been involved in an accident with a train... but they thought that he jumped, so he went into hospital then.'

In two cases, suicide attempts were associated with the 'shock' of learning some information about their illness from services. One mother recalled that her son's registrar passed over to her son the opinion he had on his illness:

'But this particular registrar I think he meant well, he was just new and he didn't realise the confidentiality situation, and so it destroyed my son's confidence and the next thing we knew the hospital rang to say he'd made a serious suicide attempt and he had taken a hundred aspirins... and he was admitted to hospital and he had liver and kidney damage so he was a patient there for a while'.

In the second case the person with mental health problems had attempted suicide after he tried to get a job as part of his rehabilitation program, and learnt the opinion of his consultant that he would not be a success due to his illness:

'The tutor said, "We would like to help you, it would help your rehabilitation. But... you must have a letter from your consultant, we will send you out a form". They sent him a form, enclosed was a self-addressed envelope for the consultant to put the medical report. The consultant gave the medical report, and handed it back to him, where it was written in block letters, "This boy will never be a success, he is paranoid schizophrenic". He was to get medication that day in the centre, he didn't appear, they rang me, he came home shaking... and he was frantic, waving the letter, "I have no life, I am finished for life"... later he was taken out of a river... He was brought back to hospital... There was a meeting held, and we were looking for a change of consultant, and they wouldn't agree... '

#### 5.4.3 Re-admission to in-patient services

Of 19 cases of the first relapse of their relative recalled by the participants, 18 (94.7%) had been re-admitted to in-patient mental health services. Twelve re-admissions (66.7%) had been voluntary, and three (16.7%) had been non-voluntary. In three cases participants were not sure whether the re-admission had been voluntary or non-voluntary.

'... and we said "You have two choices, the hard way or the soft way"...and in the end... he went voluntarily to hospital. He knew there was something wrong and he knew he should do something about it, but the hospital is too comfortable, it's like being in a hotel. I think he is in danger of becoming institutionalised.'

'And my husband had to commit him, we were both together and I said it's your turn to commit him now, it's your turn to sign... And my husband was in floods of tears and I was just stoned, we met a few extra Gardai we hadn't met before, now we know them all.'

#### 5.4.4 Perceived barriers to accessing in-patient services during re-admission

Three participants commented that it was difficult to re-admit their relatives during their first relapse, because of either a lack of beds on a weekday, or a lack of services offered during week-ends or holidays:

'He wanted to go to the hospital, it was a Saturday night, he was really trying and he said "I am deeply depressed"...They were annoyed he didn't come through the Team, the Team are only there Monday to Friday... He was not seen till the Friday week by anyone, no phone call... We phoned, they would make an appointment, and they would cancel, and he said he was suicidal...'

In two cases, the persons with mental illness had to be re-admitted to public hospitals as they had no 'credits' left for private admission:

'...and he was discharged after a period, after the VHI period of time, and he came home to me... And he was only home a week when he was extremely ill... and then I had to contact my local mental health board, through a friend of mine, and I had to take him to a health centre, and he saw a psychiatrist there and he said he would have to admit him to a public hospital.'

One participant managed to re-admit his daughter to a private hospital after her second 'breakdown', though he found it difficult due to the 'lack of credits' on her insurance cover:

'...I had to ring the private hospital again, I hadn't factored public yet, and got to a doctor who said to me "I'm looking at her file here on the computer, and she has no credits." I said "Are you a doctor or an accountant?" He said "I'm a doctor", so I said "Let's talk f\*\*\*ing medicine, my daughter is in a critical condition, and we've a real crisis here, and she'd been a customer, if that's what you call her, for the last year..." So I demanded they take her back in.'

One participant found it difficult to get her daughter voluntarily re-admitted to a psychiatric unit of a general hospital at the time of relapse:

'She had never been sectioned... We had to wait in the emergency section for nine hours. And she was getting worse and worse and I told the security guy, I said "My daughter is completely paranoid, she has schizophrenia" ..."You'll have to wait, madam..." I mean how can a guy look after a hospital and not realise that she was sick and she shouldn't even have been waiting there? I went to the nurse and I said "Look, this is getting out of hand, I've been sitting here for nine hours, my daughter suffers from schizophrenia and she's getting very, very angry, and I'm afraid she might hurt herself or somebody else." And the nurse said "Oh God she shouldn't be waiting here..." So she rang a psychiatrist and the psychiatrist came down and she said "She'll be all right, we'll take her in, we'll find her a bed..." Anyway, I rang the next day and I asked her did they bring her out straight away, "No," she said, "I fell asleep on a bench and I was brought up in the morning."

#### 5.4.5 Perceived quality of services of the Central Mental Hospital

Three participants whose relatives had used the in-patient services of the Central Mental Hospital were very satisfied with the quality of care provided to their relatives and to themselves:

‘They were excellent, they were absolutely superb. They were really super, and he responded very well to the treatment and they moved him to hospital. And somewhere along the line somebody suggested he should live in a flat, and I went along with that, and he went into a bed-sitter.’

‘The support in the Central Mental Hospital is tremendous. It is absolutely excellent and the social worker there, any problems just pick up the phone and you can talk to her... I think when a patient is admitted parents or relatives should be given information, and I think that patients should be given written information, not verbal information. I find now you can tell my son something, but because he’s unwell you don’t know what he’s taken on board. Whereas if you give them something in writing and they leave it in their room, it’s there and they can pick it up or put it down or whatever...I brought it up in the Central Mental Hospital, I said that I felt that written information should be given to all patients.’

One participant commented that his daughter had ‘turned the corner’ in the Central Mental Hospital, and that he was very satisfied that she was getting a ‘continuity of care’ that she had not got from private services.

‘She spent a year there, now it was an appalling place I have to say, I was quite depressed myself going in to it... But I have to say the staff in it were brilliant, and the regime was just what she needed, it was very rigid and she had to go to bed, and they had a strict regime about sleep, when you ate, now I know it institutionalised her a lot, but she needed that, she needed the continuity of treatment that she wasn’t getting from the private service. She got a continuous year of monitoring, counselling, and treatment, and it made a huge difference, she turned the corner in there.’

The participant had ‘the height of praise’ for the staff of the Central Mental Hospital and the public mental health services in general after his daughter’s ‘improvement:

‘I have the height of praise for the staff working in those awful, awful old buildings and conditions. I don’t know how they’re not all having break-downs themselves because they’re dreadful conditions to work in, and they’re so willing to engage with the patients. I mean I don’t think I ever saw staff being curt or rude or less than fully engaged with the patients, I have to say I have great admiration for the staff ... my daughter anyway improved to the point where she is now... She was actually helping the nurses with the other patients, it got to the stage where she was nearly a counsellor herself.’

#### 5.4.6 The vicious circle

Two mothers felt that there was the same pattern, or ‘vicious circle’ of relapse and re-admission of their relative, where ‘gaps’ in the services were contributing to the burden on the family:

‘On higher doses, back into the same hospital... Back to follow the same pattern... At this stage, you know, mother is on the war path. How do you break this up, this is a cycle... can you not see the patterning in this? And nobody is seeing, nobody is having a bird’s eye view, so I sit down and say to myself what is this about? Does it mean he’ll be in high support forever? Is there a high support hostel for people over twenty five? ...and you see, during each gap, this is where the whole burden comes back on the family, and there is no support...’

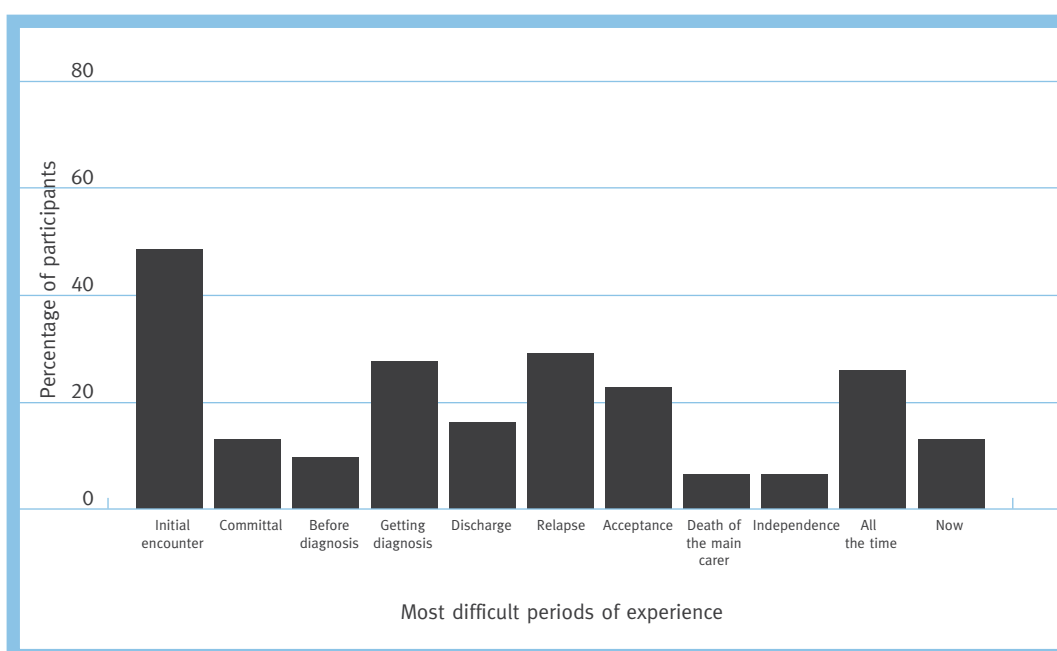
‘Anyway, it’s just a vicious circle, the whole thing goes round and round, and I find it hard to see a way out of it...’

## 5.5 Perceived most difficult periods of experience with mental illness in the family

Thirty one relatives (81.6%) provided feedback to the question about their most difficult periods of experience with mental illness in the family (see Question 9, Appendix 6). Most difficult stages, or periods of experience, emerging from the participants, were the initial encounter (n=15, 48.4%), the involuntary admission (n=4, 12.9%), between admission and diagnosis (n=3, 9.7%), getting the diagnosis (n=7, 22.6%), discharge (n=5, 16.1%), relapse (n=9, 29.0%) and accepting the illness of their relative (n=7, 12.5%) (see Figure 5.3).

Additional stages of the experience of participants with mental illness, elicited from participants by the question about the most difficult periods of their experiences, and not presented in previous sections, will be covered in the following sections of this chapter.

As can be seen from Figure 5.3, nearly half of the participants (n=15, 48.4%) mentioned that the 'beginning', or the initial encounter, including the first contact with treatment provision, had been one of the most difficult stages of their experience, followed by relapse.



**Figure 5.3** Percentages of reported most difficult stages of experiences of participants with mental health problems in the family

### 5.5.1 Acceptance of mental health problems of a relative

The theme of acceptance of the illness and its consequences for the relative and for the family was associated with learning the diagnosis and getting information about the illness. Participants who had learned the diagnosis sooner found it somewhat easier to accept the illness:

'I think the most difficult period was the period up until we got the diagnosis, the first sixteen months...We just didn't know what to do or how to cope... at least now we're starting to be able to put it in some kind of context.'

Three participants commented that it was the support of SI that helped them to better understand the illness and cope with it:

'I was trying to find what to do and I decided to go to SI and I entered this building and I just broke down really, and they took me in to talk with someone and I was able to pour all of this out for the first time... So they were absolutely fantastic, SI, that they were there, they could straight away help me. Now the person whom I saw offered me the eight stage courses for relatives of those suffering from the mental illness. So I took it and it was the making of me really because it enabled an understanding of where my son was at, where I was in relation to him, and it just started me on the road and it stood me in good stead ever since.'

### 5.5.2 Ongoing 'strain' of enduring mental illness

Eight (25.8%) participants mentioned that it was difficult for them 'to find the most difficult' period of their experience, and that it was difficult all the time. The ongoing strain of illness was reported as the most difficult thing in their experience:

'I don't think there was a particular point. It's pretty much going on for five years, but no, there's no particular point that's been hard going, the whole time.'

'Well the most dramatic ones were obviously the breakdowns... But you recover from that, I think the on-going strain, buying property, and the slog every day, and the strain when he was fighting with neighbours and that kind of thing, I found it very difficult.'

One participant mentioned that she learnt only later that she had experienced depression as a part of 'ongoing strain' of illness in the family:

'There were lots of things, life became extremely slow and I got what is known as depression... And I went to the GP about it, and she said a few years later, "You have had depression, this is now recovery." And I did sort of think "Poor me, depression", but I got over that.'

### 5.5.3 Death of the main carer

Two participants (6.5%) who were siblings of persons with mental illness commented that their most difficult period had been around the death of their parent, when they had to take on the responsibility of being the main carer of their sibling (see Figure 5.3):

'I suppose after my mother died because the onus was on me to look after him, and look after my father.'

'Well I would say this was around my father's death... It was left to me just to carry on.'

### 5.5.4 Accepting the independence of the relative

Two participants mentioned that it had been a very difficult time for them when they had to accept that their relative should live independently:

'...when I needed to say to him that he could no longer live at home. I found that very, very difficult. Even though it turned out that it was a very positive thing to do, he is standing on his own feet, you see.'

'The biggest mistake was to confront him before he went for the interview for the... job. I didn't know he did... All I've done is making him dependent on me totally, and I might as well stay in the house then, you know, make him go out and fend for himself.'

### 5.5.5 Current period as the most difficult

Four participants of the study (12.9%) mentioned that the current period was the most difficult. All four of them were mothers. Three mothers had their relative residing with them at the time of the study. The fourth was the mother of a person living in a community residence.

In three cases, the time of the study was perceived as the most difficult, as the participants' relatives were at home and were not accepting their illness. All three participants commented that there was no support offered from the private services:

'I don't like the aggression that she has at the moment, and I don't like the total, you know, haughtiness or whatever you call it, she's high and mighty at the moment... And the other thing that she's started to drink, and I did put my foot down about that, which resulted in a row... And her psychiatrist just said to me, there is only one thing for her, and that is those tablets. And there is no other way that she could be helped, end of story, and that was it. She doesn't want to admit she needs her tablets.'

'If somebody could have helped to bring him over and win him over, a lot of things would have slotted into place and then we'd just get on with accepting it and saying right at least he's in the right place, he's getting his medication, he's getting the right treatment. I feel now we're in limbo and it's a frightening limbo, because it could be long-term, and there's nobody going to be there to help or guide you as such.'

The participant whose son was living in a community residence felt that he was not motivated by mental health services and did not want to take responsibility for his own life:

'His problem at the initial stage was that he was talkative and aggressive, the problem now is he is silent. Half the time you have to drag the words from him, and there is no motivation whatsoever... He will say to you "I am tired. I want rest. I am not getting enough bed rest." He keeps repeating that, and he finds fault with everything... The thing about him is just refusing to take responsibility to do anything for himself. With the nursing staff he goes along with the system.'

## 5.6 Summary

Table 5.1 summarises the experiences, needs and support requirements of participants during initial encounter with illness, first encounter with treatment provision, discharge, and relapse of the participants' relatives.

The reported most difficult period of experiences with mental illness in the family was the initial encounter with mental illness and first admission, followed by the period of relapse.



**Table 5.1** Experiences, needs, and support requirements of participants at various stages of their encounter with the enduring mental illness and treatment of their relatives

Stages of experience	Reported experiences of participants with mental illness in the family	Needs and support requirements
<p><i>The initial encounter</i></p>	<ul style="list-style-type: none"> <li>• Mental Health problems are hard to notice due to the gradual change in the person experiencing mental health problems</li> <li>• Mental health problems are hard to notice by health services such as GPs etc as they may be easily attributed to the difficulties of teenage years</li> <li>• Once relatives and GPs notice mental health problems, it is difficult to get professional help, i.e., secure admission in a hospital or unit</li> <li>• Difficult to get timely help before the ‘breakdown’ and in case of emergency</li> <li>• Difficult to get help in case of out-of-hours emergency i.e., during the weekends and holidays, and after 5 p.m.</li> <li>• ‘Aggression’ of the relative’s first breakdown, and lack of advice on how to handle it</li> <li>• A lack of information about the procedures involved in seeking professional help, i.e., contact details, catchment areas, conditions of admissions; a lot of ‘hassle’ and arguing on part of the relatives in order to get professional help for the relative</li> <li>• Mental health services in catchment areas are not within easy reach for some participants</li> </ul>	<ul style="list-style-type: none"> <li>• Availability of information about mental health and/or mental illness at schools, GPs, open discussions/information sessions for general public</li> <li>• More training for GPs and other primary health professionals on mental health in order to spot the signs’ of build up of mental health problems and secure timely help</li> <li>• Prevention and early diagnosis in order to avoid aggression and committal of the relative to in-patient services</li> <li>• Information on admission procedures, catchment areas, and legal advice available to all family members</li> <li>• Support and sympathy from primary health care and mental health services</li> <li>• Information about SI and other support services for families with mental health problems to be made available and accessible to general public</li> <li>• Holistic medicine, whereby physical health needs are intertwined with mental health needs, a link between mental health and physical health professionals</li> </ul>

**Table 5.1** Experiences, needs, and support requirements of participants at various stages of their encounter with the enduring mental illness and treatment of their relatives

Stages of experience	Reported experiences of participants with mental illness in the family	Needs and support requirements
<p><i>The first encounter with treatment provision</i></p>	<ul style="list-style-type: none"> <li>• Shock and devastation at seeing the relative in in-patient psychiatric hospital or unit</li> <li>• Uncertainty and vagueness about what was happening upon the admission of the relative to in-patient units</li> <li>• Lack of information about illness, treatment, and diagnosis at the time of first admission, frustration at not knowing what to expect</li> <li>• Lack of human, as opposed to 'business-like', interaction with services</li> <li>• Inability to make persons with mental health problems take medication, and lack of advice on treatment from private psychiatrists</li> <li>• Abundance of written information as opposed to individual advice</li> <li>• Counselling and support groups of SI</li> <li>• Educational programme provided by mental health services of a catchment area</li> </ul>	<ul style="list-style-type: none"> <li>• Information about some basic steps involved in getting a diagnosis provided to the relatives on an individual basis</li> <li>• Availability of mental health services in the residential area of participants</li> <li>• Clarification about confidentiality issue, financial and legal advice</li> <li>• Involvement of relatives into treatment and care, partnership between mental health services and family</li> <li>• Sympathy, personal contact</li> <li>• Kindness, dedication of mental health services to treatment and rehabilitation of the relative</li> <li>• Private space for informational meetings with mental health services</li> <li>• A need to redefine the caring role of a parent after the initial encounter with mental health problems of the relative</li> <li>• Advice on 'how to behave' and how to care after the relative on discharge</li> <li>• The need to readjust expectations and accept illness</li> <li>• Information about diagnosis and prognosis, provided in a gradual and individual fashion</li> <li>• Individual or family counselling around the time of getting the information about the diagnosis from mental health services</li> <li>• Information on medication and its side-effects</li> <li>• The need for mediator, or key worker between the family and the person with mental health problems</li> </ul>

**Table 5.1** Experiences, needs, and support requirements of participants at various stages of their encounter with the enduring mental illness and treatment of their relatives

Stages of experience	Reported experiences of participants with mental illness in the family	Needs and support requirements
<i>Discharge</i>	<ul style="list-style-type: none"> <li>• Unexpected discharge of the relative home with no information about illness, treatment, and care, or follow-up</li> <li>• Discharge of persons with mental health problems who were still unwell from private mental health services</li> <li>• Difficulties in communicating with the person with mental health problems upon discharge</li> <li>• Difficulties of re-establishing relationships of persons with mental health problems with other family members after the initial psychotic episode</li> <li>• Difficulties to find help in case of emergency, especially out of hours</li> </ul>	<ul style="list-style-type: none"> <li>• Timely information about discharge, accompanied with information and advice on how to 'behave' and how to handle crises</li> <li>• Information about medication, treatment, and/or prognosis on discharge</li> <li>• Proactive, outreach follow-up day services on discharge, encouragement from the services</li> <li>• Specific, approachable contact with mental health services on discharge</li> <li>• Continuity between discharge and treatment</li> <li>• Key worker, or mediator between the person with mental health problems and the family, readily available and approachable</li> <li>• Sheltered or supported accommodation provided to relatives on discharge, if suitable; 'half-way house' towards independent living</li> </ul>
<i>Relapse</i>	<ul style="list-style-type: none"> <li>• Persons with mental health problems stopping their medication</li> <li>• Experiences similar to the initial encounter, accompanied with disappointment and disillusionment on the part of the relatives that the illness had not been 'cured'</li> <li>• Suicide attempts or aggression, lack of advice on how to handle them</li> <li>• Difficulties of securing places in in-patient mental health services for voluntary readmission and professional help</li> </ul>	<ul style="list-style-type: none"> <li>• Information from mental health services about medication, its side-effects, and possible consequences of not taking medication</li> <li>• Approachable contact from mental health services</li> <li>• Acute facilities or units easily available for persons with mental health problems at the time of relapse</li> <li>• Continuity of treatment and discharge, a good standard of treatment and support services for all catchment areas and for both public and private mental health services</li> </ul>

As reported by the participants, the majority of persons with mental health problems had been in their teens and were living at home with their parents at the time of the onset of illness. The reported number of hours of contact with the ill person significantly decreased over time, with more persons with mental health problems moving out of their family home at later stages of their lives. However, the on-going nature of enduring mental illness made it hard for some participants to rate a specific period of their experiences as the most difficult.

Most of the needs during the first encounter with mental health problems and at the relapse stage were associated with the difficulties of participants in getting timely professional help at the time of the first and second 'breakdown'. It was perceived as logistically somewhat easier to secure professional help and a place in in-patient mental health services for their relative after the outbreak of aggression or self-harm, as opposed to at the time of gradual build up of signs of illness. The participants also felt that it had been somewhat easier to get information about diagnosis, treatment, prognosis, and medication from the mental health services if the person with mental health problems had an aggressive outbreak and had therefore been involuntarily admitted to in-patient mental health services.

In the case of voluntary admissions, a perceived clash between confidentiality of information about the diagnosis and treatment, and the 'natural right' of close relatives or carers, to know what was wrong and what to expect was reported by participants. Participants had been willing to provide care for their relatives, but needed to readjust their expectations about their relative's future and redefine their caring roles after the initial encounter with the mental health problems of their relatives. In addition, the majority of participants had known prior to discharge that the relative would be discharged home to their care, and therefore needed advice about the illness, symptoms, and their own behaviour with the person with mental health problems. Some of the arguments of participants in favour of being informed as much as possible about the illness and treatment of their relatives involved reduced re-admissions of their relative in in-patient mental health services in the future.

On discharge, there was a perceived lack of support services for the family, and follow-up of treatment. Participants felt the need for proactive, outreach services after discharge, as opposed to 'fire-fighting' in cases of emergency. There was a pronounced need for an approachable, easy-to-reach contact within the mental health services for enquiries and advice on the illness and specific caring situations. Some participants who had used private mental health services felt that the untimely discharge, associated with the 'running out of credits', and the lack of follow-up services on discharge were the main disadvantages of the private sector as opposed to the public. Easily approachable and available psychiatric nurses were also perceived as the major benefit of public mental health services.

Major criticisms of the public mental health services were the 'run-down' state of in-patient buildings, and the change of registrar after every six months. Participants perceived that it had been difficult for the person with mental health problems to build up trust with each new professional, and this therefore negatively affected their treatment.

Participants voiced a need for individual appointments with mental health services and for counselling for the family at the time of getting the diagnosis. Whereas viewed as essential information for readjustment of future expectations and accepting the illness by participants, learning diagnoses was associated with shock and 'trauma' on the part of participants. Voluntary counselling, provided by SI, had been seen as very helpful and effective by the participants.

Participants also needed better communication with mental health services, recognition of their caring role, and a sense of partnership between mental health services and the family. They felt that they had not been listened to in emergencies, which might have 'softened' some of the breakdowns of their relative. They also felt they were in need of a human contact, kindness, and sympathy from professional mental health services.



## Chapter 6

Views of participants on the success of treatment and rehabilitation of their relatives

““”

So I'm kind of always being ready for the next period which is very slow, very slow in coming... And he did improve a lot, I mean he became stable, just there has been no rehabilitation.

This Chapter will describe participants' views about the effectiveness of the treatment and rehabilitation of their relatives, and the change of their views over time.

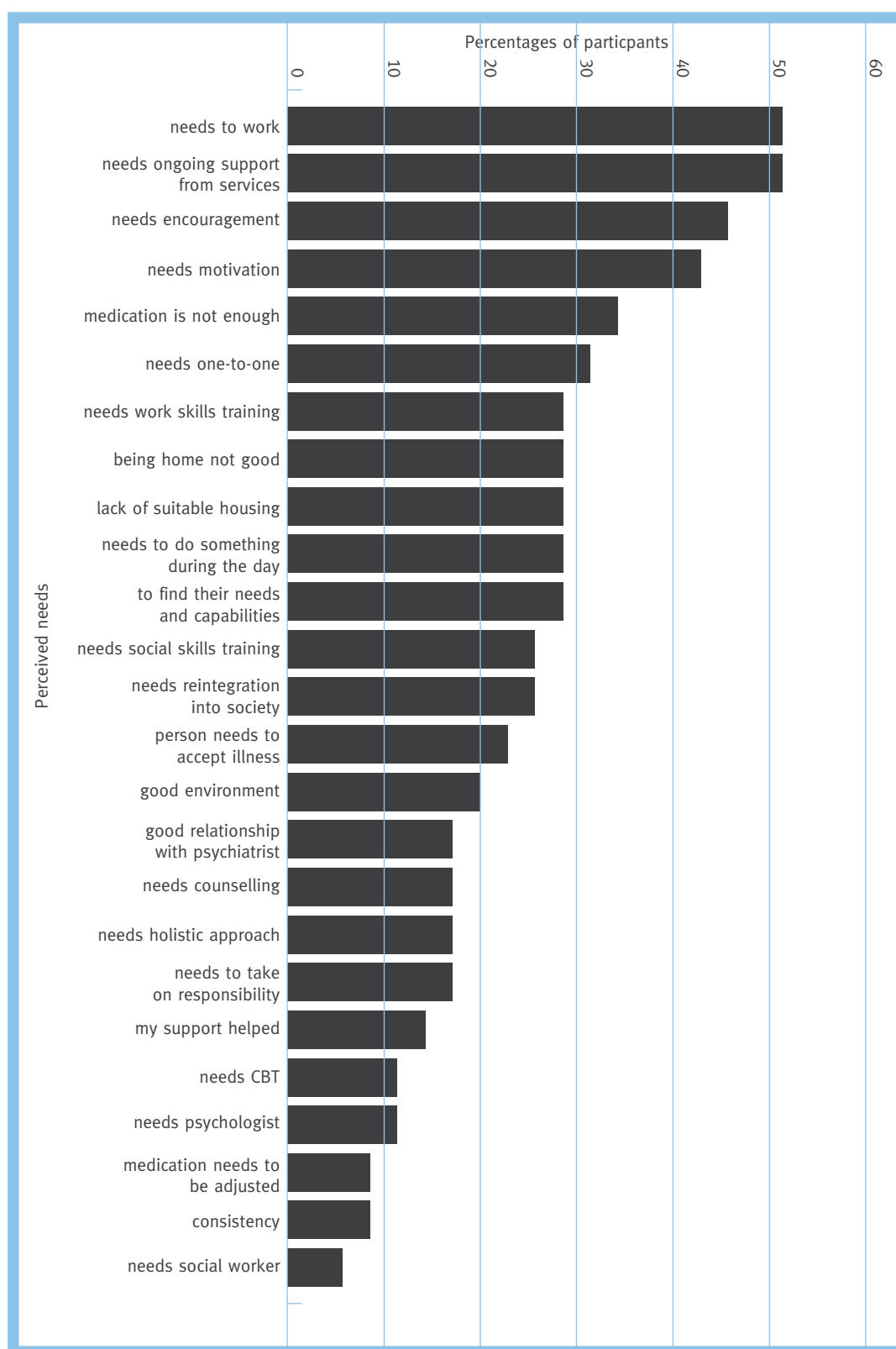
Support resources used by the persons with mental health problems will be presented, as reported by the participants. The Chapter will then present and analyse the satisfaction of participants with their involvement in their relatives' care, and the satisfaction of participants with services and support provided to their relatives.

## 6.1 Views of participants on the effectiveness of treatment and rehabilitation of their relatives

The question about expectations of treatment and rehabilitation of persons with mental health problems elicited the views of participants on the effectiveness of treatment and care of their relatives, and on the improvement, maintenance, or deterioration of the relatives' mental health, social functioning, and quality of life. Thirty five participants (92.1%) provided comments in this regard.

### 6.1.1 Perceived needs and goals of treatment and rehabilitation of persons with mental health problems

As can be seen from Figure 6.1, more than half of the 35 participants who reported their views on treatment and rehabilitation of their relatives (n=18, 51.4%) viewed employment and ongoing support from services as equally essential for the improvement of health and well-being of persons with mental health difficulties.



**Figure 6.1** Perceived needs and goals of treatment and rehabilitation of persons with mental health problems, as reported by participants of the study, by percentages of participants



Other frequently reported needs or goals of treatment and rehabilitation were encouragement (n=16, 45.7%), and motivation (n=15, 42.9%).

The need of persons with mental health difficulties for a regular one-to-one communication with a designated mental health professional was reported by almost one-third of participants (n=11, 31.4%) (Figure 6.1).

Overall, nearly half of the 35 participants (n=15, 42.9%) felt that rehabilitation was not forthcoming from mental health services. Three participants (8.6%) felt that there was a lack of professional support from services, both at the stage of the onset of mental health problems, and at the 'improvement', or recovery stage.

'And when you make some sort of recovery, I find it even with my daughter coming out, we had a long wait, she had to stay in the hospital too long... and it wasn't helping recovery, but there was nowhere for her to go. So I think in this country there needs to be support services for people who are starting to display mental health symptoms, and when they are... recovering there need to be support services to get them out of the institutional sort of treatment regime. Both ends of the services are missing, that was our experience of it.'

'The system is putting him down because there isn't room in this system to grow. They need to push out its boundaries and see what works at the early stages, because there are two ends to the stick, both sides of the stick are not developed.'

More than one-third of the 35 participants (n=12, 34.3%) felt that medication alone was not enough for successful treatment and rehabilitation of their relatives. A holistic approach to treatment and rehabilitation, promoting occupation, motivation, and responsibility of persons with mental health problems, as opposed to 'just medication', or 'the medical model', was viewed by six participants of the study as essential for improving the quality of life of both participants and their relatives:

'I think with mental illness it's not just medication, a holistic approach has to be taken you know, therapeutic, a place where they can go each day, a reason for them to get up and to feel useful and that they're doing something worthwhile, I think that's important. And it helps them to keep their dignity and they're occupied during the day, and it gives their parents a break, because I have seen parents and they all age terribly because it takes a lot out of them, takes an awful lot out.'

'What my son actually needs at this stage and if his needs are met, then my needs are met, is the support, and the behavioural modification, and therapy. If he doesn't have that, he is not going to be able to deal with this on his own. He's all right if he's in a psychiatric setting which had a medical model. He will lose it, I have watched this for the last two years, he will be put back into the hospital, he will be drugged, his drug levels are going up and up and up, which is totally and absolutely unacceptable... There is a need for a more holistic approach... if he was held responsible for his good behaviour and not using the medical diagnosis as an excuse for bad behaviour, do you know what I mean... if the medical model at this point in my son's life is not changed, my son is going to end up another dead statistic, there is no other way around it.'

### **6.1.2 Perceived level of expectations of participants of treatment and rehabilitation of their relatives and its change over time**

Although participants were not asked to rate their current level of expectations, more than half of them volunteered their own assessment of the current level of their expectations of the physical and social functioning of their relatives in the future. Out of the 35 participants who presented their views on the treatment and rehabilitation of their relatives, nineteen (54.3%) commented on the current level of their expectations and their change over time. On the basis of such 'self-rating', three distinct

groups of participants emerged through the analysis: participants with ‘low’ expectations, participants whose expectations ‘had changed’ and became ‘higher’, and participants whose expectations were self-rated as ‘high’ at the time of the study.

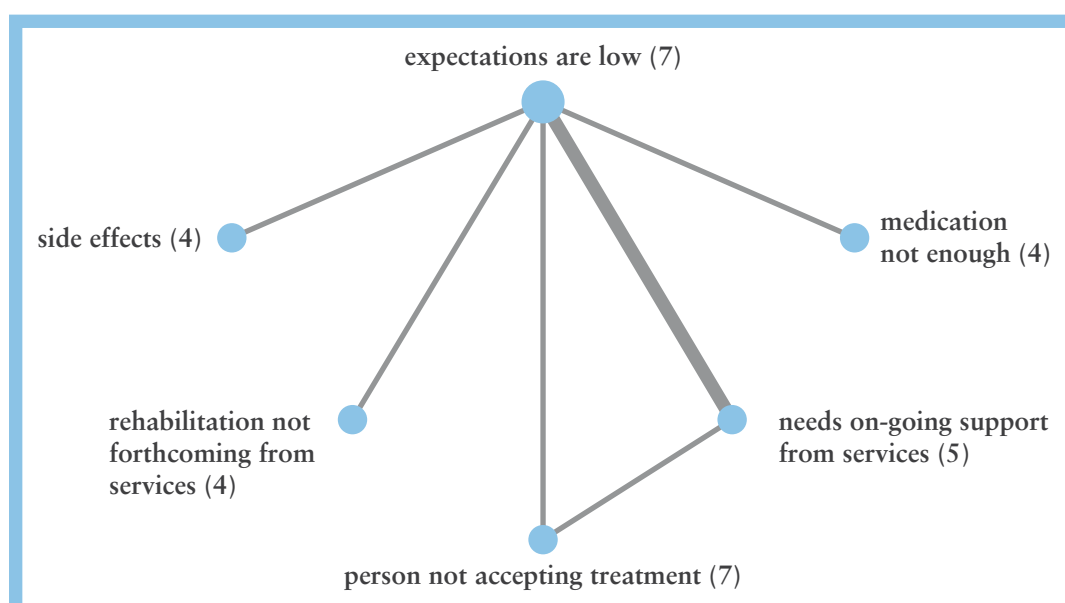
Of the 19 participants who rated their current level of expectations, seven (36.8%) considered their expectations to be quite low, and six (31.6%) self-assessed their expectations as high at the time of the study. Eight of the 19 participants (42.1%) commented that their expectations of the outcomes of treatment and rehabilitation of their relatives had become higher over time. Of eight participants who reported that their expectations had changed, two also stated that their expectations were high at the time of the study. No participants reported that their expectations of their relatives’ treatment and rehabilitation had become lower with time.

### 6.1.2.1 Views of participants who considered their expectations low

Of the seven participants who reported that their expectations of treatment and rehabilitation of six relatives were low at the time of the study, four were recruited through SI, and three via MHS. Three persons with mental health problems, whose relatives reported that their expectations were low, were residing at home with participants, and three were in an in-patient unit at the time of the study. The reported average duration of illness was 14.1 years (median=11), minimum duration of five years, and maximum 30 years. The majority of the six persons with mental health problems were reported to be unemployed (n=5, 83.3%), and one person was reported to be in training at the time of the study.

Figure 6.2 presents a diagram of most recurrent themes (at least four themes shared by respondents) emerging from the seven participants who reported that their expectations of treatment and rehabilitations of their relatives were low at the time of the study.

As can be seen from Figure 6.2, the most recurrent theme evolving from the majority of the seven participants (n=5, 71.4%) was that their relatives needed ongoing support from services in order to make sure that they would remain in good health or would not ‘end up on the streets’.



**Figure 6.2** Most recurrent themes emerging from participants who reported that their expectations of treatment and rehabilitation of their relatives were low at the time of the study<sup>1</sup>

<sup>1</sup> Visualisation diagram was created on SPSS Text Analysis for Surveys 1.5

Four of the participants who reported that their expectations were low felt that there was no or very little rehabilitation forthcoming from mental health services in order to sustain the health and well-being of their relatives.

‘Well my expectations are fairly low, I am thinking of the bottom line, I don’t want him to end up on the street when I’m gone...So if he was on his own who would contact him, that’s what we’ve been trying to build towards him, otherwise in my opinion he’d be in the street because that’s where they all end up, most of them anyway...I felt he just stopped in the middle of nowhere and going nowhere and I felt there should have been something a bit more than medication, something else there that will get people to a level, even to look after themselves at the lowest level, knowing that they can lift the phone or somebody will lift the phone and say “Listen are you still here, are you still living?”’

Four of the seven participants reported that the person with mental health problems was not accepting his or her illness, which made it difficult, as commented by the participants, to make any progress in treatment or rehabilitation.

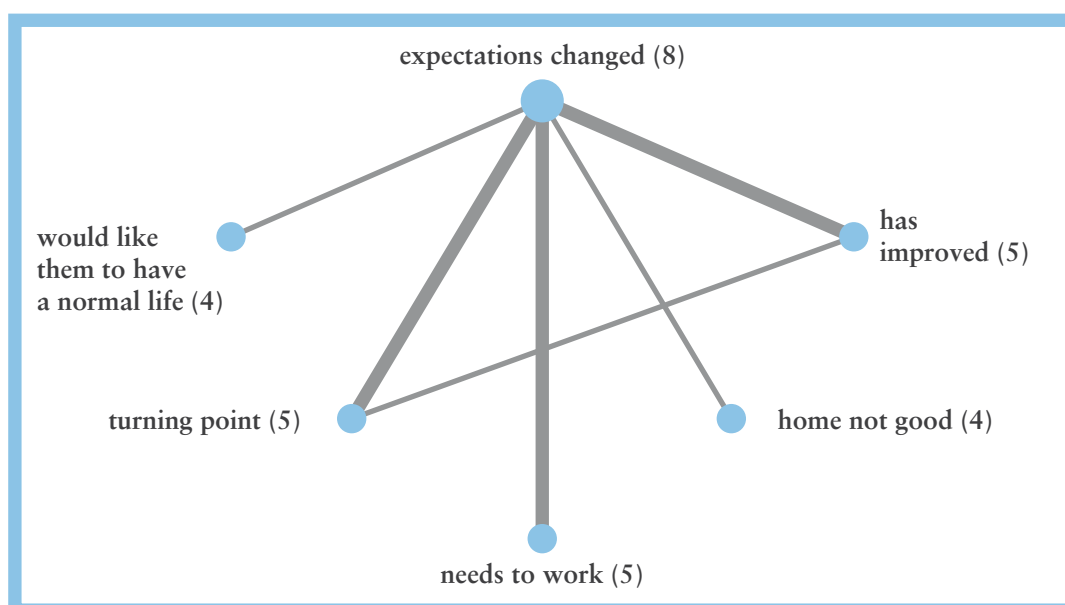
Four participants whose expectations were low felt that medication alone was not enough for their relatives’ treatment and rehabilitation, and the side-effects of medication outnumbered its benefits for their relatives’ health and well-being.

‘When I did research into his state of health I have discovered that there is very little cures other than giving a lot of medication in tablet form, or injections, which is not the answer...it may be the answer some of the time, but it’s not an overall answer... There are a lot of poison elements in medication, and of course later on in his life it’s going to have an adverse effect on the patient’s well-being.’

### 6.1.2.2 Views of participants who reported that their expectations had changed

Eight participants of the 35 (42.1%) mentioned that their expectations of treatment and rehabilitation of their seven relatives had changed for the better over time. Six of the eight participants were recruited via SI, and two via MHS. Three of the seven persons with mental health problems resided at home with participants, two lived independently, and two were community residents. The average duration of illness was 17.1 years (median=16), with a minimum duration of four years and a maximum of 30 years. Four persons with mental health problems were reported to be unemployed (57.1%), two persons were employed part-time, and one person was reported to be in training at the time of the study.

Figure 6.3 presents a diagram of the most recurrent themes (at least four themes shared by respondents) emerging from eight participants who reported that their expectations of the treatment and rehabilitations of their relatives had changed.



**Figure 6.3** Most recurrent themes emerging from participants who reported that their expectations of treatment and rehabilitation of their relatives had changed overtime<sup>2</sup>

As can be seen from Figure 6.3, the most recurrent themes emerging from five of the eight participants were that there was a ‘turning point’ in their experiences with treatment and rehabilitation of their relative, after which the health and well-being of their relative had improved, and that their relative needed to work. The themes of ‘turning point’ and ‘had improved’ were interrelated and shared by five participants.

Some of the hopes voiced by the participants were that their relative would be able to lead a ‘normal’ life, to have a job, to live independently, and to function on a social level:

‘Well at the moment she is absolutely fantastic and this is her longest ever and now she has a part-time job, she has a boyfriend, she’s engaged and she’s talking about getting married, but that’s another day... So if you saw her you wouldn’t know that there was anything wrong with her. I didn’t know what we were going to go through seven years of being in and out of hospital, it’s just all about today and that’s how I cope, I just deal with today.’

Three participants attributed the progress that their relative had made to the improvement in the quality of mental health services:

‘My expectations now are much higher because he is in the public service. I find it much more, how would I put it, I find the people are better at dealing with him, they’re extremely helpful, caring, cooperative, informative, if you need to chat to them or find something out, they’ll always take a phone call, which is fantastic, it’s absolutely fantastic. I’m happy with the service that he is getting now, I mean he is integrating, he has integrated very well into the community that he is now, and he is very active in it, and he is getting tremendous help there.’

Five participants who reported that their expectations had changed over time after some ‘turning point’ in their relatives’ lives felt that employment was essential for the rehabilitation of persons with mental health problems.

<sup>2</sup> Visualisation diagram was created on SPSS Text Analysis for Surveys 1.5

‘...as I say for thirty years or so he couldn’t hold any job and he always wanted to work, his one ambition was to work and to earn his own living and pay income tax... And he kept applying for jobs, but he rarely got a reply, and if he did and if he was going for an interview he got so up tight you know that he just didn’t perform at the interview anyhow you know... but eventually now once he went on the Clozapine he was able for some work.’

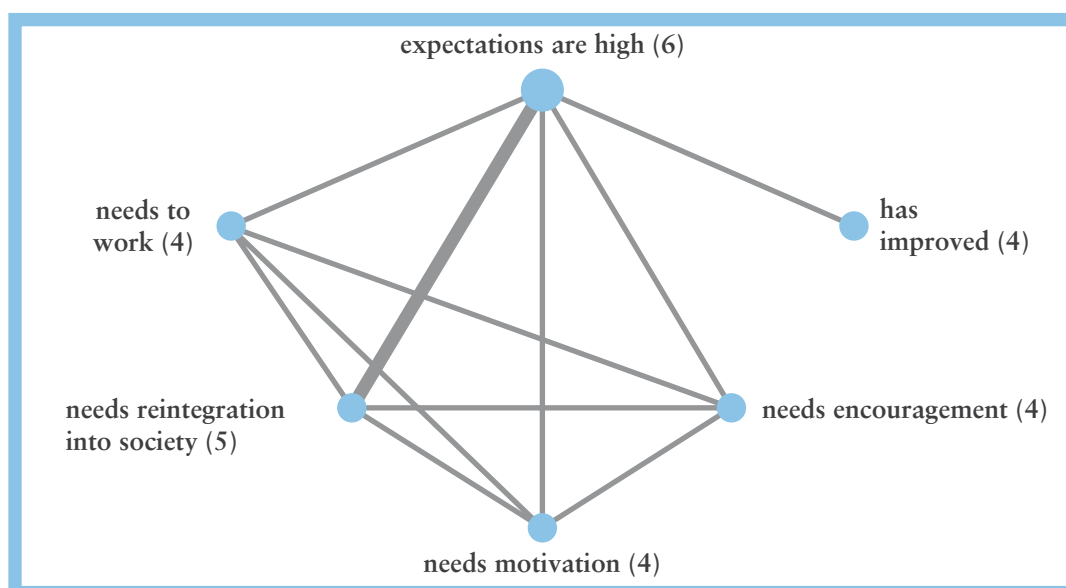
Half of the participants who reported that their expectations had changed (n=4) perceived independent living as one of the important steps on the road to improvement. Participants felt that institutionalisation severely affected the ability of persons with mental illness to make decisions for themselves. Such disempowerment was considered by some participants as a major obstacle on the road to rehabilitation or recovery.

‘...she’s getting her life together again and she’s taking decisions for herself. As she said to me herself, for a long time when she left hospital and went up to this house, she used to wait for somebody to open the door for her, she didn’t even think she had the right to open the door, like, its amazing how quickly you become institutionalised in these places... And now as I say we’ve just got... a corporation flat, so her new project now is, I went out with her today, and she bought paint and I let her pick the colours, and she’s painting it up and she’s going to get furniture, and she’s going to move in to her own flat.’

### 6.1.2.3 Views of participants who reported that their expectations were high

Six participants out of the 35 (31.6%) reported that their expectations of treatment and rehabilitation were quite high at the time of the study. Half of the participants were recruits of SI (n=3), and half of MHS (n=3). Out of six persons with mental health problems, whose relatives reported that their expectations were high at the time of the study, half (n=3) were community residents. Two persons were living at home with the participants, and one person was living in an independent accommodation. The reported average duration of illness was 19.2 years (median=21.5 years, minimum= 4 years, maximum=32 years). The majority of persons with mental health problems were reported to be in training (n=4, 66.7%), one person was employed part-time, and one person was reported to be unemployed at the time of the study.

Figure 6.4 presents a diagram of the most recurrent themes (at least four themes shared by respondents) emerging from six participants who reported that their expectations of treatment and rehabilitation of their relatives were high at the time of the study.



**Figure 6.4** Most recurrent themes emerging from participants who reported that their expectations of treatment and rehabilitation of their relatives were high at the time of the study<sup>3</sup>

As can be seen from Figure 6.4, the most recurrent theme emerging from six participants who reported that their expectations of treatment and rehabilitation of their relative were high at the time of the study, was reintegration into society of persons with mental health problems. The themes of encouragement, motivation, work, and reintegration were interrelated and shared by three interviewees.

The views of participants who considered their expectations high were very similar to those of participants who reported that their expectations had changed. Three participants, who reported high expectations, wanted their relative to lead a ‘normal life’, which included skills for independent living, suitable housing, some kind of a job or occupation during the day, and improved social skills. Four participants who perceived their expectations as high viewed the ability for the persons with mental health difficulties to work as essential for their rehabilitation:

‘He’s got to work with whatever he can to live as normal life as possible, to get out, get back in to work and get started at work, like some of these people we’ve seen at some of these meetings.’

Five participants out of six who reported that their expectations were high expressed hopes that their relative would become more integrated in the community and the society in general, and felt that they were facing difficulties integrating due to the stigma associated with mental illness.

‘So I’m kind of always being ready for the next period which is very slow, very slow in coming... And he did improve a lot, I mean he is stable, just there has been no rehabilitation really but he’s been very good, he’s very afraid of going back into the black hole again as he says... In fact at the family education therapy they were saying that some parts of the world are better for recovery of mental illness than others, it’s impoverished third world countries because there’s no medication and there’s more community centred people... the western world doesn’t live like that, I mean already I see from his neighbours that they don’t want their beautiful new houses spoiled by the look of one that isn’t so nice.’

Four out of six participants who reported that their expectations were high felt that their relative needed more encouragement and motivation as part of their rehabilitation and integration in the community.

<sup>3</sup> Visualisation diagram was created on SPSS Text Analysis for Surveys 1.5

'I just knew that he was fit for more, but all he had was pill popping, what encouragement they could give you, they have nothing to offer... No interaction and bringing you into the community or anything, though that is a wonderful bungalow and these nurses are very kind and good, and I'm sure feed them very well and you know all that, he's more responsible now, he's responsible for his own medication... But introduce to the community; take them on the bus to Dublin, so that they're not scared to get on the bus... Before God would take me to himself I'd love him to get that help, maybe he'll never be able to get any further than being non-motivated, but I think he deserves a chance.'

### 6.1.3 Perceived reasons for the improvement of mental health and well-being of service users

Overall, nearly half of the 35 participants who provided their comments on treatment and rehabilitation (n=16, 45.7%) stated that the mental health of 15 service users had eventually improved over the course of the illness. Nearly half of the total 26 SI recruits (n=12, 46.2%), and one third of the total 12 MHS recruits (n=4, 33.3%) reported that the health and well-being of their relatives had improved.

Five of the 15 relatives whose health and well-being were reported as improved were residing at home with participants at the time of the study, four in an independent accommodation, four in a community residence, and two in an in-patient facility. The average reported duration of illness among the 15 persons whose mental health had improved was 15.2 years (median = 11 years, minimum=1.5 years, maximum=32 years).

Sixteen participants who reported that their relatives' health had improved mentioned two to four reasons for the improvement. Recurrent reasons for the perceived improvement, as reported by these participants are presented below.

#### 6.1.3.1 The 'turning point'

Half of the 16 participants who reported that the health of their relatives had improved (n=8, 50.0%) recalled a specific 'turning point' from which time the gradual improvement of had started.

'He was admitted to hospital for four or five months...he was really at the bottom, you know, but in a way it was a turning point because he just jogged along there... and the best thing that happened to him in there was seeing a psychologist...on a regular basis...I think the four things that happened to him in hospital were: the psychiatrist changed his medication and it happened to be the right one, he saw the psychologist who as I said was really the best thing, he got his own motivation, and if you like, he's had my support all down the line.'

#### 6.1.3.2 Effective medication

Half of the 16 participants who reported that their relatives' mental health had improved mentioned that their improvement had started since their medication had started 'to work' (n=8, 50.0%). Seven participants (43.8%) commented that medication of their relatives had been changed some time ago, which they viewed as one of the important steps towards the improvement of their relatives' mental health, despite the various side-effects of the medication:

'...but finally he did go on Clozapine and again he was there for quite a while until he got quite stabilized on it, and he had you know all the side-effects, he put on weight and he sweats a lot at night... It was quite slow at the start for him to improve, but once he did improve it's made quite a huge difference for him, he's really been very well... so he was able then... to move on to sheltered employment and he went to a community employment scheme.'

However, nearly one-third of the 16 participants commented that medication alone was not enough for the improvement of their relatives' mental health (n=5, 31.3%).

#### 6.1.3.3 Employment

One of the most frequently recurring themes mentioned by participants who reported that the health of their relatives had improved (n=11, 68.8%) was employment:

'He always wanted to have open employment, he hated being on social welfare or disability allowance, he felt he was a drag on society, so he was delighted once he could earn his own money.'

#### 6.1.3.4 Research on the needs and capabilities of persons with mental health problems

Five participants out of 16 who reported that their relatives' health had improved felt that it was necessary for rehabilitation services to find out the individual needs and capabilities of their relatives in order to place them in suitable employment or training.

'She really needs somewhere where rehabilitation is to do with somebody really talking to them and finding out what their needs are and what their wants are, you know, maybe once a week, just a lecture with questions back and forward or maybe, I don't know, some art, if she could do art or something, or music appreciation, or something like that.'

#### 6.1.3.5 Barriers to successful employment

Some barriers to successful job placement of persons with mental health difficulties mentioned by participants were the stressful environment of contemporary jobs, lack of flexible hours, boredom of repeated activities of sheltered employment, emotional vulnerability of persons with mental health problems, and difficulties of social interaction.

'All these sort of jobs I suppose that were more suited to people like N are gone, there's no job there that hasn't stress, life has become so aggressive anyway, generally people are aggressive in every job...I mean there are so many companies now, you could have maybe one job from one person like that in a company... But not have it that everybody in the company will know that person is "the one", because these people have feelings... I know it's very difficult to find out what their capabilities are, some of them are very highly intelligent and then others are not, and sometimes the medication can make people that they can't concentrate.'

'I say "Well what would you like to do?" and he says "I would like a workshop but not to go back to the simple things we used to do..." I often say to him "There's so and so, packing shelves in the supermarket", "Oh I wouldn't do that", he is scared of things. I know other people who do that sort of things, now for some reason he's very nervous, but whether people with learning difficulties have emotional problems I don't know, and I think possibly people with mental illness have more emotional problems.'

#### 6.1.3.6 Encouragement

More than half of the 16 participants who reported that their relative's health had improved (n=9, 56.3%) perceived encouragement as essential for their relative's progress.

'And they enabled him, there are two very lovely caring people there, total support for him. They encouraged him along, if he didn't get up in the morning and he arrived in there between twelve o'clock or twelve thirty, no problem. So really he was allowed to work at his own pace.'



### 6.1.3.7 Good relationships with service providers

Nearly one-third of the 16 participants (n=5, 31.3%) attributed their relatives' improvement to good relationships of their relatives with their psychiatrist, registrar, or social worker. A one-to-one approach and consistency of support were viewed by these participants as necessary steps in their relatives' recovery:

'I suppose it was the fact that she was so open herself and she was so honest with the consultant and they had a very good relationship and that really was the making of her... And she saw him on a regular basis and I know that registrars change every six months and it was a difficult time because she would build up a relationship, but he was always there and if there was a problem we'd go to him... So he would have been the main person and the most consistent person... One of the first things that impressed me about him was that when he saw her for the first time he had read her file from cover to cover.'

### 6.1.3.8 Integration into society

Six participants out of 16 (37.5%) mentioned that integration into society, friends, and communication with other people through support groups, and work skills workshops also helped the improvement of their relatives' mental health.

'They had a workshop in an industrial estate... and now they have turned it into a club. They can go in there any time, and have tea or coffee... he seems to like this idea of a club anyway... He has a good friend who kind of takes him under his wing a bit. This friend himself had a mental breakdown, but he managed to qualify as a nurse, as a mature nurse, he went back to college and he is working full-time now, he has his own apartment and he is driving a car, and he takes him and some friends out at weekends... He doesn't hide the fact that he did have a mental breakdown, and psychiatrists did say to his family that he would be like this for the rest of his life, but with his family help and with his own outlook and that sort of thing he managed to overcome it.'

'He went to Phrenz group which was a big help, he was very isolated, he lost all his friends, and then he made friends in the Phrenz group. And then he lost all those but he has one friend at the moment from that group that he meets very occasionally.'

### 6.1.3.9 Suitable accommodation

Six participants who stated that their relatives' health had improved were happy with the current accommodation of their relatives. Three of these relatives were community residents, and the other three relatives lived in independent accommodation.

'And he is living in what one would term a much more normal, another word I do not like, environment, you know, it's in a house run like a home, you know, with people managing the situations there, and it has definitely helped him, and he is there such a short space of time.'

'Now she has a lovely little house and a beautiful back garden, her back garden is huge, it's lovely and that had been a tremendous help to all of us. So accommodation is terribly important...'

### 6.1.3.10 Family support

Four participants of 16 who felt the mental health of their relatives had improved (25.0%) attributed some of their relatives' improvement to their own support and involvement in the rehabilitation.

'But she's coming together, her first project was her car, she loved driving, so I got it taxed and insured for

her, and did the road test, so it was all ready. It needed some repairs, I gave it to her as a project, so she took the car on a project, and I said “Finish off the repairs on it”, and then she started driving. So she had her mobility.’

#### 6.1.3.11 Services of psychologists

Three participants who stated that their relatives’ health had improved (18.8%) attributed some of the improvement to sessions with psychologists. They viewed the psychologist’s input as an important element in their relatives’ treatment and rehabilitation. They perceived that service users could have a more ‘personal chat’ with psychologists, than with psychiatrist or registrars, and that psychologists could assess their well-being, their skills and capabilities:

‘They need many more psychologists because I think psychologists have a lot to say in helping people with psychiatric problems because they are somebody to talk to. Whereas the consultant psychiatrists... know exactly what to do and they’re experts in the medication but the psychologists can have a more personal chat. She did have a course with a psychologist who she found very helpful, and she was told how to look at different things, questions to ask herself when she’s very vulnerable, how to deal a little better with it and it was very helpful... I would like her to be seeing a psychologist on a regular basis.’

#### 6.1.3.12 Approachable contact with mental health services

The majority of participants who reported that their relative’s health and functioning had improved, also reported that they knew whom to contact within mental health services for help and advice (n=12, 75.0%). A significantly higher number of participants who had such contact reported that their relatives’ health had improved (n=12, 57.1%), than of those who did not know whom to contact for queries (n=4, 23.5%) [ $\chi^2(1) = 4.35, p = 0.037$ ].

#### 6.1.3.13 Happy with the present state

Out of a total of 35 participants who provided their comments on the treatment and rehabilitation of their relatives, nine (25.7%) mentioned that they were happy or satisfied with their relatives’ current state of health.

‘But he’s really doing very well, he’s a member of SI himself and he’s in touch with them you know... Clozapine has made a huge difference, now that’s very good and he’s really keeping very well and he takes responsibility for himself now, like our task now is to be good friends to him, that’s what I’d say to myself, my job is to be a good friend.’

‘...the programme they put in place for her was very effective. I can see my daughter back to me for the first time in probably eight years... she’s bright, she can engage, she can have lucid conversations, she’s planning to get on with her life... she is very comfortable with the female psychiatrist that she is dealing with, they have a good relationship, and I think generally at this stage I’m confident that we really have turned the corner, hopefully.’

### 6.1.4 Views of participants on treatment and rehabilitation of their relatives whose health was reported as deteriorating

Two participants commented that their relatives’ health had deteriorated. Both of their relatives were elderly and were residing in in-patient units at the time of the study. They attributed such ‘deterioration’ in their relative to too much medication, lack of rehabilitation, and the fact that their relatives had stayed too long in in-patient units.

‘...he has schizophrenia and the doctors think he should be there, you have to accept it, but I couldn’t accept it because he knew everything that was going on, he was able to hold a conversation and all, but gradually by degrees he got more agitated, and I found he was on an awful lot of drugs, I found he was on more drugs than he was, he was on about eighteen or nineteen tablets a day... He wants to stay at home, he keeps saying ‘I’m not going back in there, I’m not going back in there.’

‘But she’s deteriorating I would take it, you see her medicine and I suppose everything adds up...I take it that she’s not going to get better, all they can do is control, she’ll never be able to walk out and say “I’m better”, never, unfortunately because she’s down for too long.’

## 6.2 Reported support resources used by persons with mental health problems

As reported by study participants, the majority of the 33 persons with mental health problems (n=21, 63.6%) did not participate in any support programmes for service users at the time of the study. The reported proportion of relatives participating in support programmes was equal for SI (n=8, 36.4% of 22 service users) and MHS (n=4, 36.4% of 11 service users) groups of participants.

As can be seen from Table 6.1, 10 various support programmes used by 12 persons with mental illness at the time of the study were reported by participants. Service users were reported to participate in from one to three support programmes. An equal number of persons with mental health problems used SI Phrenz Support Groups, and AWARE support groups (n=3, 25.0%) (Table 6.1). Two participants reported that their relatives participated in some support programmes provided by mental health services (16.7%).

**Table 6.1** Support programmes used by service users at the time of the study, as reported by the participants

Support programmes used by service users	Number of service users	Percentages of 12 service users
SI Phrenz support group	3	25.0%
AWARE support group	3	25.0%
Support programme offered by MHS	2	16.7%
Reach	1	8.3%
FAS training programme	1	8.3%
Cultural experiences programme	1	8.3%
Support and rehabilitation programme offered by a catchment area of Dublin 1	1	8.3%
National Rehabilitation Board	1	8.3%
A support group for service users	1	8.3%
Parental skills programme at a community residence	1	8.3%

The two groups of participants reported use of different types of support programmes by their relatives. Use of such support resources by relatives, as SI Phrenz support group, AWARE support programmes, support programmes offered by mental health services, and three other rehabilitation programmes was reported by participants recruited through SI. Participants recruited via MHS

reported that their relatives used Reach, FAS, cultural experiences programme, and parental skills support programmes.

### 6.3 Satisfaction of participants with the extent of their involvement in treatment and rehabilitation of their relatives

All 38 participants provided comments to the open-ended question about their satisfaction with the extent of their involvement in their relatives' care (see Question 6, Appendix 6). Nearly half of the participants (n=16, 42.1%) were satisfied with their involvement in the treatment and care of their relative at the time of the study, and viewed their involvement as a positive contribution towards both their relatives' recovery and their own sense of usefulness.

'Yes, at the moment I am satisfied, as I say the hospital have kept me abreast of everything that's going on and even where she is, they will phone me also if she didn't come in or anything, to ask me did I know where she was. Yeah that also makes you feel useful or makes you feel you're doing something in her recovery, you're helping. Well I think the doctors will only see her in the hospital environment and she can give a good picture, where I will see her when she's not well and in her different moods which they don't see... Yeah and how she would relate in the family situation, with friends and that.'

Two participants commented that they were satisfied that their involvement in their relatives' care was minimal at the time of the study. They left it either to the services, or to their relatives themselves to decide what would be the best for their treatment and rehabilitation. In both of these cases the relatives were residing outside the participants' homes:

'I would never query them, I wouldn't because I wouldn't actually know what it meant, apart from not needing it I would have to start then going down the road and I wouldn't... They tell me whatever medication she is on, fine, you know, accept that.'

'Well my involvement with his treatment is nil I could say. He just comes home at weekends, but he doesn't like to be dictated or told what to do. Like I mean he comes and goes, we don't supervise him or anything like that, he has his circle of friends, maybe takes the odd drink, and like he socialises a good bit, that seems to be his only outlet from living in the hostel.'

Two participants felt that they were not sure if their involvement with treatment and rehabilitation was beneficial for the person with mental health difficulties at the time of the study.

'At the moment now I'm reluctant to interfere... He tells me what they tell him, I know the medication he's on; I don't know why they took him off what he was on. But you see I hate interfering with him because I feel it's got to come from him, I don't really want to make an appointment and see the psychiatrist and talk about him behind his back, I don't think that's right... With his permission yes, he talks to me when he comes home and I keep saying "What on earth are they doing with your medication?"' but then he says "Well I'm not as depressed as I was."

Over one-third of the participants (n=14, 36.8%) reported that they were dissatisfied with the extent of their involvement with their relatives' treatment and rehabilitation and wished it had been more intense. They felt that they could have contributed more to the recovery of their relative had they been more involved. Most frequently reported reasons for under involvement were the refusal of the relative to allow more involvement by their family (n=8, 57.1%), and lack of interest of services in the relatives' experiences with mental illness (n=6, 42.9%).

'I think in some cases the parents of these people can contribute quite a lot...Because I had lived with the patient from the time the problem started. And I think I knew that I should have been listened to from day one which I wasn't... They don't want to listen, but at the same time they haven't got the answers. It's very complicated. Basically I have no involvement in his treatment, and he wouldn't want me, I think, to be involved... But the medical people in the hospital where he is have never approached me to become involved.'

Three participants commented that they had become more involved with their relatives' treatment over time.

'Those who are caring should be involved in a way that they have knowledge of this. I think when you're close to somebody you know them very well as a person, as an individual. When the person goes into hospital they cannot know everything about them... I needed to say what I wanted for my own self, for the benefit of my son, and I feel for the benefit of mental illness. So there's a greater understanding, it's getting there, it's better.'

Three participants were satisfied with their involvement with their relatives' rehabilitation or recovery but not with their treatment or therapy. They commented that they were not aware of their relatives' treatment plan and would have liked to become aware of it if it existed.

'I have no involvement in any treatment... I was never given the diagnosis for my son... I do play a very important role in my son's life and although I could be five hours a week there, he is in communication with myself... As far as I can see there is no plan, the plans I would love to see...medical plans and rehabilitation plans. It seems to be on the hoof.'

There were no significant differences found in the extent of the satisfaction of participants' involvement of participants with their relatives' care by source of reference of participants to the study, by place of residence of the persons with mental health problems, gender of participants, duration of illness, or any other factors.

## 6.4 Satisfaction of participants with services and support provided to their relatives

Half of the total of 38 participants of the study (n=19, 50.0%) were either dissatisfied (n=7, 18.4%) or very dissatisfied (n=12, 31.6%) with the services and support provided to persons with mental health problems. Eleven participants (28.9%) reported that they were neither satisfied nor dissatisfied, and eight (21.1%) were either satisfied (n=6, 15.8%) or very satisfied (n=2, 5.3%).

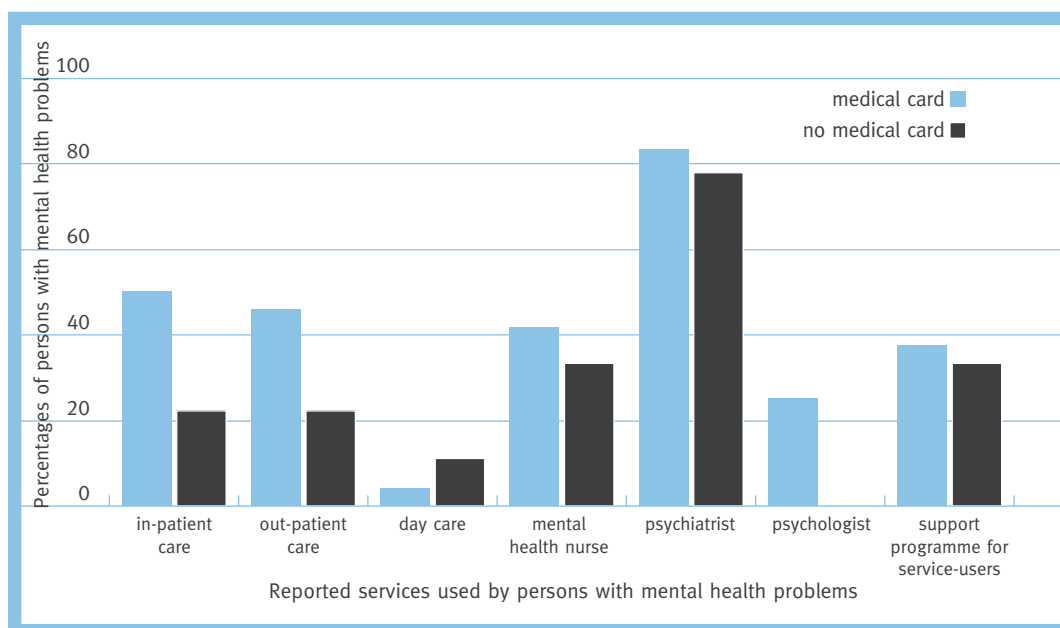
Participants whose relatives resided at home with them at the time of the study were significantly less satisfied (mean=0.86) than those whose relatives resided elsewhere (mean=1.79) at the time of the study [t (36) = -2.37, p= .024]<sup>4</sup>

The reported average level of satisfaction of participants with the services and support provided to their relatives was significantly higher among those participants who reported that they had a specific contact person within the mental health services provided to their relatives at the time of the study (mean=1.81). The level of satisfaction was significantly lower among those who reported that they did not have such contact (mean=1.00) [t (36) = 2.08, p= .045].

The reported average level of satisfaction with services and support provided to persons with mental

<sup>4</sup> Only findings reaching statistical significance are presented in this section

illness was significantly higher among participants whose relatives had medical cards (mean=1.70) than among those whose relatives did not have medical cards (mean 0.82) [ $t(36) = 2.08, p = .045$ ]. In the light of this finding, further analysis of services used by persons with mental health problems at least once a year was carried out. Figure 6.5 shows percentages of persons with mental health problems using various support services, as reported by the participants.



**Figure 6.5** Use of support services by persons with mental health problems at least once a year, as reported by participants, by medical card status

Slightly more services were reported to be used by 24 persons with mental health problems who had medical cards, than by nine persons who did not have medical cards. Half of those with medical cards used in-patient care at least once a year ( $n=12, 50.0\%$ ), whereas less than one-third of those who did not have medical cards used in-patient care ( $n=2, 22.2\%$ ). Nearly half of those with medical cards used out-patient care ( $n=11, 45.8\%$ ), whereas only two who did not have medical cards did so ( $n=2, 22.2\%$ ). A slightly higher proportion of medical card holders used the services of mental health nurses ( $n=10, 41.7\%$ ), than those who did not hold medical cards ( $n=3, 33.3\%$ ). Use of services of psychiatrists was almost equally high among both medical card holders ( $n=20, 83.3\%$ ), and non-holders ( $n=7, 77.8\%$ ), as well as participation in support programmes for service users (compare  $n=9, 37.5\%$  of medical card holders, and  $n=3, 33.3\%$  of those who did not hold medical cards). Only those who had medical cards were reported to use the services of psychologists ( $n=6, 25.0\%$ ).

Participants whose relatives were female reported significantly higher average levels of satisfaction with the services and support provided to their relatives (mean=2.33), than those whose relatives were male (mean=1.17) [ $t(36) = -2.63, p = .012$ ].

Participants who reported that their relatives had a good relationship with their psychiatrist at the time of the study also reported higher average levels (mean=2.33) of satisfaction with the services and support for their relatives, than those who did not report good relationships of their relatives with psychiatrists (mean=1.28) [ $t(36) = -3.41, p = .003$ ].

Participants who felt that their relatives' mental health had improved over time reported higher average levels of satisfaction with services (mean 2.13), than those who did not feel that their relatives' health had improved (mean= 0.95) [ $t(36) = 29.60, p = .003$ ].

The reported average levels of satisfaction with services offered to the relatives were significantly higher among those participants who commented that they were happy with the mental health state of their relative at the time of the study (mean = 2.67) than among those who did not provide such comments (mean=1.07) [ $t(36) = -3.98, p < .000$ ].

Participants who reported higher overall PRADLI scores describing the ability and willingness of their relatives to fulfil some basic daily tasks were significantly more satisfied with the services and support provided to their relatives (mean=1.45) ( $r = .429, n=38, p = .009$ ).

Significantly higher overall PRADLI scores were reported by participants who felt that their relatives' mental health had improved [ $t(34) = -2.77, p = .009$ ] and also by participants who were happy with their relatives' present mental health condition [ $t(34) = -2.67, p = .011$ ].

## 6.5 Summary

To summarise, most of the participants wanted their relatives to have a 'normal life', which included such elements as the abilities to live independently, some employment or occupation during the day, and suitable housing. Living in the family home was viewed as not beneficial for persons with mental illness. Nearly half of the participants reported that their relatives' health had improved. Encouragement, motivation, and taking responsibility were seen by participants as essential tools of rehabilitation, or recovery of persons with mental health problems.

Consistent support from services was viewed as essential for the improvement of health and well-being of persons with mental health difficulties. An holistic approach was advocated by some participants, including both medical and rehabilitation tools such as medication, counselling, services of psychologists and cognitive behavioural therapy (CBT).

Participants felt that rehabilitation was not readily forthcoming from mental health services. Several participants felt that there was a lack of support on the part of mental health services during both 'ends' of enduring mental illness, such as the stage of the onset of mental health problems and the stage of rehabilitation, or recovery.

Several participants commented that the needs and capabilities of persons with mental health problems needed to be explored and assessed in order to find work placement or an occupation best suited to their individual needs and to ensure successful employment.

As reported by some participants, expectations of treatment and rehabilitation of their relatives had become higher over time, following improvement in the mental health and well-being of their relatives. Approximate duration of illness reported by participants did not prove to have any significant effects either on the level of expectation of participants or on the perceived mental health status of their relatives.

Participants with perceived low expectations reported that their relatives were not accepting that they were unwell and resisting treatment or medication, and felt that their relative needed ongoing support from services. The majority of participants who self-rated their expectations as low reported that their relatives were unemployed.

Participants who reported that their expectations had changed and were higher than before at the time of the study also reported that there had been a 'turning point' in the health and well-being status of their relatives after which their health and functioning had improved. This improvement was associated with several events, or factors, including the improvement of mental health

services, effective medication, good relationships with psychiatrists, development of motivation, encouragement on the part of mental health services to make their relatives more integrated in the society and specific rehabilitation programmes offered by mental health services. Two participants who commented that their expectations had changed reported that their two relatives were employed part-time, and a smaller proportion of relatives was reported to be unemployed, compared to that reported by the participants whose expectations were low at the time of the study.

Participants with higher expectations wanted their relatives to become integrated into the community, to find a job or occupation suiting their abilities and needs, and to develop their social skills. The majority of persons with mental illness whose relatives self-assessed their expectations as high were reported to be in training; one person was reported to be employed part-time, and only one person was reported to be unemployed at the time of the study.

Regardless of the reported level of expectations, nearly half of the participants commented that their relatives' health and functioning had improved. A significantly higher percentage of participants who reported that their relatives' health had improved, also reported that they knew whom to contact from mental health services for help or advice.

As reported by the participants, about one-third of their relatives participated in some support programmes or groups for service users. The support resources for service-users reported by participants were different among MHS and for SI recruits.

Nearly half of the participants were satisfied with the extent of their involvement in the treatment and rehabilitation of their relatives, and saw their contribution to their health and well-being as positive.

Half of the participants were dissatisfied or very dissatisfied with the services and support provided to their ill relatives. The level of satisfaction was significantly lower among those participants whose relatives resided in their homes at the time of the study. The level of satisfaction with services provided to their relatives was significantly higher among participants who had a specific contact person within mental health services at the time of the study.

The extent of satisfaction with services and support was also significantly higher among participants whose relatives were female, had medical cards, were reported to be in a good relationship with their psychiatrists, whose health was reported as improved, and whose PRADLI scores of ability and willingness to fulfil daily living tasks were higher. Persons with mental health problems who had medical cards were reported to use more support services than those who did not have medical cards. In particular, the use of services of psychologists only by service users who had medical cards was reported by participants.





## Chapter 7

Current supports, needs  
and views on the future

“ ”

I think that's a huge help to families, it's a very high comfort level, to know that he is in a safe place, that he is being properly looked after, and that his needs are being met, to the best of anybody's ability.

This chapter will describe reported support resources available in the area and their utilisation by participants at the time of the study, reported current needs and support requirements of the participants, and their future plans and aspirations.

## 7.1 Reported use of supports and their availability in the area

### 7.1.1 Reported participation in family support groups or programmes

All study participants were asked to fill out information about their participation in any family support groups or programmes at the time of the study. Twenty seven participants (71%) responded in the questionnaire that they had been using some family support programmes.

The majority of the participants attended SI carer support groups (n=17, 63.0%). This had been expected, as most of the overall sample had been recruited via SI (n=26, 68.4%). Other support resources utilised included educational programme for families with mental illness provided by a catchment area of Dublin outside the MHS (n=12, 33.3%), public family counselling (n=4, 11.1%), an educational programme for families provided by MHS (n=2, 5.6%), and stress management (n=1, 2.8%).

### 7.1.2 Voluntary support resources

Voluntary supports provided by SI, such as support groups, information about illness and treatment, emergency helpline, counselling, lectures, and conferences were highly praised by the majority of participants who used SI resources. In most cases, SI was the main source of support for the family at all stages of their experience with enduring mental health problems:

‘I think over the years the support groups run by SI are the one thing that has been the most help for us in coming to terms with the illness and understanding what it is, and how to respond to a relative, you know, because in the early years, firstly I just didn’t know how to respond, over the years I hope I’ve learnt a lot, and I think it’s important for the relatives to accept the situation. If the relatives don’t accept it, there’s very little chance of the person who is ill themselves accepting the situation.’

### 7.1.3 Perceived differences in availability of support resources in different areas

Several participants commented that some of the support resources that they were using, such as SI or MHS support groups, nurses, and other resources were not available in their catchment area:

‘Well I attend a parents group, it’s way out of my area, I think they are very aware of what’s required... That’s another thing with the mental health services, it depends on where you are living, you know, you have to go to the hospital within your area and the difference in one area and another is horrendous, huge, it’s unbelievable...’

'From going to family support group, I found that there's so much stuff there, there's so many openings, they were saying to the other people in the class, the other carers, like if you need something ring this number, you'll get one of the support nurses... and because it was very nice of them to let me go on the programme in the first place, it's a different area altogether, so I was very grateful for that family support programme, but at the end of the day there's nothing else, we can't contact any of those nurses, the social worker, nobody, it's not our area at all, we're confined... Nothing that we are aware of, just support groups.'

#### **7.1.4 Other supports in the area**

In addition to participation in family support groups and programmes reported by the participants in the written questionnaires, participants also mentioned friends, relatives, public counselling, private counselling, and some others (see Table 7.1) as available support resources. On the basis of the data collected by written questionnaires, and reported during the interviews, a full list of support resources available to the participants was identified and compiled (see Table 7.1).

Twenty various supports were reported by participants. Participants reported using multiple resources, up to four per participant, resulting in a total of 75 reported uses of resources (see Table 7.1). For the purposes of the analysis, support resources were divided into broader categories of formal and informal support for families. Formal support included family education programmes provided by the MHS of two catchment areas of Dublin, family support and advocacy groups provided voluntarily by SI and AWARE, and public and private counselling (n=40, 53.4% of reported total use). The rest of the supports were informal (n=35, 46.6% of total reported use) and included individual information resources, social support, informal family consultation or crisis intervention provided by community nurses or social workers and stress management such as the Alexander Technique.

**Table 7.1** Categories of support resources used by the participants at the time of the study

Formal family support resources used by participants		
Voluntary resources		
	Number of responses	Percentage of the total use of resource by participants
Support groups and other resources of SI	17	22.7%
AWARE	1	1.3%
Nar Anon	1	1.3%
Public or private resources		
Another catchment area educational programme	12	16.0%
MHS educational programme	2	2.7%
Public counselling	5	6.7%
Private counselling	2	2.7%
<b>Total reported use of formal resources</b>	<b>40</b>	<b>53.4%</b>
Informal family support resources used by participants		
Social support in the area		
Friends	7	20.6%
Relatives	3	8.8%
Neighbours	3	8.8%
Guards	1	2.9%
Clergy	1	2.9%
Information resources		
Buy own books	4	11.8%
TV	3	3.8%
Public library	2	5.9%
Lectures	1	2.9%
Internet	1	2.9%
Informal family consultation/crisis management resources		
Community psychiatric nurse	5	14.7%
Social worker	3	8.8%
Stress management		
Alexander Technique	1	2.9%
<b>Total reported use of informal resources</b>	<b>35</b>	<b>46.6%</b>
<b>Total reported use of all resources</b>	<b>75</b>	<b>100.0%</b>

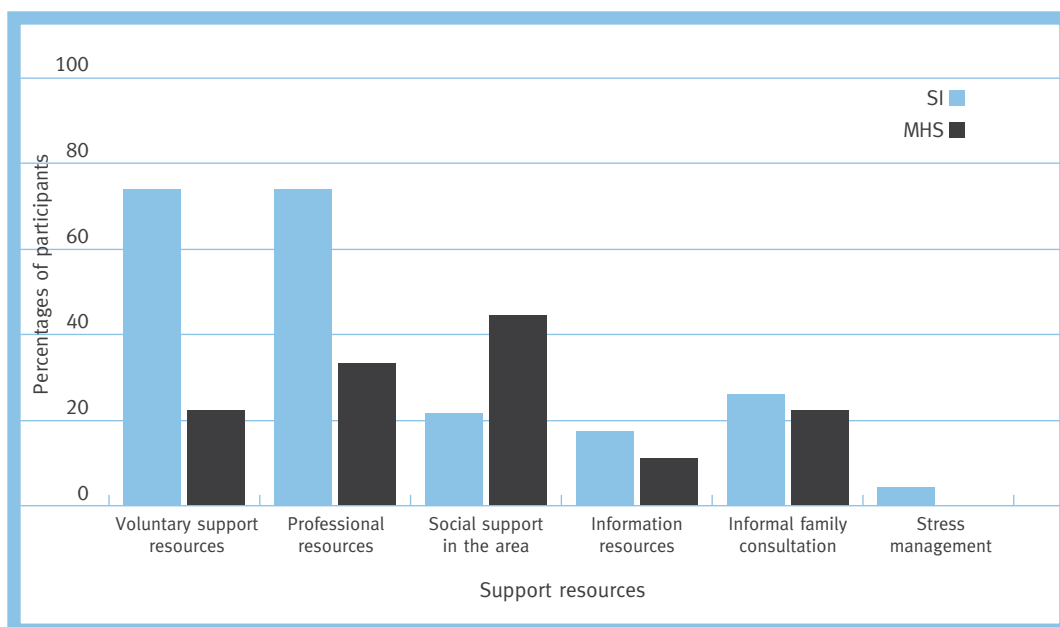
Out of the total 38 participants of the study, 27 (71.1%) used formal resources for families, and 20 (52.6%) used informal resources. Out of 27 participants who used formal resources for families, the majority (n=19, 70.4%) used voluntary resources of SI, AWARE, and support group for families with drug abuse (Nar Anon).

The five most frequently reported support resources used by the participants were support groups and other resources of SI (n=17, 44.7% of all participants), educational programme of other catchment area (n=12, 31.6%), friends (n=7, 18.4%), public counselling (n=5, 13.2%), and the services of the community psychiatric nurse (n=5, 13.2%).

### 7.1.5 Professional family support resources

Three reported types of formal support resources were offered to the participants by the public mental health services within their catchment areas. These were: educational programme of a catchment area outside of the MHS (n=12, 35.3%), the MHS educational programme (n=2, 5.9%), and counselling offered by public mental health services (n=5, 14.7%).

In total, less than half of the participants in the study (n=18, 47.4%) reported that they were using professional support resources for families offered by mental health services of their catchment area. The majority of these (n=16, 88.9%) were recruited via SI support groups (see Figure 7.1). Only two relatives of MHS service users reported use of the MHS support programme, and one relative reported using public counselling of the MHS.



**Figure 7.1** Categories of support resources used by participants at the time of the study, by source of referral to the study

As can be seen from Figure 7.1, not only did participants of SI group use more voluntary support resources, than those recruited via MHS, they also used more professional support resources, more information, family consultation, and stress management resources. Participants recruited through MHS seemed to be relying more on informal social support in the area (n=4, 44.4%).

### 7.1.6 Lack of information about support resources

As reported by several SI participants, information about supports had not been available until they joined SI and started to participate in family support groups:

'I just looked for it myself, nobody told me about SI, you know. So I went looking for it myself, and when I started looking, say contact SI, and they say "Well there is a support group..." "Oh, that's very good, I'll get in touch with them." By word of mouth.'

There seemed to be much less availability and information about supports in the MHS catchment area:

'There is definitely no support groups... Some parents find that because of lack of information they are not able to go forward, and they're not able to set up these support groups.'

### 7.1.7 Limitations of existing support resources

Two participants recruited via SI mentioned that it was difficult for them to participate in support group meetings as they were held too early in the evening on working days:

'Well SI is very good, there's an educating thing which I put my name down for and I can never go because it's very early in the evening, it's half-seven, and it's not very easy for me to get there...'

Several participants commented that the SI voluntary helpline was very helpful, though it was open only several hours a day:

'You can ring the helpline, but it is not always open. Remember, they are volunteers.'

### 7.1.8 Effectiveness of various support resources at different stages of family experience

Four participants recruited via MHS (33.3%) and three participants of SI (11.5%) commented that they were not looking for any support resources at the moment, as their relative and themselves were getting enough support from mental health services and they felt that they did not need to participate in any support groups.

'So that part of programme is in place, and they're looking after her, and of course, myself and my wife go down to meet a counsellor in the hostel, and we do some counselling ourselves around the issues that we have...I went to one meeting, a schizophrenia meeting, but as I say, I don't think it was helpful to us... I don't think we need a great deal of support... and I'm satisfied that if we need advice or counselling it's there and it's close by.'

'SI, they did ring up...I don't know what support resources they have in SI, they have meetings in the evenings once a month... But we are not in dire straights, we find two to one counselling more effective.'

### 7.1.9 Use of existing support resources by participants by place of residence of their relatives

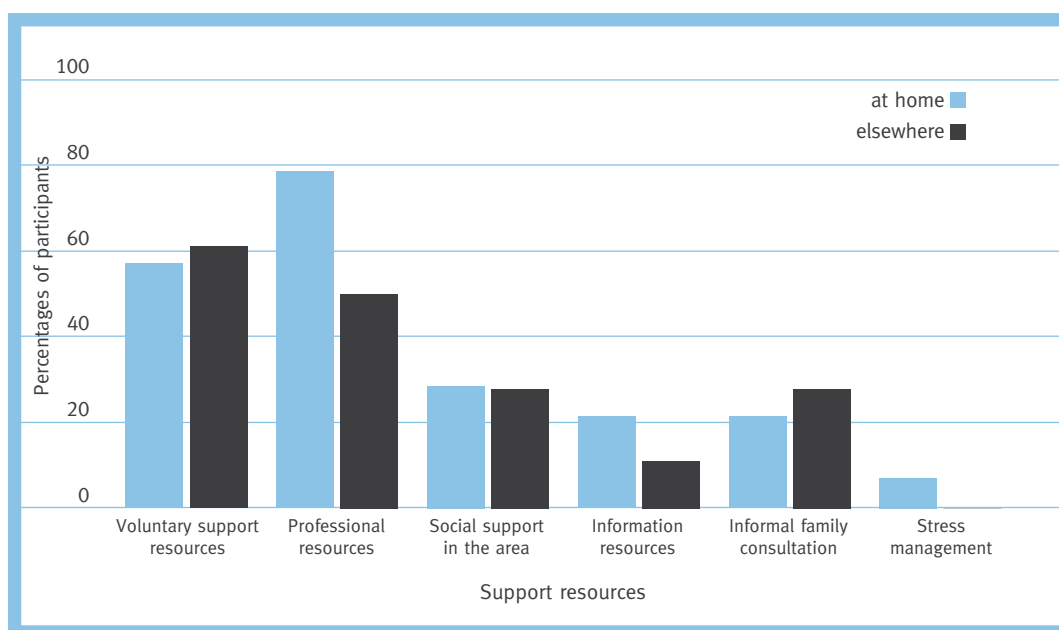
A higher percentage of SI participants were residing with their ill relatives at the time of the study (n=14, 53.8%), and all the MHS service users were residing elsewhere (n=12, 100%), namely, in an independent accommodation, in a community residence, or in in-patient units. The reported duration

of mental health problems in the family was slightly higher for those relatives who resided elsewhere away from family home (mean =20.1 years), than for those who resided at home with participants (mean 12.6), [  $t(31) = -1.93, p = .063$ ]. One of the possible explanations of this fact would be that the participants whose relatives with mental health problems were residing at home at the time of the study were at earlier stages of their experience with mental illness. Their support requirements could have been somewhat different from those whose relatives were living elsewhere.

Indeed, reported support resources used by participants whose ill relatives resided with them were slightly different from those whose relative resided elsewhere at the time of the study (Figure 7.2).

The majority of participants whose relatives resided at home tended to use more professional support resources ( $n=11, 78.6\%$ ), such as public or private counselling, another catchment area educational programme, and MHS educational programme for parents, as compared to those whose relatives resided elsewhere ( $n=9, 50.0\%$ ). They also tended to use slightly more informational resources ( $n=3, 21.4\%$ ) than those whose relatives resided elsewhere ( $n=2, 11.1\%$ ).

However, both residential groups tended to use voluntary support resources quite often, with the percentages of usage being almost equal for those whose relatives resided at home ( $n=8, 57.1\%$ ), or elsewhere ( $n=11, 57.9\%$ ).



**Figure 7.2** Categories of support resources used by participants at the time of the study, by place of residence of persons with mental health problems



## 7.2 Contact with mental health services for help and advice

More than half of the participants in the study (n=21, 55.3%) reported that they knew whom to contact from mental health services in case of emergency, or if they needed some information or advice regarding their relative with mental health problems.

Less than half of the participants recruited via SI (n=12, 46.2%) knew whom to contact within the mental health services if needed. In contrast, the majority of MHS recruits (n=9, 75.0%) had a personal contact with mental health services for help and advice. Although not statistically significant for the total sample, these differences were quite pronounced [ $\chi^2(1) = 2.76, p = .096$ ].

Out of 21 participants who reported having a contact with mental health services, ten (47.6%) felt that they could contact psychiatrists of their relatives, seven (33.3%) reported that they could approach psychiatric nurses, two (9.5%) were in contact with the secretary of psychiatrist, and two (9.5%) were in contact with care workers of their relatives.

‘She’s at home, she just goes to see her psychiatrist every couple of months, but if there’s a problem we can ring him and he’d see her immediately...’

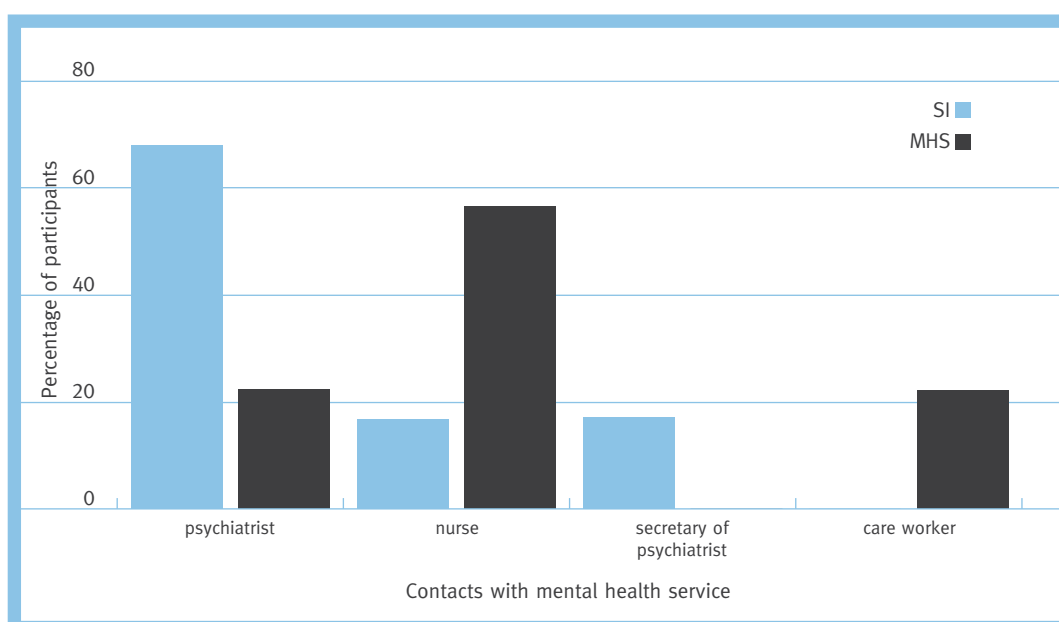
‘I think at the moment it would be the counsellor that I’m dealing with... And all the psychiatrists... are very available, we have phone numbers and they’re very contactable, and always ready to talk and discuss whatever concerns are... But we don’t abuse it, but we feel there’s a contact there, if we need to lift the phone they’ll answer, they’ll discuss it, so we’re happy enough that there’s that sort of backup for us, you know.’

### 7.2.1 Contact with mental health services for help and advice across the two groups of participants by source of their referral to the study

As can be seen from Figure 7.3, most of the SI participants (n=8, 66.7%) reported that they could contact the psychiatrist of their relative, whereas only two relatives of MHS service users (22.2%) could do so. Two SI participants (16.7%) could contact the psychiatrist via their secretary, whereas none of MHS participants reported secretaries as their contacts. However, the reverse scenario emerged in relation to contacting nurses and care-workers. Whereas more than half of the MHS participants who reported being in contact with mental health services (n=5, 55.6%) could contact nurses of their relative, only two SI participants (16.7%) reported nurses as their contact, and none of SI participants reported being in contact with care workers of their relative.

‘Some of the nurses there’re very, very compassionate, and very cooperative, and that’s as far as it would go really.’

‘The secretary, I would ring the secretary...The secretary can’t do a whole lot either, she’d say ‘I’ll promise you I’ll get back.’”



**Figure 7.3** Available contacts within mental health services, as reported by the participants, by source of referral to the study

### 7.2.2 Limitations of available contact with mental health services for help and advice

Some of the participants commented that, though they had a contact with mental health services, they could avail of it only during certain hours or days of the week, whereas the persons with mental health problems could have become unwell at any time:

'You can contact the clinic thirty four hours a week. But what happens, life goes on twenty four hours a day, like when he went missing.'

### 7.2.3 Perceived availability of contact with mental health services for help and advice across public and private sectors

Three SI participants whose relative had been discharged from, or was using private mental health services at the time of the study, reported that there was no social worker, psychiatric nurse or psychiatrist that they could easily contact in case of emergency or for any queries after discharge:

'There's no social worker involved. Normally it's the social worker, ideally a psychiatric nurse, they're the people who should know, and I think if you're in the private service you don't seem to have anything, apart from them seeing the psychiatrist and the medication.'

However, there were not enough social workers in public services either, as reported by some of the participants:

'On one occasion when she was in hospital... I rang one morning to ask to speak to a psychiatric social worker, to be told there wasn't one for the whole area.'

Two SI participants whose relative was using public out-patient services also commented that they had no contact with the services and were getting no replies to their calls or written correspondence:

'I have so little contact with them it's disastrous... They're completely indifferent. They sent a letter, you know, please attend for an out-patient...They say you can contact them but there's no response. I have called them and asked them to keep our management programme... They haven't replied...You know, you just badger, unless you badger you get nothing.'

#### **7.2.4 Perceived reasons behind the lack of contact with mental health services for help and advice**

Four participants commented that there was no point in trying to contact anybody from mental health services because they were too busy, because the previous contact retired, and because previous appointments were not kept.

'The psychiatrist who had been dealing with my son retired about two years ago...The new psychiatrist I think is very good, but we haven't seen him at all... like he gave a talk to our support group one day, but he was saying that he had so many patients... it was an impossible number of patients, and he doesn't have much of a back up in the way of psychologists, social workers, nurses, you know, very thin on the ground.'

#### **7.2.5 Available contact for help and advice for families outside mental health services**

In cases when no contact was available from mental health services for help and advice, participants contacted their GPs, SI helpline, or the guards:

'Well I have the GP I told you about... he would allow me to come in and talk about it.'

'...to be able to ring somebody if he gets agitated... or anything....there isn't anything like that, like the night that that incident happened with me, the only people I could turn to were the guards and I didn't want that but I had to do it, instead of being able to ring somebody in the psychiatric.'

### **7.3 Reported needs of participants at the time of the study**

Most current needs and support requirements reported by the participants were closely connected with the perceived needs and support requirements of treatment and rehabilitation of their relatives.

#### **7.3.1 Interaction of reported needs of carers with perceived needs of persons with mental health problems**

Table 7.2 presents reported support requirements of participants, roughly grouped into three categories of the perceived needs of carers and families, perceived needs of persons with mental health problems, and joint needs of carers and persons affected by mental health problems. As can be seen from Table 7.2, more than half of the reported current needs and support requirements of participants (n=43, 55.7%) were associated with the health and well-being of their relatives, such as their accommodation, employment, treatment, and rehabilitation. About one-third of the perceived needs (n=26, 29.5%) directly involved relatives, such as home help, respite, advice from services, and approachable contact with mental health services. The third category could be described as needs involving both carers and sufferers (n=13, 14.8%), such as a 'mediator' between the carers and the person with mental health problems, research on recovery, and involvement of the general public in discussions and research on mental health and mental illness.

**Table 7.2** Reported current needs and support requirements of participants and their families, and of the persons with mental health difficulties

Reported current needs and support requirements for carers and families		
	Number of responses	Percentage of total reported needs of participants
Home help	1	1.1%
Respite care	1	1.1%
Information about treatment	6	6.8%
Information about illness	2	2.3%
Approachable contact within services available at all times	5	5.7%
Ongoing advice from services	4	4.5%
Support from services on discharge	3	3.4%
Advice on 'how to deal' with person	3	3.4%
Family and friends network	1	1.1%
<b>Totals</b>	<b>26</b>	<b>29.5%</b>
Reported needs and support requirements for persons with mental health problems		
Encouragement	3	3.4%
Speech therapy	1	1.1%
Persuade the persons to take medication	4	4.5%
Help the persons accept their illness	4	4.5%
Help the persons build up trust in doctor	3	3.4%
Community nurses	4	4.5%
Advice and help with employment	3	3.4%
Social skills training	2	2.3%
Outreach services	2	2.3%
Advice and help with housing	7	8.0%
Advice on how to make a will in the persons' best interests	2	2.3%
Suicide and self-harm prevention and management	3	3.4%
Regular discussions on medication, its side-effects, and change	5	6.1%
Social worker	3	3.4%
Psychologist	3	3.4%
<b>Totals</b>	<b>49</b>	<b>55.7%</b>

**Table 7.2** Reported current needs and support requirements of participants and their families, and of the persons with mental health difficulties

Reported current needs and support requirements for carers and families		
	Number of responses	Percentage of total reported needs of participants
'Mediator' between families and persons with mental health problems	9	11.0%
More research on recovery	3	3.7%
Involve general public in discussions and research on mental illness	1	1.2%
<b>Totals</b>	<b>13</b>	<b>14.8%</b>
<b>Total reported needs</b>	<b>88</b>	<b>100%</b>

### 7.3.2 Key worker or mediator

As can be seen from Table 7.2, over one third of the participants (n=9, 34.6%) felt the need for some contact person, be it a key worker, or a case worker, for the family. As explained by participants, this person would act as a mediator between the family and the person with mental health problems on an ongoing basis, and especially at times of crisis:

'I feel if there was somebody specifically there that could have helped us, maybe not at the psychiatrist level, maybe at a lower level, somebody who could have taken over... built up rapport with him and actually got down, I think at the end of the day it probably would have been just a question of talking to him, and that's what we needed...Somebody, a mediator, somebody we could have rung up and said, can you guide us to what to say to him...So we kind of feel there's a gap there and if we had somebody there that could have filled that gap... that could have helped us, that would have been terrific.'

### 7.3.3 Accommodation for persons with mental health problems

The next frequently mentioned need was advice and help with housing for persons with mental health problems (n=7, 26.9%). Several participants felt that it was not beneficial for mental health of their relatives to live in the home of their childhood, as it hindered their rehabilitation and in some cases led to relapse of mental health problems.

'The whole question of housing... They're back in the family home in the same conditions they were when their illness developed and this is one of the major causes of relapse.'

'Well I asked for housing every time, could they put him in even for a while, and the answer was "No he's not bad enough..." There's no place for him and he's not bad enough.'

Participants felt that it was not just accommodation per se that their relatives needed, but some kind of sheltered, or supervised accommodation, so that somebody from mental health services could 'keep an eye' on their relative in the times of crisis.

'Even if she is living in a house of her own that there would be a psychiatric nurse locally that would maybe keep an eye on her'.

'I don't think (housing) is entirely the local authority because the local authority as such don't employ health workers and everything and can't supply the support that's needed. They can supply the housing but the support has to be provided by the health services.'

### 7.3.4 Information about treatment and medication of persons with mental health problems

Information about treatment (n=6, 23.1%) and medication (n=5, 19.2%) was also viewed as important by participants. Several participants were 'worried' about the medication and its side-effects on their relative:

'I worry about the medication as well...being conscious of the long-term effects of the medication, that worries me... I used to know the medication off by heart, but I'd still like that to be reviewed and maybe a discussion with my son and with us, a review of medication, just to know more about it, I'd like somebody with an open mind.'

'Well I would have loved if he had not been on so much medication, one of my priorities and I always think that he's on too much of it.'

### 7.3.5 Advice on 'how to deal' with persons with mental health problems

Four participants (15.4%) were concerned that their relative was not taking medication, or not accepting their illness. They felt they needed some advice from services on 'how to deal' with the person in order to make the person accept the illness and take some of the burden off the family:

'How to deal with the condition and how to deal with my son, because he is in total denial about it, he doesn't think he is sick... So he was invited to a meeting with the psychiatrist and it was just empathy and no action, loads of empathy, empathy is no use to us, we need action... I asked the psychiatric nurse about the housing problem... So a psychiatrist and a psychiatric nurse both asked me what was the solution, I don't have it, I only have enough that I can protect myself and my daughter and I've done as much as I can around that... Years into his condition, my family are bored with it, do you know, and I'm bored telling the story... I'm not happy at the service that we've received and that he has received.'

'Well my most important requirement now would be that he would put the trust in this doctor, and he would take whatever they prescribe for him... Less stress for us because it means that there's something being done about him you know, rather than as it used to be you'd have to call the police and the ambulance and they have to put him in, I wouldn't like that to happen to him.'

### 7.3.6 Encouragement of persons with mental health problems

Participants perceived that their relatives needed some kind of encouragement and involvement on the part of the services, in order to aid their rehabilitation and recovery:

'Key worker who he would trust enough that he'd be able to go and have a cup of coffee and have a chat with him and see how he's going or if he's not getting a job, help him get a job or that kind of thing...There should be some support systems that would minimise future costs of hospitalisation... I think if he comes out in hospital and goes into some kind of flat or something, that's exactly what he'll end up doing, just sitting there doing nothing, so there is a definite need for some kind of way of involving him, but if he's refusing it I don't know if people can encourage him, he's got to see the need for it himself, and how do you get people to that point I don't know.'

### 7.3.7 Research and information on recovery of persons with mental illness

Three participants felt that more research and information on recovery would help their relative and themselves as it would give them hope, aid recovery of the person, and help to fight stigma of the mental illness:

‘...they talk about recovery, this is where I’m baffled, recovery, it’s a great word but how does it happen without us being there, how does my son recover to a certain degree? I want him to recover, I don’t expect him to be perfect because if you have an illness you have an illness but if there’s recovery, what level of recovery, or how do you get on to that stream of recovery, who communicates with who so as this person can be seen? Not just to take tablets after five years, that there is some sort of thing happening to them in a little way that people say.’

### 7.3.8 Prevention of self-harm and suicide

Suicide and self-harm prevention and management were reported by the participants as their most serious concerns and support requirements. Participants felt that a lack of ongoing support from services on discharge and during relapse, and the lack of communication with the services were adding to the risk of suicide by the person with mental health problems:

‘And a large proportion of people committing suicide have mental illness, schizophrenia in particular, and this is due to the lack of community service once somebody is discharged from hospital. I mean if they don’t choose to keep in contact with the services the services don’t keep in contact with them, and they very soon forget about the services altogether, and when they run into problems and get depressed they just see no hope for the future and I think this is why so many commit suicide.’

‘...Huge lack of communication with the hospital, my son is the patient, those services should be there, to help him...It’s not as if I am on the phone day or night or whatever, but when I am on I would like to be listened to, it’s over a year since the last time, but why do they wait till the crisis? It’s like telling me you can’t go to A & E, you have to go at a time like, do you know what I mean? And then no follow up.’

### 7.3.9 Legal advice in the best interests of persons with mental illness

Two participants commented that they needed advice on how to make their wills to ensure that the person with mental health problems would benefit from them in the future:

‘I’d like advice now on how I’m supposed to make a will, I have a will made but how I can make a will to protect her.’

### 7.3.10 Social skills training for persons with mental health problems

Two participants felt that their relative needed some kind of training in social skills to improve their interaction with the outside world and to aid their employment opportunities. Other needs and support requirements of participants included home help, speech therapy for a relative, respite care, forming a family and friends network, and involving public in discussions about mental illness and treatment in order to tackle the stigma associated with mental illness:

‘Maybe if there was a service out there for, people can get together and do something actively, rather than people just supporting each other though their individual families and friends...and if there is something I am completely unaware of it, so that really says it all, doesn’t it?’

'I mean maybe they could bring some members of the public in to try and educate about stigma for example. I mean we have a session where everybody talks about their own troubles or we share experiences confidentially, but there's no open day where people from the public will be specifically, "Come in, come in everybody and we'll tell you how the other half lives"...We'd have to leave that to SI and the media.'

### **7.3.11 Comparison of needs reported by participants by place of residence of persons with mental illness at the time of the study**

As can be seen from Figure 7.4, the ten most frequent support requirements reported by the participants whose relatives resided at their home (n=11, 42.3%) were: information about treatment (n=5, 45.5%), information and discussion of medication (n=4, 36.4%), advice and help with housing (n=4, 36.4%), help from services to persuade the persons to take medication (n=4, 36.4%) and to accept their illness (n=4, 36.4%), a mediator between the persons with mental illness and the family (n=3, 27.3%), social worker (n=2, 18.2%), advice on how to 'deal' with the person (n=2, 18.2%), psychologist (n=2, 18.2%), and more research on recovery (n=2, 18.2%) (Figure 7.4).



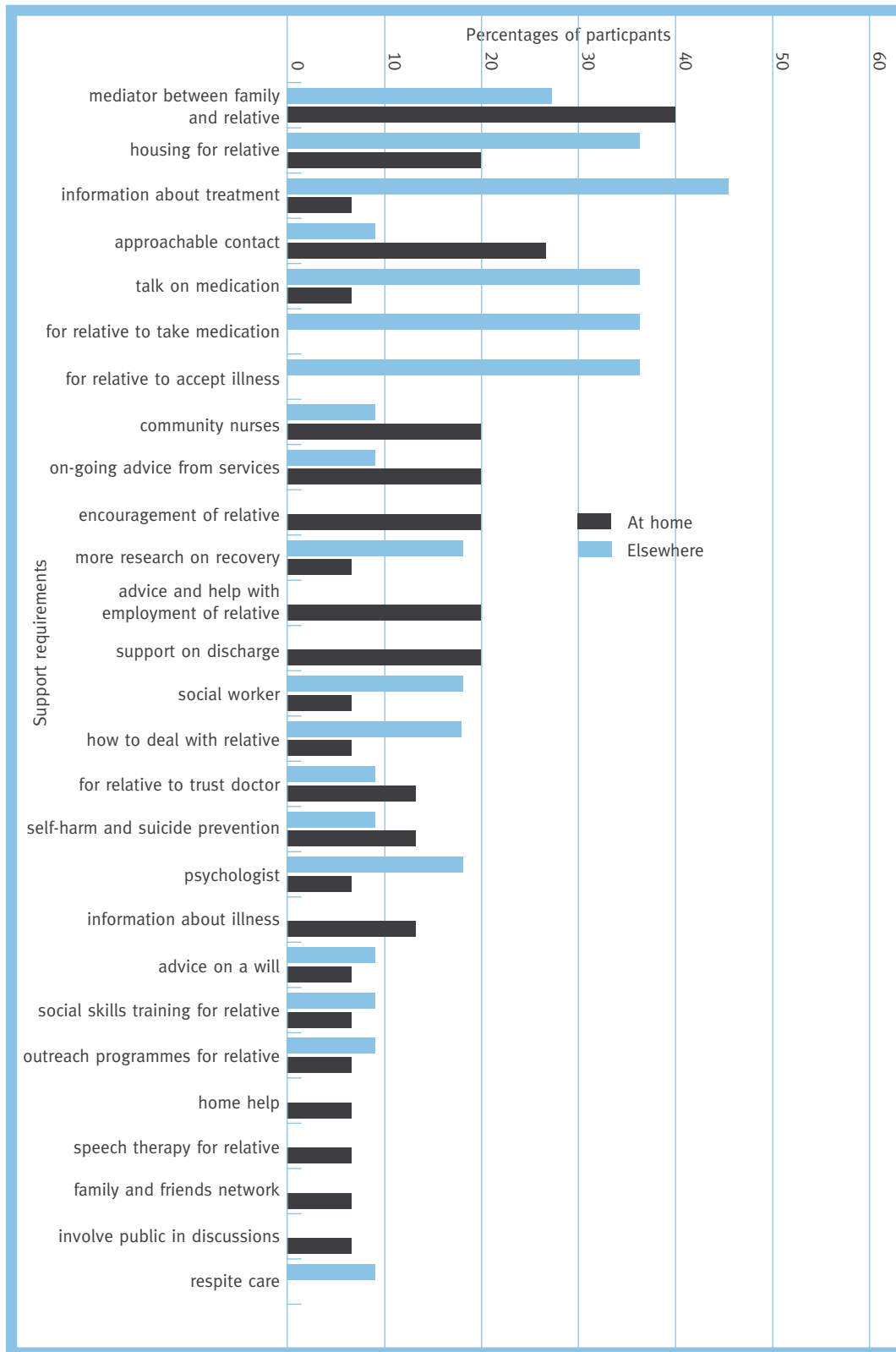


Figure 7.4 Percentages of current support requirements of participants by place of residence of their relative

As for those participants whose relative resided elsewhere (in independent accommodation, in an in-patient unit, or in a community residence) (n=15, 57.7%), their ten top priorities included a mediator (n=6, 40.0%), approachable contact within services (n=4, 26.7%), information and help with relative's employment (n=3, 20%), support on discharge (n=3, 20.0%), advice and help with housing (n=3, 20.0%), ongoing advice from services (n=3, 20.0%), encouragement of the person with mental health problems (n=3, 20.0%), community nurses (n=3, 20.0%), information about illness (n=2, 13.3%), and the relative's trust in his or her doctor (n=2, 13.3%).

As can be seen from Figure 7.4, the only request for home help was expressed by a participant whose relative resided elsewhere, namely, in an in-patient unit. The participant commented that she would not have minded that her relative was discharged home at some stage, but she felt that without home help she wouldn't be able to provide care for her relative.

'At my stage now you wouldn't get full time back up and I don't think I'd be able for him all the time. Well I'd like somebody, such as when I'd go to the shops, somebody there with him. Yeah and if it's a thing that he needed to have a bath, things like that you know.'

## 7.4 Satisfaction of participants with services and support provided to themselves and their families

Most of the participants (n=23, 60.6%) were either dissatisfied (n=14, 36.8%) or very dissatisfied (n=9, 23.7%) with services and support offered to themselves and their families. Four participants (10.5%) were neither satisfied nor dissatisfied, and 11 (28.9%) were either satisfied (n=10, 26.3%) or very satisfied (n=1, 2.6%).

There was a significant positive relationship between the levels of satisfaction of participants with the services and support provided to their relatives and satisfaction of participants with the services and support provided to themselves and their families. Participants who were more satisfied with services provided to their relatives were also more satisfied with support provided to themselves and their families ( $r = .378$ ,  $n=38$ ,  $p = .019$ ).<sup>1</sup>

Participants whose relatives resided in their homes were significantly less satisfied with services and support provided to themselves (mean=0.71), than those whose relatives resided elsewhere at the time of the study (mean=1.92) [ $t(35.94) = -3.82$ ,  $p = .001$ ].

Similarly to findings presented in Chapter 6, participants whose relative had a medical card were significantly more satisfied with services and support provided to themselves and their families (mean=1.74), than those whose relatives did not have a medical card (mean=0.82) [ $t(26.07) = 2.607$ ,  $p=.015$ ].

## 7.5 Views of participants on the future

The majority of participants (n=35, 92.1%) provided information on how they saw the future. In most cases, when asked about their plans for the future, participants spoke about their hopes and concerns regarding the health and well-being of their relatives (n=31, 88.6%). Four participants (11.4%) spoke about their own plans and hopes for the future.

<sup>1</sup> Only findings reaching statistical significance are presented in this section

### 7.5.1 To be of service

Most of the parents expressed a wish to stay healthy and energetic as long as they could in order to be of service to their relative. They worried what would happen to their child and other family members after they were gone.

'I just hope to live as long as possible to be of service, to be of help to my daughter and the others.'

Three mothers and one father mentioned that they had been diagnosed with some progressive illnesses, such as cancer, Parkinson's, or diabetes. They were worried that because of their illness they might not be able to provide adequate support to their relative:

'I've been there for him basically all the time, now whether it will continue for the rest of my life or whether it will come to an end or whether it will move up I don't know... my own health is one thing, but it's relatively part of...whether I'd be able to do something... It's always giving myself the option of being available.'

A mother felt that she was not providing as much support to her son as previously because of her progressive illness. She hoped that she would not become dependent on him in the future:

'Well because I have a progressive illness which I intend to fight the best I can and hopefully remain on my feet as long as I can, I would hate to become dependent, because I know that he worries about me and I suppose the future, because I had hoped to remain healthy and active and stay involved with him and fight his corner really.'

A mother was worried that when she became older one of her grandchildren might become a carer of her daughter with mental health problems:

'I just hope that I can be there for her, you know, that's the thing, that's the problem ... That the boy in ten years time... doesn't become a carer.'

### 7.5.2 Community services meeting the needs of persons with mental illness

Seven participants hoped that their relatives would get enough support from both services and the community in the future, so that their needs were met. This was perceived as one of the most important needs of participants:

'I think that's a huge help to families, it's a very high comfort level, to know that he is in a safe place, that he is being properly looked after, and that his needs are being met, to the best of anybody's ability.'

### 7.5.3 Employment and accommodation of persons with mental health problems

Employment and housing for the person with mental health problems were mentioned by participants among their worries and hopes for the future of their relatives.

Six participants felt that employment played a major role in the quality of life of persons with mental health difficulties:

'Well that is the big worry, that is the very, very big worry and that's what I would like to know, if somebody could say to me, "Well at some stage your daughter will be fine, she'll be employable." But nobody has said anything to me, so I'm in limbo at the moment, is she ever going to be able to work, who's going to support her, I'm not in a very good financial situation.'

Independent or sheltered housing with some kind of supervision or support was also viewed as one of the 'keys' to the persons' future independence and quality of life by six participants:

'I hope that in the next year he will find some kind of accommodation, where he can start some kind of independence. At the moment he has absolutely no quality of life, I mean he sleeps all day, stays up all night, without any care for people around him...So ideally I would love to see him either on a training course or in some kind of job, but definitely in some kind of supported environment, you know that there was someone checking up on him, to see that he's doing OK.'

#### **7.5.4 Social and coping skills training for persons with mental health problems**

Several participants felt that their relatives needed some kind of coping skills or social skills training in order to become and stay employable. This was considered especially important given the high anxiety levels and the competitiveness of the modern working environment:

'Some kind of programme to get him into...a working environment...I know recently he talked to a social worker in the clinic and he said he got quite nervous talking to her, and kind of got a panic attack... in his present state, I don't think he's actually capable of working.'

'He draws a lot, now that's his hobby and he loved this course, but the job coach whom I met at a meeting said that he enjoyed the course but he hasn't a hope of getting a job in that because it's too competitive.'

#### **7.5.5 Ensuring independence and quality of care for persons with mental illness**

Two participants commented that they were trying to ensure in their wills that their relatives were financially and residentially 'independent' in the future, and that nobody could take advantage of them:

'I tried to go and make a will, I tried to make my daughter independent by giving her stock and she's a fair portfolio of stock... because they have no interest in property.'

One participant was buying a house for his daughter in the same catchment area to ensure continuity of her treatment at the same hospital and the same level of services:

'I'm trying to buy a house for my daughter, which can be a home for her in a few years time so she wouldn't be a burden on the state... And it will be left in trust to her because then nobody can take advantage of her. The catchment area we're in is so expensive... Yeah, you have to be in the catchment area, I would like her to stay in the same system that she is and the same hospital.'

#### **7.5.6 Help from society for persons with mental illness**

Four participants were hoping that their relative would recover in the future and lead an active and happy life. One of the participants commented that for their relatives to 'move forward' it was necessary that there was some help from the society:

'I think if something different happened to him, I think he would be good in society, he would be able to get a job, but if nobody has any interest in him outside his mother and father how can you move forward, like if nobody cares about these people, lots of people like this are going to be around, they say one in 100, one in 100 is quite a big number isn't it...'

### 7.5.7 Physical health of persons with mental health problems

Two participants were concerned about the physical health of service users because of their unhealthy living habits and possible side-effects of their medication:

'And ideally I'd like to go down on the route of nutrition, ...they actually do a blood test to find out what is wrong with the patient, which the psychiatric hospitals don't do...Everyone is treated the same with anti-psychotic drugs which don't seem to do any good, they stop the patient being psychotic but they have all other side effects of lessening motivation and there are hundreds of side effects... tremor, you know I see all the patients and they all ramble around.'

'I hope that his team also tries counselling and some kind of programme to get him off smoking, to improve his future...General health, because there's no point in curing his mind, if his physical health is damaged by smoking. And it has to be seriously impaired with the amount of cigarettes he smokes.'

### 7.5.8 'Getting on' with own life

Four participants spoke about their own plans for the future. Two participants whose relative resided in their homes at the time of the study were hoping to lead their lives independently from their relative in the future:

'Well in my future I think the only way for me to continue, I'll probably end up travelling hopefully... I feel like, there is no future with her, I've gotten to the stage where... We've tried for years you know, I don't see any way of having a normal relationship with her.'

One mother commented that she just wanted to have a quiet life and that she had no energy to 'go back and fight' with the services to ensure that her son who was living at the house was getting support or sheltered accommodation from the services:

'I just want to shut that out of my life, and they're all "Oh you should go back and fight", I don't have the energy and I don't want to... So I just want to have that over and done with it, I've no big plans or anything like that, I'm getting to the stage in life where... a quiet life is all I want, just doing what I like.'

### 7.5.9 Positive outlook on the future

Most of the participants who provided their views on the future (n=28, 80.0%) felt relatively optimistic about both their relative's and their own psychological well-being:

'With an odd blip here and there, it's better than anticipated... He is some help. He's good at buying stuff and getting stuff, he'd know exactly what to get, I wouldn't have a clue...So that's a big advantage. And I can leave him, and I mean everything will be in order...he'll have the wash up done and he'll have it in order. Yeah, it's a big plus now.'

'At the moment we're very happy with the situation and as I say he's living a very normal life now which is more than we ever hoped for.'

One participant felt optimistic about the changes taking place within the mental health system:

'If the man above lets me live for another maybe four years...all this medication, hospitals, a bit of change anyway... But in general hopefully all these things, they'll never be fully sorted out but it will be a better place, it will be a better place for residents, a better place for staff in four years time hopefully, that's how I read it.'

### 7.5.10 No hopes for the future

Five participants commented that they had no hopes for the future for either themselves or their relative, or that the future was 'bleak'. Some of these participants reported that their relative was not accepting that they were ill and needed treatment. Relatives of participants who commented that they had no hopes for the future were using private in-patient or out-patient mental health services at the time of the study. The reported duration of illness of the relatives of these participants ranged from two to thirteen years.

'Very bleak, very depressing, because of the situation... I just do not see, unless there's some special person, some angel that can come along and convert him, I feel it is going to be very depressing and very lonely in the sense that it's a battle that we're going to go along with ourselves, and I don't see myself telling certain people.'

'I think the only thing that keeps me going is my religion, nothing else.'

### 7.5.11 Relocation

Two participants were hoping to relocate to another country in the future as they were disappointed with mental health services or the stigma associated with mental health problems in Ireland.

'Well in the future...I have invested many years in getting him good health and happiness... Better facilities, we checked these out, and if it offers what we feel he could like, then it would be worth taking... Because I always go after everything.'

## 7.6 Summary

The majority of the participants used formal family support services, such as SI family support groups and educational programmes offered by catchment areas. However, less availability of support resources were reported by MHS recruits. As reported by study participants, the availability of formal support resources seemed to vary dramatically between different catchment areas of Dublin.

Voluntary support resources provided by SI, 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 offered by mental health services in two catchment areas of Dublin were also viewed as helpful.

Participants whose relatives were residing at home at the time of the study, or who were at somewhat earlier stages in their experience with enduring mental illness, tended to use more professional support resources, such as counselling, educational programmes, and informational resources. However despite any differences in residential status or duration of illness of the relative, all participants tended to use the voluntary resources of SI quite often.

Some of the barriers to use of available support resources were the lack of flexibility in schedule of support groups (too early in the day), the general lack of resources in the area and limited hours of the emergency line. In some cases participants felt that they were at the stage of experience when they did not need formal supports that much.

Most of the current needs and future concerns of participants were associated with the quality of services and support provided to their relatives by mental health services and their quality of life. Some of most urgent needs of service users perceived by participants were ongoing support from services, especially on discharge and onwards, semi-supported housing, self-harm and suicide prevention and promotion of recovery.

All participants expressed the need for an emergency contact with mental health services, who would be available to families at all times. Participants voiced the need for a key worker, or a mediator between families and persons with mental health problems, regardless of their source of referral to the study or the residential status of their relative. Fewer SI than MHS participants tended to have information about a contact person within mental health services, or felt that this person was approachable at all times.

The majority of participants were either dissatisfied or very dissatisfied with the services and support provided to themselves and their relatives. Participants who were more satisfied with the services provided to their relatives were also more satisfied with services provided to themselves. Participants whose relatives resided in their home were least satisfied with the services and support provided to the family.

Participants whose relatives had medical cards, and had higher reported PRADLI scores, were significantly more satisfied with the services and support provided to themselves and their families.

Most participants were worried about the future of their relative after they were gone, the ability to live independently and coping skills of their relative. Despite their worries, participants were relatively optimistic about the future well-being of their relatives, and expressed hope for improvement in their quality of life in the future.

Participants whose relatives were using private mental health services or whose relatives were not accepting their illness and treatment were pessimistic about their own and their relative's future. At the time of the study, such participants were less hopeful that their relative would gain the skills necessary for independent living or recovery.

## Chapter 8

Advice to other families with mental illness, to policy-makers, and to the general public

“ ”

I find that most people in Ireland are caring people, but they're frightened by the unknown and somehow people with mental illness scare them.



This Chapter will describe the advice provided by the participants to other families with mental health problems, to policy-makers, and to the general public.

### 8.1 Advice to other families with mental health problems

The majority of participants (n=32, 84.2%) provided advice to other families with mental health problems, elicited by the open-ended question 11 of the interview schedule (see Appendix 6). The rest of the participants (n=6, 15.8%) commented that they would not be able to provide any advice as everybody's family situation would be different.

Figure 8.1 summarises the advice provided by participants to other families with mental illness.

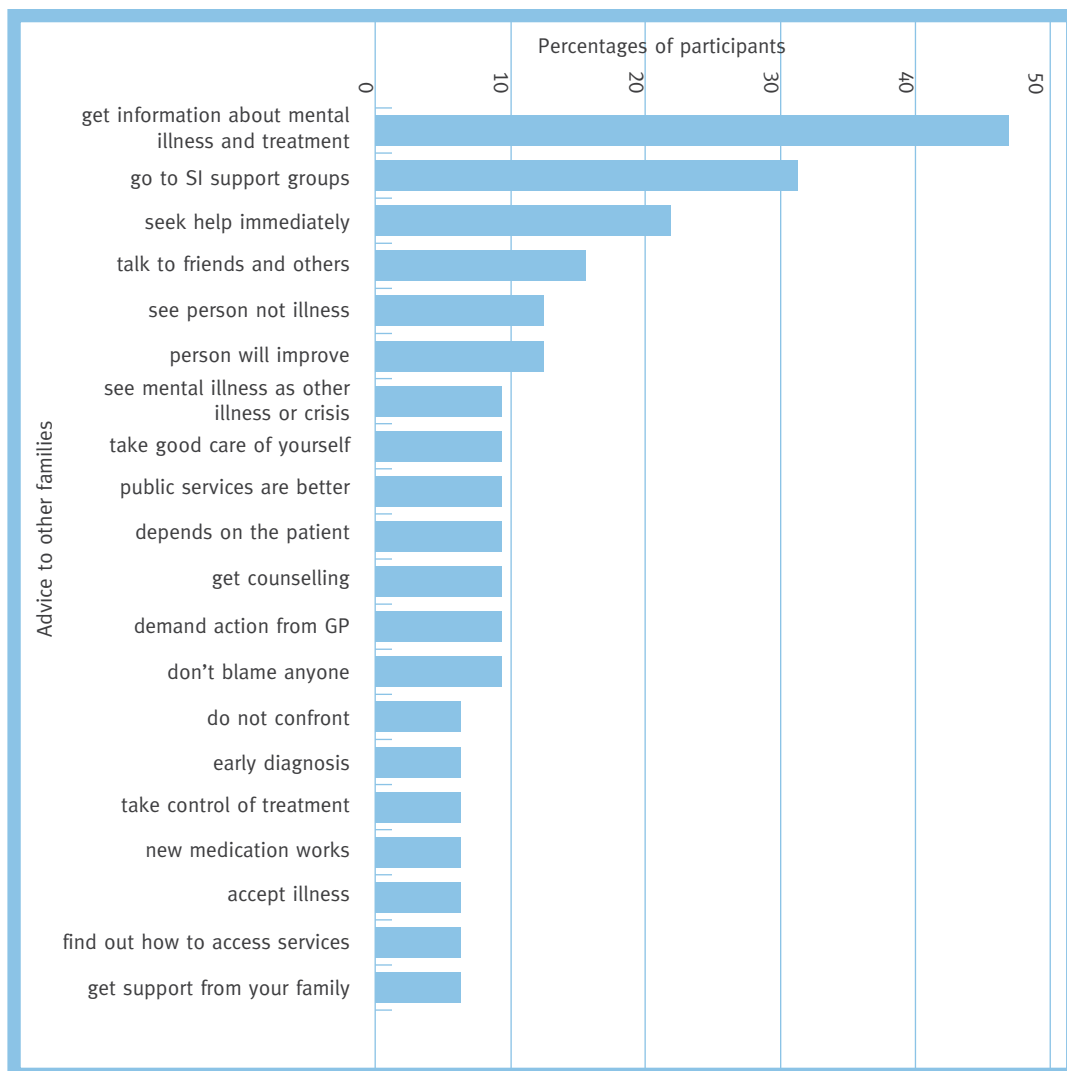


Figure 8.1 Advice provided by participants to other families with mental health problems

### 8.1.1 Get more information

The most frequent advice given by participants (n=15, 46.9%) was to get more information about the illness, its consequences, treatment and rehabilitation. The importance of reliable and recent information about research and progress in treatment of mental illnesses was underlined:

'I'd advise people to take some of the books out of the libraries because there's been progress made in the last ten years, and fantastic progress made in this line, and people are reading books going back ten years which would frighten the life out of you, books like that should be taken off the shelves every now and again and books should be brought up to date with information that people can get in their libraries, that's where we had to go, get a book out about the medication so as we'd understand what he was on.'

### 8.1.2 Talk to others

Nearly one third of the participants (n=10, 31.3%) advised families in situations similar to their own to join SI family support groups, so that they could share their experiences with others, learn more about the illness, and talk to others about their feelings. Five participants (15.6%) also advised to talk through their situation with friends or family.

### 8.1.3 Seek help immediately

Seven participants provided advice to seek help immediately after noticing any unusual or aggressive behaviour in their relative (21.9%), and if necessary, demand action from their GP (n=3, 9.4%). Participants believed that timely help and early diagnosis (n=2, 6.3%) were vital for future recovery:

'Seek help immediately if he is doing anything untoward other than playing up on you as a teenager. That is different. But like if he is displaying unusual behaviour, or aggressive behaviour, and that is not their usual persona then seek help immediately. Well first of all go to your GP and insist that no, you are not just upset by this, be more mature than that, be almost stubborn in that and decide that you are going to take the initiative and seek further help, you must get help. That will save all the intervening years passive, wherein and whereby you will find out sooner than later what is wrong... And everybody is saying it now, this is the big thing, early diagnosis.'

### 8.1.4 See the person, not the illness

Four participants (12.5%) thought that it was important to remember that it was not the person, but the illness that was causing problems, and that the person was still the same and would improve with time (n=4, 12.5%), especially with the new medication that was available now (n=2, 6.3%):

'I think also to see their loved one as being the same person, they have this illness superimposed but they're still themselves, you know.'

'I'd say be optimistic because it's not the end of the world. Like they can, if they get medication, they can lead quite a normal life, I would say to them not to get depressed about it and not to think it's the end of the world, it's not. It is in a way but it doesn't mean that they can't have a life, semi-normal lives, you know. I mean like I'd tell them to expect their lives to change a lot but not to change so much, you know what I mean.'

### 8.1.5 Take good care of yourself

Participants advised persons in similar situations to take good care of themselves (n=3, 9.4%), which included getting support from other family members (n=2, 6.3%), counselling (n=3, 9.4%), and getting away on holidays if possible (n=1, 3.1%):

‘... to support a person through this and to support oneself... taking good care of yourself first. And then it’s them.’

### 8.1.6 See mental illness as any illness or family crisis

Another piece of advice given by participants was to see mental illness as any other illness, or to see it as some kind of spiritual crisis in the family as opposed to mental illness (n=3, 9.4%):

‘I would say to them, see it as a special crisis... If you were to talk to somebody and say “My son is a schizophrenic”, you’re a victim. There is nothing you can do about it and you’d be dependent on the person who is going to give medication...You have choices...because you have power in seeing this as a life crisis, it’s a spiritual life crisis.’

### 8.1.7 Depends on the person with mental health problems

Three participants (9.4%) advised that a lot was depending on the persons with mental health problems themselves and their motivation, no matter what the hopes and efforts of their relatives were:

‘No matter what you do it’s dependant on the person who has the problem to get on with things... I mean we could have him back in the house, we could buy a place, but until he actually accepts that he has it he can’t move forward. Now if he does accept that he has it he can go back and study, he can get a degree, he can get a job, you know, he can have a much better quality of life.’

### 8.1.8 Do not blame anyone

Participants also felt it was important not to blame anyone (n=3, 9.4%), be it themselves, the person with mental health problems, or other members of the family. They recommended accepting the illness (n=2, 6.3%) and being supportive of all members of the family (n=2, 6.3%):

‘So I mean it breaks up families and that’s another thing I would say to somebody, I would say “Look you need to be very strong”, and if it was a couple they need to be very supportive of each other, I would say there’s no point in pointing fingers, no one person is a result or a cause... So I would say to them don’t blame each other, don’t say “It’s your fault” because it’s nobody’s fault, it’s just a glitch, it’s like a virus.’

### 8.1.9 Do not confront

Two participants advised other families not to confront their relative with mental health problems, and to treat their complaints with understanding:

‘...be as understanding as you can, learn the implications, because if you don’t understand you can become intolerant and impatient and make things worse...if somebody is ill with schizophrenia they get a fixed idea, the worst possible thing is to try to dissuade them and say “Don’t be talking rot, it’s a load of rubbish”, we’re supposed to say “Well you may think that but really it doesn’t look like that to me”, you mustn’t confront them if they’re in a kind of psychotic state.’

'There are different forms of mental illness isn't there?...People hear voices in their head and this type of thing...The thing is not to laugh about it, you're going to have to go half way of appeasing the person, think about it, "What's the voices telling you now, try to get them to do something that they don't want to do..." So you try and come at it from a different perspective, like "The next time those voices are talking to you, find out if there are any tips for horses."'

### 8.1.10 Use public mental health services

Three participants gave advice to other families to use public services rather than private ones (9.4%).

'Well I would say put them into the public health service as quickly as you can.'

### 8.1.11 Get to know how to access services

Two participants thought it was very important to get to know how to access the services better, and what support resources and entitlements both persons with mental health problems and their relatives could avail of. Both participants commented that this information was not easily available from services and it would have been very helpful for families:

'But I think now having been through it, I would understand that the services are there now, and if you don't go down drunk, if you go down slightly off-kilter they'll talk to you, I mean they're nice people...I learned it too late, in a way, for us, but again there's probably a need... to publicise more, even the limited services they have...I don't think I've ever seen leaflets offering early interventions for if you've a relative suffering, you might see one around suicide...We should know how to go for help, how to access the services that are there, I don't think that type of information is readily available to citizens.'

### 8.1.12 Be in control of treatment

Two participants (6.3%) advised getting actively involved with the treatment and rehabilitation team of the person as soon as possible, being in control of medication and treatment plan, and communicating any controversial issues to the treatment team:

'I would say take control of the patient's treatment as much as you can, try and have the medical people in charge of the patient to rethink this whole situation and say "Well there is a track record there that this medication is not working..."'

## 8.2 Advice to policy-makers

Thirty two interviewees (84.2%) provided their responses to the open-ended question 12 of the interview schedule (see Appendix 6) regarding their advice about families with mental illness to the government of Ireland.

Figure 8.2 summarises the advice provided by the participants to policy-makers.

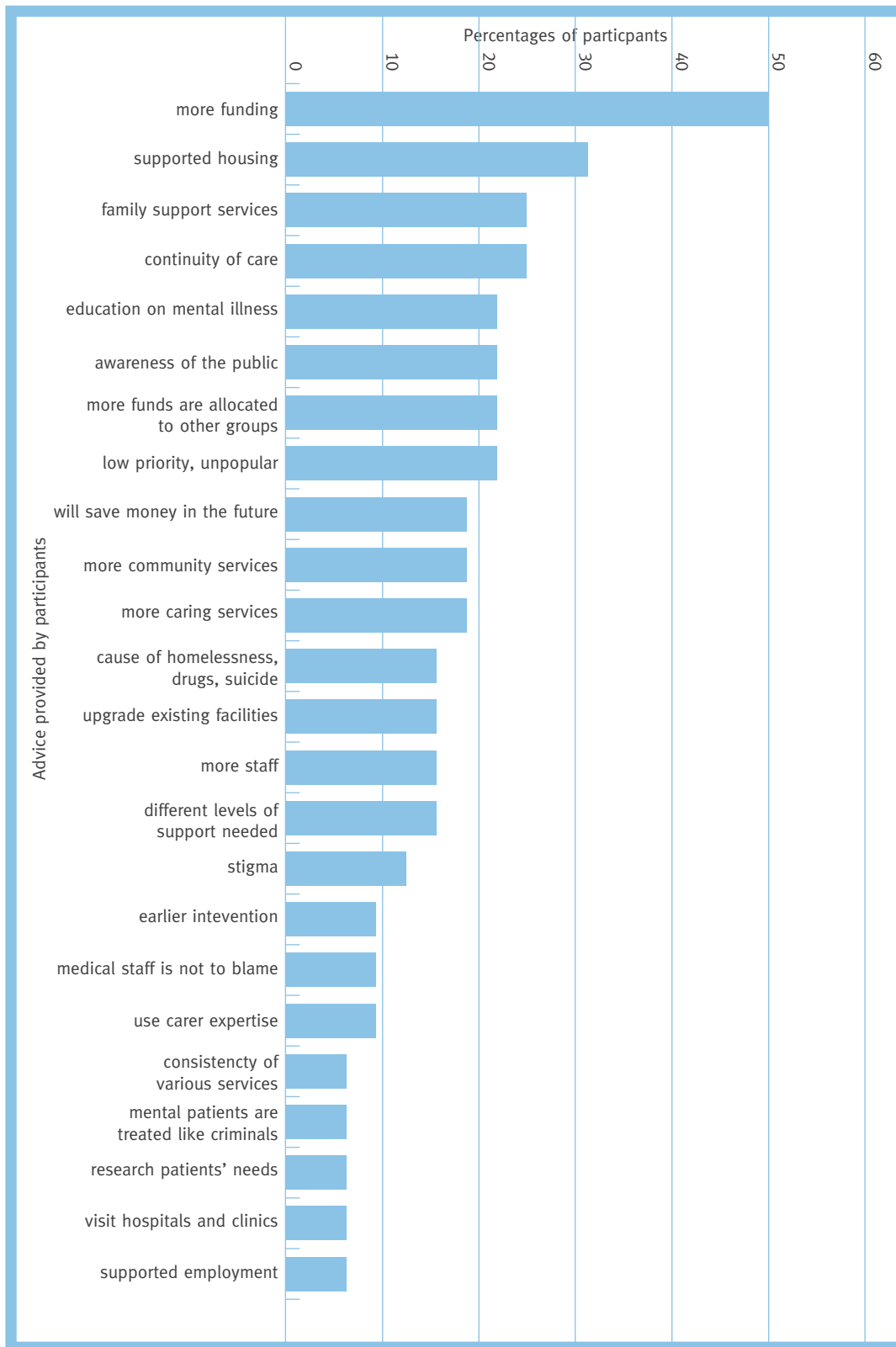


Figure 8.2 Advice provided by participants to policy-makers

### 8.2.1 More funding for mental health services

Half of the participants (n=16, 50.0%) thought that more funding needed to be allocated to the area of mental health in order to improve and develop existing mental health services. Participants felt that the government needed to provide more funds for upgrading existing in-patient and out-patient facilities (n=5, 15.6%), recruiting, training, and motivating the staff of mental health services (n=5, 15.6%).

Some of the reasons behind the lack of adequate allocation of resources, as viewed by the participants at the time of the study, were the perceived unpopularity and therefore low priority of funding of the area of mental illness (n=7, 21.9%), and the stigma associated with mental illness (n=4, 12.5%).

'Well I think I would tell them that the first thing is to try not to hide it, because an awful lot of people you come across... it's an embarrassment and they try to hide it... and this is a big issue in society, and society doesn't hear that these people have it. I think one thing is try and help educate society. I think Schizophrenia Ireland is doing a very good job and I think it does get money from the government but again it's on too limited a scale.'

### 8.2.2 Awareness raising

The interviewees felt that in order to tackle the stigma there should be more awareness in society of mental health problems and their consequences (n=7, 21.9%), and more accurate information available in press and media about mental illness (n=7, 21.9%):

'A huge amount of fear, people are afraid of the words I think even 'mental illness'... And I think a lot of it too may be because of the way in movies and television programmes, and even on news bulletins, you know, the portrayal of mental illness is very inaccurate, you know, very inaccurate. So a lot of it is mis-information.'

### 8.2.3 More community services

Interviewees felt that, due to the move towards closing some big psychiatric hospitals and promoting integration of persons with mental health problems in the community, more funds should have been allocated or reallocated to the area of mental health. From the participants' point of view, some of the major priorities for funding within the area of mental health were development of supported housing for persons with mental health problems (n=10, 31.3%), preferably with different levels of support (n=5, 15.6%), development of family support services and resources (n=8, 25.0%), ensuring continuity of care of persons with mental health difficulties (n=8, 25.0%), and improvement and further development of community services (n=6, 18.8%):

'I maintain that if they're closing down big hospitals, their money should be going back in, I mean they're putting people out in the field, support should be out there, either a middle hospital or a middle recreation or a place with the proper surrounding, proper facilities... Not just saving money... The money should be put in to support, they're closing down hospitals now and big places but I can tell you they'll be opening them up, unless there is some sort of miracle with medication.'

'I would tell them about the poor condition of the health service. There needs to be more information on mental illness, more help for families. More hostels, more housing. They need to talk to the carers, use their expertise... More outpatient care, ongoing nursing and don't keep waiting for the patient, you should go to them, the patients are not going to go and ask, they should be called on the way community nurses call on young mothers to see the baby.'

### 8.2.4 Perceived low priority attached to mental health issues

Interviewees felt that because of the unpopularity of the issue of mental health (n=7, 21.7%), persons with mental health problems had been given low priority by the government in the allocating resources or housing, and that people with mental health difficulties, especially single males, were 'last on the list' after such groups of population as prisoners, people with learning disabilities, people with drug or alcohol abuse, and single mothers (n=7, 21.7%).

'This is the terrible price for housing, there are so many on the street who have mental health problems... He's on the housing list, but he's gone down from last year, instead of going up, because single mothers with babies... have pushed him down, now don't get me wrong, they have a need as well, but I am here fighting for my son... But that is the fact, there is nowhere for single men, they're the last on the list for housing, do you understand?'

### 8.2.5 Mental health problems are an underlying cause of other problems in society

Five participants believed that mental health problems were one of the underlying causes of other problems in the society, such as homelessness, drug addiction, and suicide. Therefore, funding provided for supported accommodation and development of community services for persons with mental health problems was considered essential for saving other governmental expenses in the future.

'Obviously put more money into the services, build accommodation, accommodation is terribly, terribly important and different type of hostels are required, high support, medium support, low support, its very, very important that they have their own place, because the parents are not going to be there all the time and what will happen when we're dead you know, are they going to end up on the street? And I think most of the homeless are mentally ill, honestly, even if they have got drug problems... But there's another underlying reason why they're taking the drugs... Oh yes accommodation is terribly, terribly important.'

'I mean they need to be living independently, they need to have proper supports, proper health service personnel available to them. They need to be able to contact a social worker when they need them, otherwise your just going to have people in hospital, discharged from hospital and stabilised on medication, maybe after weeks or months they go off their medication and almost inevitably then they relapse, and back in hospital, and you have all the cost of providing hospital services for them you know... But they're not providing the services or the supports in the community, and it's leading to an awful lot of frustration and depression and loss of life because about one in ten commits suicide and a lot more attempt it.'

### 8.2.6 Return on investment in early intervention

Participants felt that money invested in the area of mental health was money well spent, as it would save on the cost of in-patient services (n=6, 18.8%), especially in the case of early intervention:

'What would I ask the government, I would ask them to think like a mother, economise. Run the country like a glorified county, we have four million people... There is an abundance of wealth. Distribute it equally. Finance support, if they finance these things, their outlay on mental health would be cut by two thirds. They would save money in the long run.'

'And that's my main complaint about the services, and its all about resources, there is such limited resources put into this whole area of mental health, its an absolute scandal in this day and age that people have to deteriorate to the point where they're debilitated, entirely debilitated, before the state helps,

its wrong for the patient and its wrong for the family around them... I really think that competent early intervention would stop an awful lot of people having to sit for years in mental institutions, I really think a quick action service is what is needed.'

### 8.2.7 More training for primary service personnel

Further training on mental health problems for primary health care personnel, and better communication by GPs with the family were viewed by participants as essential for earlier intervention:

'The family plays a key role in this, you know, particularly in the initial stages because they say prevention and early intervention is the key to this. This is the situation, you know, and the GPs are absolutely crucial because I mean if the persons themselves won't go, parents are going to end up there, and the GPs are crucial in this... And they don't offer any assistance or help whatsoever, or they say get him to come up to see me, and even if they do go up to see them they don't do much. Yeah, education, education, education.'

### 8.2.8 More caring and proactive services

Participants commented that the services provided to people with mental health problems should be more caring and proactive, that there was a lot of apathy both in hospitals and in outpatient services towards persons with mental health problems, which did not help their treatment and rehabilitation (n=6, 18.8%):

'To be better looked after. Support. One of the things I felt about the hospital was there was a lot of apathy.'

Two participants felt that sometimes persons with mental illness were treated 'like criminals' by society:

'There was a priest at the family home and he was saying that he'd been to visit this prison somewhere down the country and it was beautiful and everybody had their own room, so I said well go down to see what the government should be spending their money on, people in hospital, not because they've done anything wrong but because they have an illness and they're getting treated like criminals, they're in dormitories with just beds, no privacy, and they might have a curtain between them or whatever...By all means spend money on prisons, rehabilitate them or whatever but they should get their priorities right and look after people that are sick, through no fault of their own.'

### 8.2.9 Not to blame mental health staff

Three participants commented that staff should not be blamed for short-comings in mental health services, as they were doing their best in the existing 'awful conditions' of mental health facilities and resources.

'These people are doing a job, how do they work in them conditions, facilities, its not a job I think that people maybe make a career of, I think you should be able to move on, and I don't mean just push people on, people should be willing to put their knowledge back in and yet move on to another area maybe or something like that and they're all the time growing.'

'I know they're under-staffed and the government have even cut back on the amount of money that they're spending on mental health now... We've got a population that's growing and we are going to have more people with mental illness because there's pressure on everybody now at the moment... and I do see the nurses and the doctors work very hard.'



### 8.2.10 Consistency of service all over the country and across different health services

Three participants commented that support for persons with mental health problems was different in different catchment areas of Dublin, and that there should be a standard level of care and support in all regions:

‘Oh another thing, its catchment areas, you see, this gets on my nerves, catchment areas. He was moved from... our area... away off the beaten track altogether... There shouldn’t be these catchment areas, and have the same standard of care in all areas.’

Two participants felt that there should be more training for staff to promote better communication between various mental health professionals and the family:

‘He definitely needs some kind of support at hospital, now whether it is high low or medium, I don’t know, but I get played off between the social worker and the psychiatrist. The social worker tells me the psychiatrist has to recommend him for the hostel and the psychiatrist tells me it’s the social worker. So I’m lost in the middle.’

### 8.2.11 Visits from policy-makers

Two participants felt that it might be beneficial for some representatives of the government to visit mental hospitals in order to see the existing conditions and facilities, and to reduce the stigma of mental illness in society:

‘And I reckon that they should get a visit from a minister of health or somebody, they should send somebody to visit the hospitals, just to say hello, I don’t mean a minister because they’d be rolling out red carpets here and there, I know the score about VIP visits... They definitely need to upgrade everything and work on certainly the accommodation, and that now would certainly need a good face lift, make it brighter.’

### 8.2.12 Supported employment and needs analysis for persons with mental health problems

Other advice provided to policy-makers was providing assistance with sheltered, or supported employment of persons with mental health problems, and to research needs and capabilities of persons with mental illness in order to help their integration into society.

## 8.3 Advice to the general public

The majority of interviewees provided their message to the public with regard to families with mental illness (n=31, 73.8%) in response to the open-ended question 12 of the interview schedule (see Appendix 6).

An overview of the major issues raised by participants is presented in Figure 8.3.

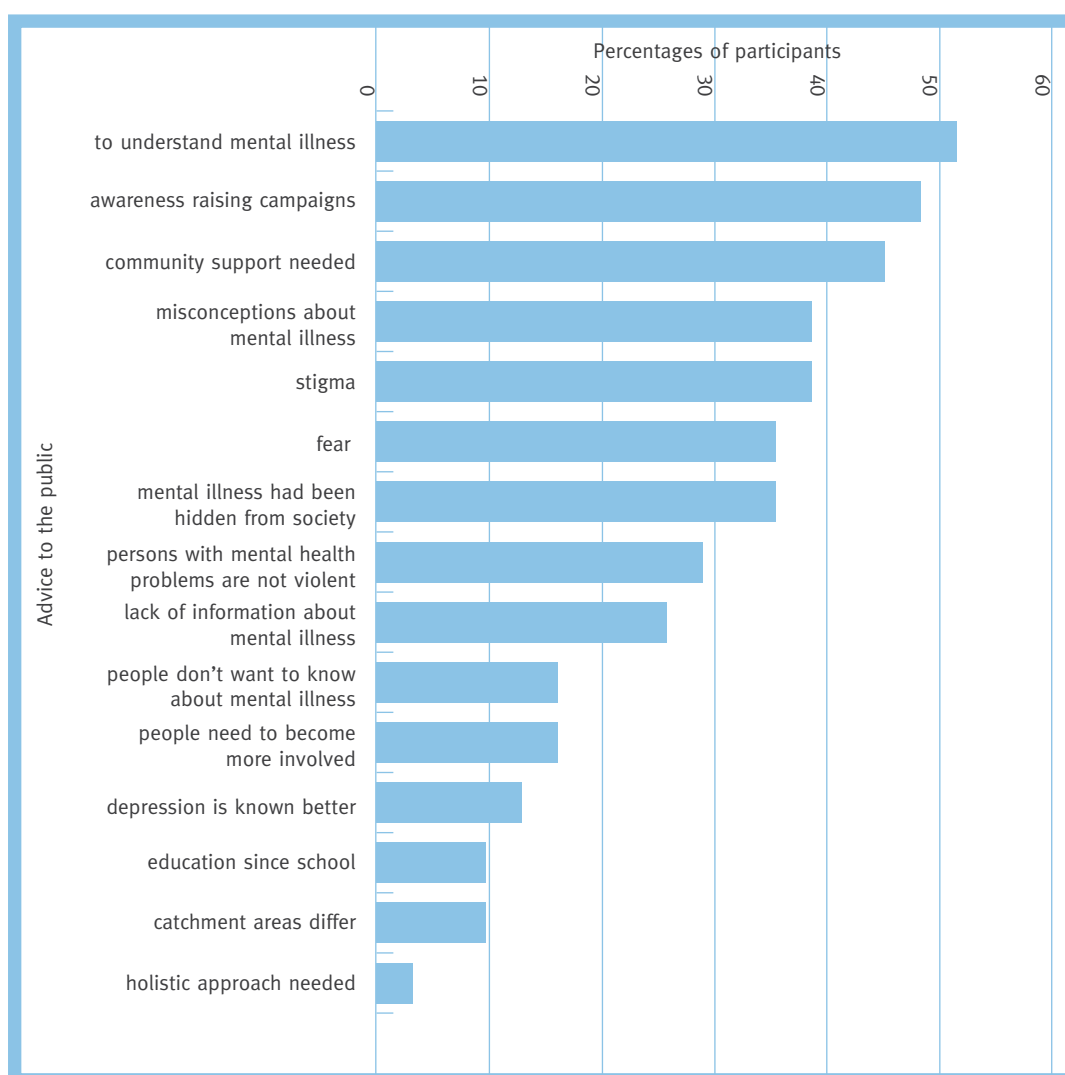


Figure 8.3 Advice provided by participants to the general public

### 8.3.1 Lack of understanding of mental illness

More than half of participants who provided advice to the public ( $n=16$ , 51.6%) felt that there was a lack of understanding of mental illness in society. Nearly half of the participants ( $n=15$ , 48.4%) felt that awareness raising campaigns were necessary in order to inform the public about mental illness and its treatment, which would make it easier to improve and develop community care:

'The government needs to spend money on a public relations campaign, to rehabilitate mental health... I think if they explained to people the nature of mental illness, and that the people recover and that there is a professional backup service there, and they're not going to be trouble in communities, I think it would make the whole idea of community care much, much easier.'

### 8.3.2 Community support needed

Participants felt that there was not enough support forthcoming from the community for the rehabilitation and reintegration of persons with mental health problems (n=14, 45.2%). Interviewees commented that there was a certain stigma associated with mental illness (n=12, 38.7%), which was caused by misconceptions regarding mental illness and its sufferers (n=12, 38.7%), fear of mental illness (n=11, 35.5%), or lack of information about mental health (n=8, 25.8%).

'I find that most people in Ireland are caring people, but they're frightened by the unknown and somehow people with mental illness scare them. People get nervous. I mean I know from talking to people here that there might be a house in the community for people recovering, like, people go berserk with the idea of having a house in the area.'

Several participants (n=5, 16.1%) commented that communities needed to get more involved in the reintegration of persons with mental health problems in the community:

'I would say be supportive of them, if there is a family or two in the estate with a child suffering from mental illness, by all means be there, you know, don't keep them in isolation. Be communicative with them, drop down for tea some evening, you know, get them involved in social activities. Just try and give them as much support as possible. Who knows what their story is. And you might be looking for support in the future.'

### 8.3.3 Underlying causes of stigma

Participants felt that the lack of information and stigma surrounding mental health problems was caused by the tendency of society to keep persons with mental problems behind the walls of the hospitals in the past, and for the family to hide from the community the fact that a family member was suffering from mental illness (n=11, 35.5%):

'I think we need a lot more honest open discussion about it, to me mental health seems to have huge stigma. I think people feel that it's a reflection on the whole family, that if there's a member of the family has a mental illness, I think society feels that the whole family has a mental illness, and perhaps it's because it was so hidden for so long, you know.'

### 8.3.4 Persons with mental health problems are no more violent than the general public

One of the main misconceptions reported by the participants was that persons with mental health problems were violent, and that they posed a threat to the community and to society in general.

'People think is a split personality... there's a need for some kind of education to actually try and help people understand what this is, and that these persons are more of a threat to themselves than they are to society and they need support, that's what society is afraid of because of all this stuff in the past.'

Nine participants (29.0%) commented that in most cases persons with mental health problems were shy and sensitive people, and presented no more danger to society than the general public. Participants commented that persons with mental health problems could become aggressive or cause harm to themselves during psychotic episodes because of their illness:

'I would stress the fact that people with schizophrenia are no more likely to violence than the general public. Many of them including my son, are shy, quiet, and extremely sensitive. Even when he was having a psychotic turn, he was aggressive but not violent.'

### 8.3.5 People do not want to know about mental illness

Five participants felt that because of the fear and misconception surrounding mental illness people did not want to know about it as long as it did not affect their families:

'It takes a little bit of effort and it takes a little bit of understanding... and a little bit of heart...You see, a modern day person, they're very self centred, only thinking of the "now", ten minutes time, twenty minutes time, and then its tea time, they're thinking of themselves and...there's other things worth thinking about, that's my opinion, we've got to stop and think.'

### 8.3.6 More information about depression than schizophrenia

Four participants felt that there was more information and awareness in society about depression than schizophrenia, and therefore persons and families with schizophrenia were more stigmatised than those with depressive disorders:

'They have someone on television, who would sort of say they have manic depression, but you won't get someone on television who will say they're schizophrenic, it has a bad name...people have a misconception about it, you know, people think that they're violent... They are more violent to themselves, but it's used in court cases, you know, for a lighter sentence for the schizophrenic.'

### 8.3.7 Awareness about mental illness should start at school

Three participants felt that information on mental illness and/or schizophrenia should be introduced into the school curriculum, which would reduce stigma and help the integration of persons with mental health problems in the community:

'I think there should be enlightenment for children, maybe not first year in secondary level education but at least from there on. In their civics, or if they're doing biology, it should be brought in and just to open it up completely and let people discuss it. Maybe some teachers need to do courses, because lots of teachers wouldn't know anything about it either, unless they've experienced it in their family, which they're not going to admit.'

### 8.3.8 Holistic approach

One person felt that it was necessary to view mental illness holistically, as part of a person's general well-being, in order to understand the nature of the mental illness:

'Not to look at it in isolation, not to treat it as one part of the human being. That's like, if I have a fungal infection in my toe, it means that my whole body is acid alkaline unbalanced. I stop sleeping. If I stop sleeping and I don't have an appetite and I don't eat, how long will it take me before I become mentally ill, without any abuse or anything like that? It starts like that.'

## 8.4 Other issues raised by participants

Less than half of the participants (n=18, 42.9%) provided feedback regarding other issues at the end of the interviews. A summary of other issues raised by the participants is provided in Figure 8.4.

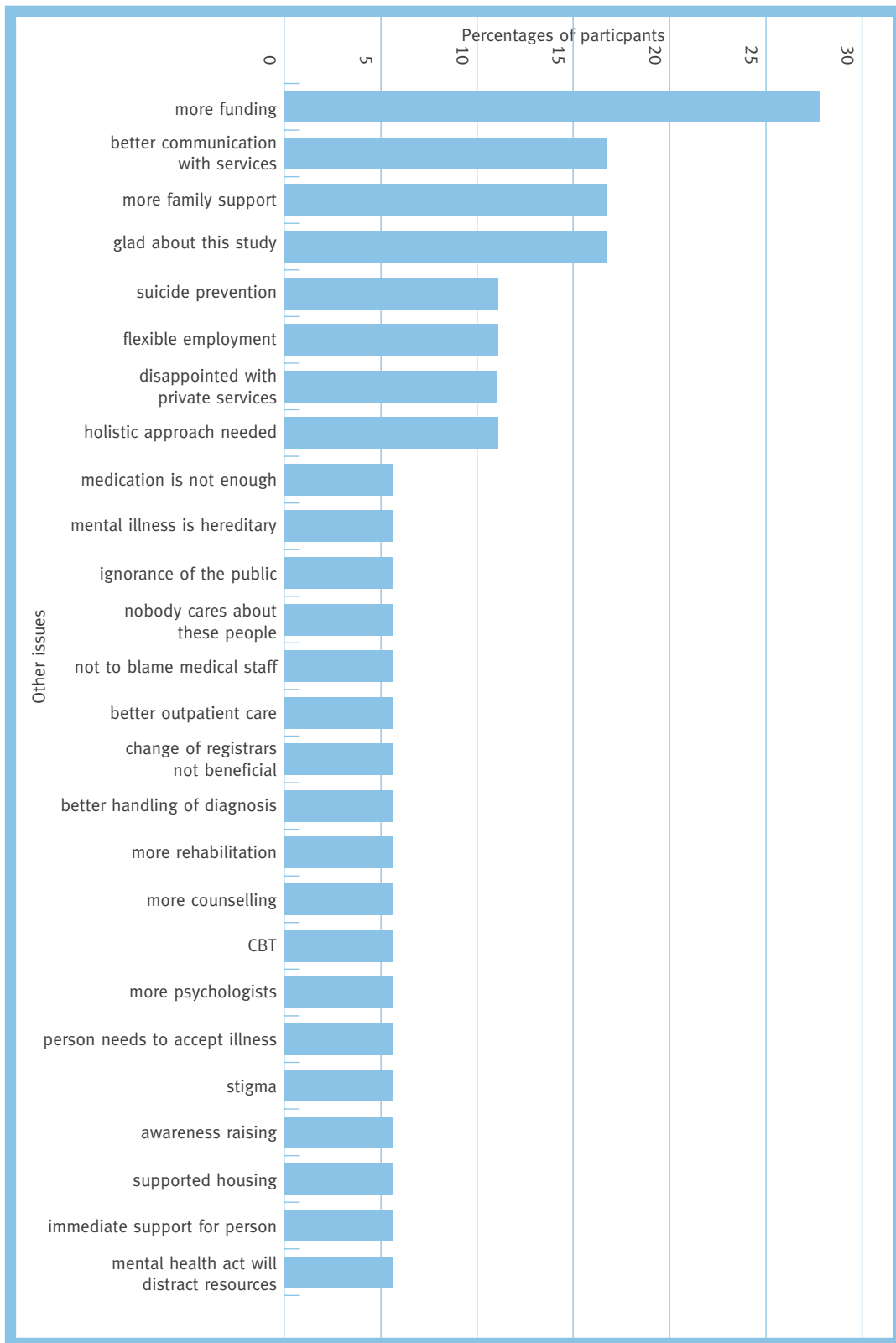


Figure 8.4 Other issues raised by participants

As can be seen from Figure 8.4, most of the additional comments provided by the interviewees were reiterating the previous needs and support resources for families with mental health problems brought up by participants during the interviews. The most frequently recurring issue was the need for more funding of mental health services (n=5, 27.8%), followed by improvement of communication between mental health services and families with enduring mental illness (n=3, 16.7%), and family support services and resources (n=3, 16.7%).

'I'd tell them I'd be very angry with the system. Well there's no back up for the carers...I remember one morning I had an appointment to have a blood test done, and I was told to ring this person in the clinic and she told me that somebody would call to just keep an eye on him... I never got that help that I was supposed to get that morning, but I still had to go for the blood test and thank God when I came back he was OK.'

Among other issues, that of the lack of support provided to families with mental health problems by private mental health services, and the need for further development of public services was reiterated by two participants of the study:

'I'm completely disillusioned with the private mental health care in this country. I mean my experience of the private and the public mental health services couldn't be more dramatic, and part of my concern is that there seems to be a mood at the moment to privatise all health services in this country, and I'm sure mental health will be privatised also, and having seen that service, I would be very concerned for people with mental health, because I think its purely profit making, very little concern shown for the patient...Whereas I think, properly resourced, the public mental health service has huge potential to do a really good job for the citizens of this country, but it needs to be resourced, that's my overview of the whole thing.'

One person expressed the view that mental illness was hereditary, and that the number of persons with mental illness was probably higher than the number of persons admitted to hospitals:

'Well its hereditary isn't it, there's no two ways about it and you will find that you'll come across families who haven't actually gone into a hospital but are still bad with their nerves as they call it...There's no perfect being I don't think...'

One person commented that neither the general public, nor even the clergy, cared about persons with mental health problems, and did not want to communicate with them. The participant found that it took very little effort to successfully communicate with persons with mental illness:

'There is nobody really in a holy religious cead mile failte country, nobody cares about these people... When I go to visit my son in the hospital, sometimes three or four patients would want to go for a walk with me. And they would sit for maybe an hour talking to me and I would find these people very sensible and very rational, and very interesting, and I would look upon that as being my privilege to have spent the time with them... And they would feel great, and they would be thanking me, and when I'd go back up the next time they would remember that I did that for them, which was absolutely a minute effort to please them.'

One participant reported that he was disappointed with the lack of communication with services and that the provisions of the Mental Health Bill were helpful only for the lawyers but not for the patients and their relatives, as they would have required further diversion of the limited mental health resources from service provision:

'I'm just very disappointed permanently in the inability to make contact with the services... and I also think that it's a waste of time with the Mental Health Bill where it states they'll have to be going to court to make decisions, it will be an enormous strain on resources, taking them away from what they should be doing.'

Three participants expressed their satisfaction with the current study, hoping that sharing experiences of relatives of persons with mental illness would provide recommendations for improving funding for existing support resources, such as SI, and would help both persons with mental illness and their relatives in the future.

'Just delighted that this project is ongoing, because I'm sure you'll have other people who have much worse and longer experience in the system than we have, but I mean anything we can do to help is what we've decided we would do... I think the biggest thing is that you try and allow Schizophrenia Ireland be funded through.'

'Well I would like to think that this interview, which I gave you voluntarily... that if one patient was to benefit from this interview, you would make an old man very happy.'

'Thank you for giving me a voice.'

## 8.5 Summary

To summarise, the majority of interviewees provided advice to other families with enduring mental illness in Ireland. Most of this advice included accessing information about mental illness and its treatment, participating in SI family support groups, seeking help immediately, trying to see the person behind the illness, and bearing in mind that the person's health would improve with time. Only SI participants provided advice to attend SI support groups, talk to friends and relatives about the illness in the family, to remember that the persons' health would improve with time, and to get counselling.

The majority of participants provided advice about families with mental illness to policy-makers. Half of their recommendations included the provision of more funding for supported housing for persons with mental health problems, more funding for family support resources, ensuring continuity of care, and awareness-raising campaigns around mental illness. Participants felt that the area of mental health had been given low priority at the time of planning state resources, and that more funding had been allocated to other groups, as compared to persons with mental illness. Interviewees perceived that due to the move to close some of the psychiatric hospitals and relocation of persons with mental health problems into the community, more funds should be reallocated to the improvement and development of community services, which would save money in the future and help tackle other problems in the society, such as homelessness, drug addiction, and suicide.

The majority of interviewees provided their advice to the general public about families with mental illness in Ireland. They felt that the public needed to have more understanding of mental illness, and to get involved in the support of persons with mental illness in the community. Participants believed that there had been a lot of misconception and stigma associated with mental illness, based on lack of information and fear. As suggested by the participants, one of the reasons behind such fear in the public was the fact that, in the past, information about mental illness had not been forthcoming from either the services, or families with mental illness, and had therefore been hidden from society. Participants wanted the public to become aware that persons with mental problems were not as violent or dangerous as portrayed by the media, and needed more support from the community in order to become rehabilitated.

Most of the other issues raised by the participants at the end of the interviews were reiterating the needs and support requirements of families with mental illness described in earlier chapters of the study. Among these were the need for more funding for mental health services, improving communication between relatives and carers and mental health services, and developing family support resources. Several participants expressed satisfaction with the current study and hoped that it would help to provide more support for families with mental illness in Ireland.



# Chapter 9

Discussion and  
conclusions



## 9.1 Introduction

Against the background of change in the Irish mental health service provision and the recommendations outlined in the most recent policy document *A Vision for Change* (Department of Health and Children, 2006), this study provides some timely first-hand evidence supporting the findings of the consultation process carried out by the Expert Group, and highlighting more directions for developing comprehensive, continuous and responsive mental health services for families with mental health problems across the country.

Based on the individual experiences of 38 participants whose experience with mental illness in the family in some cases lasted almost half a century, the study explored needs and support requirements of family members from the onset of illness to the rehabilitation or recovery stages. Due to the fact that the study participants had relatives with mental illness of varying duration, the current and future needs and support requirements of families, identified by the study, served a dual purpose of validating the retrospective needs of the more experienced representatives of the study, and exploring the existing needs, aspirations, and support resources of families with enduring mental illness in contemporary Irish society.

The study also attempted, within the limitations of the sample, to explore and identify some coping mechanisms and support requirements of various subgroups of family members, such as mothers, fathers, sisters, brothers, spouses, and offspring of persons with mental health problems, either directly or indirectly represented by the study sample. In addition, some gender differences in the coping mechanisms and support requirements of relatives of persons with enduring mental health problems were explored by the study.

The level of satisfaction of participants with the support and services provided to them and their relatives served as indirect indicators of the overall quality of mental health services provided to persons with mental illness and to their carers and families, and helped to identify the ‘strengths’ and ‘weaknesses’ of the existing service provision. The relevance of some of these strengths and weaknesses is supported by *A Vision for Change*, published by the Department of Health and Children in January 2006, at the time of the completion of the fieldwork for this study. Several new themes emerging from the study highlight directions for further development and improvement of existing mental health services.

The first section of this chapter will discuss the sample of study participants. The discussion of the findings of the study will thereupon follow the objectives laid out in Chapter 2, namely:

- The effects of mental illness on the family, and family adaptation to the burden of mental illness;
- Coping mechanisms and needs of different kinship and gender subgroups of relatives;
- Experiences, needs and support requirements of family members at various stages of the enduring mental illness; views of participants on treatment and rehabilitation of their relatives;
- Support resources available to the study participants, their utilisation, and other supports needed; views of participants on the future;
- The extent of satisfaction of participants with the services and support offered to persons with mental health problems, and to their carers and families.

Advice of participants to other families, to the government, and to the public will be discussed in terms of contribution to the findings. Some of the limitations of the study will be presented, and conclusions will be drawn on the basis of the discussed findings of the study. Recommendations to service providers, policy makers, researchers, and the general public, arising from the analysis and advice provided by the participants will be presented in Chapter 10.

## 9.2 The study sample

Due to the lack of published studies in Ireland involving individual interviews with family members of persons with mental illness, it was difficult to predict the response rate and the final number of the volunteers of the study sample. Some international studies involving carers of persons with mental health problems (Jubb & Slaney, 2002; Pickett-Schenk *et al.*, 2000) provided an insight into the expected response rates of such a sample in the US and elsewhere, which was on average about 20%. This study reported a 15.2% response rate, which was somewhat lower than what has been reported by the limited number of international studies of this kind. One of the explanations may be the reported stigma associated with mental illness in Ireland, and the unwillingness of some families to discuss their experiences outside the family circle. Another explanation could be the limited support resources of families, also reported by the participants, and the difficulties associated with the logistics of finding time, energy, or respite care in order to participate in the study. Indeed, the research team received three telephone calls from potential participants who were willing to participate but either could not find time or were in poor health at the time of the study. Due to confidentiality reasons personal details of potential participants were not available to the researcher. Therefore, specific reasons behind such low response rates were unavailable in this study. The issue of response rates in such contexts requires further investigation.

However, the 38 participants who made it to the interviews formed a relatively diverse and representative sample, sufficient for the purposes of this exploratory study. The majority of the participants were females, and in most cases the mothers of persons with mental health problems, which was in line with previous studies (see, e.g. Pickett-Schenk, 2003; Hanson & Rapp, 1992) reporting that females and especially mothers tended to be the main carers of persons with mental illness, and more actively participated in family support programmes and studies allowing them to voice their needs and concerns. Three sisters of persons with mental illness also participated in the study, providing their 'voice' for siblings of persons with mental health problems. One wife added her insight into the needs of spouses, which was quite valuable for the exploratory purposes of the study.

Male carers and relatives also constituted a substantial part of the study sample ( $n=11$ , 28.9%), most of them being fathers ( $n=9$ , 81.8%). A brother and a step-father of a person with mental health problems also added their insight into the family experiences collected by the study.

However limited the participation of siblings and spouses was, most of the participants provided additional comments about the perceived needs and support requirements of these kinship groups. Their comments were indirectly validated and elaborated by the feedback of spouses and siblings who participated in the study. Three participants also volunteered unexpected data regarding perceived needs of children of persons with mental health problems. Though limited and indirect, this input was invaluable in terms of supporting previous findings and providing directions for further research. In general, input from the family network in addition to the individual carers' perspective, made it possible to slightly 'push the boundaries' of the existing sample and get a glimpse of family dynamics, and the spectrum of needs of individual family members.

The fact that the response rate of the sample recruited via support groups of SI was higher than that of MHS sample was also supportive of some previous findings whereby participants of family support groups or programmes were more experienced in verbalising their needs, had access to more support resources and more motivation to use them (Hanson & Rapp, 1992). Participants recruited via SI represented a younger and somewhat more socially and vocationally active group than those recruited via MHS. However, the two samples complemented each other's experiences and provided a more representative overall sample regarding socio-economic, educational, and residential status of families with mental health problems.

The age of participants ranged from 20 to 81 years, with an average of 61.3 years, providing a broad insight into the views and needs of, mostly older but some younger family members. The reported duration of mental health problems of relatives of interviewees ranged from 1.5 to 49 years, with an average duration of 17.3 years, which made it possible to provide a retrospective view on the experiences of the participants at various stages of illness of their relative and suggest a tentative continuum of their evolving needs and aspirations.

Similarly to the findings of previous studies (e.g., Chen & Greenberg, 2004), the majority of the persons with mental health problems related to the study participants were males, and sons of study participants. However, about one-third were females, which provided sufficient data for the qualitative analysis of the needs and support requirements of families of male and female persons with mental health difficulties.

The sample also varied across the place of residence of persons with mental health problems, with more than one-third of these residing at home with participants, and equal numbers residing in independent accommodation, in-patient units, and community residencies. This added to the spectrum of the analysis of needs and support requirements of families at different stages of integration of persons with mental health problems in the community, and the barriers and facilitators of such integration. The varied educational level and employment and marital status of persons with mental health problems also provided a more diverse representation of their needs, perceived by the participants of the study as closely linked to their own needs.

Whereas diagnosis was not part of the inclusion criteria for the study, the majority of the study participants reported that their relatives had been diagnosed with schizophrenia, with few being diagnosed with bipolar disorder and some of the participants not being sure at all about the diagnosis of their relative. This can be partially explained by the fact that the majority of the sample had been recruited by SI, which was founded as a support organisation for families with schizophrenia.

## 9.3 The effects of mental illness on the family and family adaptation

*Oh it was terrible, I cried, every night I cried, why did it have to happen, why me, why her?*

### 9.3.1 The perceived effects of mental illness on the family

Despite the fact that participants of the study were not asked about any possible impact of the family itself for the onset of the mental health problems of their relative, several participants perceived that some behavioural or genetic factors in the family might have contributed to the mental illness of the family member. Some behaviours of family members, especially fathers, described in retrospect by participants as contributing to the mental health problems were hostility, criticism, or abusive relationships, in agreement with some previous studies' definitions of expressed emotion (Thorncroft & Szmukler, 2001). Some participants commented that mental illness had occurred in the past in other distant relatives of their extended families, or affected two siblings of the same family at different times. Some of the participants felt that it was not possible to totally rule out the impact of genetic or behavioural factors in the family on the emergence of mental illness. Some families may be more at risk of mental health problems than others, and may need more support from mental health services in order to reduce or offset such risks. More qualitative and quantitative research on contributors to mental illness in the family is needed, with findings incorporated into family education or family counselling programmes, in order to avoid or reduce the potential negative effects of behaviour or psychiatric morbidity on the mental health of family members.

Regardless of social or educational status, age and gender of the participants, all of them reported the negative impact of mental illness on the family and its individual members. The elements of subjective and objective burden emerging from the interviews were intertwined and in some cases proved impossible to separate for the analysis of the effects of mental illness on the family. In fact, most of the qualitative themes pertaining to the negative effects of mental illness on the family were emotional and social in their nature, affecting the psychological well-being of the family and its members, and fewer of these were associated with specific care-giving tasks, time, or financial resources.

However, some elements pertaining to the objective and subjective burden of mental illness in the family, as described by previous research (Thorncroft & Schmuckler, 2001; Marsh, 2001; Lefley, 2001) did emerge from both quantitative and qualitative data and added to better understanding and description of the nature of the effects of mental illness on the family. Participants whose relatives with mental health problems resided at home seemed to bear a heavier burden of caring for their relative, and were more at risk from disruptive behaviour, than those whose relatives resided outside the family home at the time of the study. They spent significantly more time looking after their relatives, their social, financial, and career opportunities were more at risk and, in some cases, due to stigma and lack of understanding of the illness by other family members or friends, they became completely isolated from the community.

Most of the persons with mental health problems did not have any physical impairment and required minimal assistance in fulfilling such basic daily living tasks, as eating or going to the toilet. However, more than half of them, as reported by the participants, were resistant or needed reminding to getting in and out of bed, changing clothes, taking showers, taking their medication, and participating in social activities, which required more patience and energy on the part of their carers. Trying to persuade their relative to take medication was the most problematic for carers, especially when the relatives did not accept that they were ill which, from the point of view of participants, led to further deterioration in their mental health and increased the risk of potential self-harm or disruptive behaviour. Whereas participants acknowledged that persons with mental health problems were adults capable of their own decisions, they were concerned about the safety and psychological well-being of themselves or other members of the family. Participants often felt helpless and trapped in their own house when their relative refused to accept that they needed treatment and stayed in the family home as there was nowhere else for them to go. In line with previous studies (Marsh, 2001), participants reported spending a lot of time and energy on help-seeking, negotiating, and arguing with primary and secondary health services, especially when their relative with mental health problems resided in their home.

Some of the elements of the subjective burden of mental illness in the family were feelings of worry, anxiety, stress, depression, fear, loss, and mourning, reported by the participants. Perceived inability to help the person and lack of hope for the future of their loved one emerged from the interviews, supporting most of the previous findings (Muhlbauer, 2002; Lefley, 2001; Marsh, 2001). Some of the participants commented that their feelings of helplessness or hopelessness had been caused by the lack of information about the illness, symptoms, treatment and recovery of persons with mental health problems.

### 9.3.2 Family adaptation

*It altered my whole way of thinking about life and humanity, there's no dividing line between the haves and have nots.*

In line with some previous findings on the effects of mental illness on the family (e.g., Marsh, 2001), all participants of the study reported some extent of family disintegration as a result of the mental illness in the family. Partners, spouses, or other children either left the family

completely or discontinued regular contact with their relatives. Seven carers (18.4% of the sample) reported their complete isolation from the rest of the family as a result of the mental illness. This finding is quite worrying and underlines an urgent need for development of proactive family support resources aimed at preventing family disintegration and isolation of persons with mental illness and their relatives from society.

Despite the negative effects of mental illness on the family, and the partial or full isolation of study participants from other relatives and friends, some participants managed to constructively adapt to the phenomenon of mental illness in the family. In support of some recent studies of constructive adaptation of families to mental illness (e.g. Chen & Greenberg, 2004), several participants reported that the mental health problems of their relative made them change their outlook on the whole family, and clarify their values and priorities in life. Some participants adapted to mental illness by seeing it as inherent in their family, and preferred to view it as part of the personality of their relative, rather than as mental illness per se.

### 9.3.3 Coping mechanisms and needs of different kinship groups of relatives of persons with enduring mental illness

*An illness in the family affects everybody in a different way, but it affects everybody.*

#### 9.3.3.1 Coping mechanisms and needs of mothers of persons with mental health problems

Mothers of persons with mental health problems constituted the majority of the sample, and in line with previous findings (see, e.g., Marsh, 2001) seemed to have borne most of the burden of mental illness on the family. More mothers than other family members were residing with their ill relative at the time of the study, and on average spent more hours per week in direct contact with persons with mental health problems. They were more often 'at the receiving end' of their relative's disruptive behaviour, and reported worry and fear about the well-being of their ill child and the rest of the family more often than other kinship groups of participants. In addition, mothers whose relatives with mental health problems had children reported taking an active part in the upbringing of their grandchildren when their relative was not well. Overall, more mothers felt that they needed support, reported that they had been actively seeking support from a variety of sources, and more often complained that they were not getting support when needed, than other participants of the study.

A lot of mothers accepted their responsibility to care for their ill child as inherent in their family role, and took an active part in their child's treatment and rehabilitation. They sought information and advice from mental health services, family support groups, via mass media, books, and internet resources, and coped by talking to other family members, friends, and family support groups if available. Most of the participants who were mothers felt that people needed to be more open about mental illness in the family, and wanted recognition of their caring role by mental health services.

Most of the needs of mothers highlighted by this study were in agreement with previous findings on support requirements of carers of persons with mental illness (Mental Health Commission, 2005; Department of Health and Children, 2006). These needs were: individual or group counselling or family therapy, education about mental illness and its treatment and a permanent contact, or a key worker for a family. Information and help with housing of persons with mental health problems were also viewed as essential by mothers. In addition, mothers felt that they needed some kind of training or advice on handling crises, stress management and coping skills. This sort of training is sometimes referred to as family psycho-education (Marsh, 2001) and is offered to families with mental health problems in the US and Europe.

### 9.3.3.2 Coping mechanisms and needs of fathers of persons with mental health problems

Most of the themes regarding the perceived effects of mental illness on the family emerging from fathers were very similar to the themes emerging from mothers. In addition to anxiety, inability to relax, and worrying about their child, fathers seemed to be more affected by the ongoing nature of mental health problems, inability to solve problems and their perceived lack of control of the situation. Inability to help a child, felt as inherent in their role as a father, clashed with the lack of control and solution which added to their anxiety. Fathers seemed to bottle up their emotions more than mothers, and did not feel comfortable sharing them in a group setting. Fewer fathers participated in SI family support groups, than mothers. This study confirmed some previous research on gender differences in caring and coping (Wackerbarth & Johnson, 2002; Pickett-Schenk, 2003), reporting that more fathers than mothers tended to seek information on their own, rather than via support groups or other people outside the family circle. A higher number of fathers who participated in this study seemed to have benefited more from individual or family therapy and educational programmes, than from family support groups. According to the participants of this study, fathers were more emotionally affected by the stigma associated with families with mental illness, and needed counselling in order to prevent the escalation of their hidden distress and in extreme cases, their disengagement from the family.

### 9.3.3.3 Coping mechanisms and needs of sisters of persons with mental health problems

Sisters who participated in the study were deeply affected by the 'loss' of their sibling to mental illness, and were concerned about their sister's or brother's future and well-being. In line with some previous findings, sisters were concerned with the effects of the stigma on their own career and relationships, and feared that they themselves or their children could suffer from mental illness in the future (Marsh, 2001). In addition, sisters who participated in this study were concerned with the perceived lack of solutions to the mental health problems of their relative, and expressed the need for available contact and practical advice on how to handle disruptive behaviour. Sisters felt that it was not beneficial for their well-being to share the same accommodation with the person with mental health illness. Like fathers, sisters felt uncomfortable in support group settings, and felt that individual counselling could have been more beneficial for them. Some of the effective support resources for siblings suggested by previous studies (Marsh, 2001), included home-based programmes and family therapy. Supported housing for persons with mental health problems would also have benefited the psychological well-being of their sisters.

### 9.3.3.4 Coping mechanisms and needs of brothers of persons with mental health problems

One brother who participated in the study felt that it was not beneficial for either himself or his sibling with mental health problems to share the same accommodation. Several parents who participated in the study commented that brothers of persons with mental health problems were deeply affected by the loss of their sibling, but did not feel comfortable expressing their emotions or participating in family support groups. Some brothers could not accept the illness of their relative, could not forgive their siblings for their disruptive behaviour, and often disengaged themselves from the family. From the participants' point of view, individual counselling could have benefited brothers more than participation in support groups. Home-based counselling or therapy, suggested by Marsh (2001) for siblings, could be beneficial for brothers of persons with mental health problems in order to help them accept mental health problems in the family and stay in touch with their relative.

### 9.3.3.5 Coping mechanisms and needs of spouses of persons with mental health problems

One wife who participated in the study experienced social isolation, had to take on extra responsibilities for the well-being of the family, and reported lack of emotional support from the services. She felt the need of practical advice on how to handle the disruptive or unusual behaviour of her husband, and respite care or home care services. The participant adapted to mental illness in the family by accepting that caring for her husband was inherent in her role as a wife, and doing more household chores when stressed. She also felt that she needed more information from services about the medication and treatment of her husband.

### 9.3.3.6 Perceived needs of children of persons with mental health problems

Three relatives of study participants had children. The participants of the study who were grandparents commented on the perceived experiences and needs of children of persons with mental health problems. They felt that children of persons with mental health problems were worried, confused and fearful about their parent's behaviour during crises, and needed unobtrusive and child-friendly explanations about the mental health problems of their parent. One participant felt that a child of a person with mental health problem was afraid that she was getting her parent's 'sickness'. These comments support some previously described findings on the effects of illness in the family on the children of persons with mental health problems (Marsh *et al.*, 1996). Participants felt that children of persons with mental health problems needed individual counselling or group therapy with participants of similar age and family situation. Only one participant reported that children of a person with mental health problems were about to get some counselling from mental health services. The other two participants commented that the children were left 'to their own devices', and that they were counselling them in their own 'amateurish way'. Such situations should not be viewed as acceptable by mental health services. The need for support of children of service users was underlined by *A Vision for Change*, including provision of practical support and communication with community services, if necessary.

### 9.3.3.7 Coping mechanisms and needs of male and female groups of relatives of persons with enduring mental illness

Coping mechanisms and support requirements of male and female participants proved to have more similarities than differences in this study. Contrary to some previous findings (Pickett-Schenk, 2003), not only female but also several male participants of the study felt that the support groups of SI were valuable for sharing information and experiences with other people in situations similar to their own. However, due to the fact that the majority of participants were recruited via support groups of SI, male participants who participated in family support groups could have adopted more coping mechanisms than other male carers or family members.

In support of previous findings, female relatives of persons with mental health problems, such as mothers, seemed to value social interaction and emotional support from other people more than male relatives, such as fathers and brothers (Lutzky & Knight, 1994). Fathers and brothers seemed to be more reluctant to express their emotions and share their experiences in a group setting, and tended to look for solutions on their own. Male carers and relatives tended to get more involved in the technical details of treatment and rehabilitation of their child, in order to feel in control of the situation. A gradual, step-by-step unobtrusive awareness-raising was suggested by the participants of the study for fathers, brothers, and sons of persons with mental health problems.

Mothers, sisters, and a wife who participated in the study reported using household duties, chores, or studying as a means of calming down when stressed. In addition, some female participants reported to take one day at a time approach to family problems. Such coping mechanisms were not reported by fathers who participated in the study.

In some disagreement with previous findings on gender differences (Lutzky & Knight, 1994), two sisters who participated in the study also expressed their reluctance to participate in family support groups and share their experience outside the family circle. Among the reasons for their non-participation in family support groups of SI was the lack of support groups provided to people of their own age. Also, both fathers and sisters seemed to have been more concerned with the stigma associated with families with mental health problems. This highlights the needs to address the stigma in society, and to carry out more research on the feasibility of various support resources for siblings of persons with mental health problems.

## 9.4 Needs and support requirements of participants at different stages of their experience of enduring mental illness in the family

*At each stage in the illness you need a different type of help, I think.*

The stages of experience of participants with enduring mental health illness in this study were somewhat predefined by questions in the interview schedule, and included first encounter with mental illness of a relative, first encounter with mental health service provision, discharge and relapse (see Questions 1-4 of Appendix 6). Several other stages of family experience were elicited by question 9 of the schedule (see Appendix 6), which addressed the most difficult stages of family experiences with mental illness. Additional stages described as difficult by participants were committal, or involuntary admission of their relative, before diagnosis and getting diagnosis, relapse, acceptance of mental illness in the family, and accepting the independence of persons with mental health difficulties. The question regarding expectations of treatment and rehabilitation (see Question 5, Appendix 6) elicited the stage described by participants as the ‘turning point’ in the illness of the relatives. According to the participants, there had been a turning point after which the health and well-being of their relative had gradually improved, their expectations of the outcomes of treatment and rehabilitation of their relative had become higher, and their own sense of well-being had increased.

Three of the stages elicited by the questionnaire and brought up by participants support previous research on family adaptation to enduring mental illness. They include initial encounter, getting diagnosis (Muhlbauer, 2002), and acceptance of mental health illness as an inherent part of family life (Spaniol & Zippel, 1994; Karp & Tanarugsachock, 2000). Additional stages emerging from the participants in this study and not mentioned by the previous studies described in Chapter 1 were committal, which could be viewed either as a separate stage, or as part of broader stages of either the initial encounter, or relapse, and the stage of independence of their relative, which could be viewed as either inherent in the acceptance stage, or as a separate phase related to the turning point in the mental health of the relative, or recovery stage. The stage described by participants as the ‘turning point’, since which the health and well-being of their relative had improved, and the hopes and aspirations of participants had increased, was not mentioned in any previous studies described in Chapter 1. More research is needed to validate these findings.

### 9.4.1 The initial encounter with mental health problems in the family

*The train is coming down the track and I don't know whether you can avoid it, but it probably could be handled better, because it just doesn't only affect the person, it actually affects the family.*

The onset of mental health problems was characterised by gradual, rather than ‘overnight’ change in the person’s behaviour, and was preceded by or coincided with some stressful



events, poor physical health, or substance abuse mentioned by the study participants. Some of the reported stresses were studying for the Leaving Certificate, college exams, pressures of work, bullying at school, or abusive relationships at home. The physical ill health reported by participants included stomach problems, flu, acne, accidents, insomnia and others. Excessive use of substances as reported by participants included perceived misuse of alcohol, cannabis, and ecstasy. All participants reported deterioration of social, educational, or occupational functioning of their relative at the time of the onset of mental health problems, which was characterised by loss of friends, skipping classes, poor study results, or problems at work and at home.

The onset of illness, as reported by most participants, had occurred in the family homes during school years of their relatives. The findings of the study suggest that the burden on the family could have been the heaviest at the onset of illness, with higher number of contact hours spent with the relative, and the most disruptions of family life occurring at this stage.

The initial encounter, also referred to as 'before a diagnosis' by some studies (Karp & Tanarugsachock, 2000; Marsh, 2001) was characterised by confusion, denial and seeking assistance. An additional theme elicited from the participants of this study was the gradual change in their relatives at the onset of illness, which was hard to notice and account for by either family members or health professionals. However, even after mental health problems were noticed by the participants, it was very difficult to get help. The majority of persons with mental health problems had voluntarily sought help from GPs, psychologists, psychiatrists, a general hospital, and a psychiatric hospital during the onset of mental illness. As reported by the participants, the signs of gradual deterioration of mental health were not always recognised or 'acted upon' by either primary or secondary health services. Most of the first contacts for help were GPs.

Only one-third of GPs, contacted by either participants or their relatives for help during the onset of mental illness, referred persons with mental health problems to public or private hospitals or units. Other professionals who referred persons with mental health problems to hospitals or units were psychiatrists, psychologists, guards, a general hospital, and a school teacher.

The duration of untreated mental health problems, recalled by some participants, ranged from one day to ten years, with an average duration of 1.97 years. Persons who were younger at the time of the onset of mental illness had a significantly longer period of untreated illness, as reported by participants. One of the possible explanations of this finding could be difficulties of recognising the signs of mental health problems at a younger age by health or educational professionals. However, not enough data were collected in this study to allow for deeper analysis of the untreated' period of illness, which requires further investigation.

Participants felt that GPs needed better training in mental health problems, and that information should have been made available to parents by the school, as very often the onset of illness occurred during school years.

In some cases it was only at the stage of 'breakdown', which involved somewhat aggressive behaviour towards other members of the family, or attempted self-harm, had it become possible to get help. Though most of the first admissions reported for the study were voluntary, most cases of 'breakdown' led to involuntary first admission to psychiatric hospitals or units. Participants felt that committals were not beneficial for either the persons with mental health problems or themselves and affected future family relationships, but viewed them as a 'necessary evil' in the absence of other help offered to the family.

The procedures of admissions and getting help were not clear to most of the participants, either at the time of the first admission or during relapses. Participants felt that information on admission procedures, catchment areas and choice of hospitals should be made available to the public. Also, training of primary health care services would help early intervention, which

in some cases could have avoided the breakdown of the person with mental illness and their involuntary admission.

The need for better links and access between primary care and specialised mental health services was also one of the themes permeating the consultation process of *A Vision for Change*.

#### 9.4.2 The first encounter with mental health service provision

*My point from the very beginning was that he was going to return to his home, which was going to be his main place of support, and I needed to know what was going on, and I needed to know the best way of helping.*

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 at the time of the first admission to an in-patient unit or hospital. Participants complained about the lack of information regarding illness, treatment, and diagnosis of their relatives during the first admission, and reported that they had been frustrated at not knowing what to expect from treatment and on discharge of their relatives back to their homes. Participants whose relatives had never been admitted to in-patient mental health services and used services of private psychiatrists also complained about the lack of information about diagnosis, treatment, and medication, and advice on how ‘to behave’ with their relative. Several participants felt that after the initial encounter with mental health problems they needed to redefine their caring role as family members of persons with mental health problems, and needed as much information and advice as possible in order to readjust their expectations and accept that mental illness was a part of their family life. Most of the participants had known that their relative would be discharged back into their care and needed information about how to handle crises, what to do and what not to do.

In some cases, information about diagnosis was not provided to participants by mental health services. Participants offered various explanations for non-provision of diagnosis, such as: admission being voluntary; non-provision of any information about the illness in general and the diagnosis in particular by the private sector; and refusal of their relative to communicate information about illness and treatment to their families. However, there were no significant differences between private and public hospitals, and voluntary or non-voluntary admissions in how participants learnt the diagnosis. In some cases, when service providers refused to divulge the diagnosis, the persons with mental illness informed their family members themselves about their diagnosis. There seemed to be no consistency across mental health services in the procedures of informing families about the diagnosis of persons with mental health problems. Clear guidelines on revealing information about diagnosis should be drawn, agreed with service users, their carers and relatives, and mental health services, and adhered to by all services, in order to alleviate distress and confusion associated with the provision of information about diagnosis.

The information about diagnosis, though long-awaited, was always a shock. Participants felt that they needed gradual introduction and an individual appointment at the time of learning the diagnosis of their relative. The need for a key worker, or a ‘mediator’ between the family and the person with mental health problems, was emphasised at this stage. Participants also reported a lack of sympathy, support, and human interaction with mental health services when being informed about diagnosis.

Participants who had experiences with both public and private services felt that there was more support provided to families by the public services, than by the private, in terms of more approachable contacts, more information and advice, and more sympathy offered by staff during first admission. More research on first admissions to private and public hospitals and units is needed in order to address this issue.

Participants who had received individual counselling reported it as highly beneficial at the time of getting the diagnosis from mental health services. Also, educational programmes and family support groups were mentioned as helpful at the stage of the first admission. However, several participants also felt that too much information about the illness and possible behaviours could be overwhelming at the stage of the first encounter with service provision, and that a gradual flow of information would have been more helpful, delivered through personal, sympathetic contact, rather than in writing.

Some of the needs during the first encounter with service provision voiced by the participants, such as timely and appropriate information and education, and appointment of a key worker by the multidisciplinary team, are covered by Recommendation 3.6 of *A Vision for Change*. Inclusion of relatives in the care planning process, as specified in the report, should occur only with the agreement of the service users. Participants recognised the difficulties associated with confidentiality in the issue of information about illness and treatment. However most of them felt that being main carers of the person with mental health problems in their homes prior to and after the first admission, they had the right to know what to expect, how to 'behave', and how 'not to behave'.

One possible solution to this dilemma could be a family psycho-educational programme for relatives of persons with mental health problems, such as that designed and tested in the US and in Europe. This interactive programme includes problem solving, crisis intervention and coping skills, provides information about mental illness and caring, and is focused more on family needs, than on the needs of the ill relative (Marsh, 2001). Some studies have shown that psycho-education may reduce relapse, improve the functioning of the ill person and family well-being (cited in Marsh, 2001). Also, family consultations provided in the US at the time of the first admission proved to be very successful in addressing the feelings of distress and alleviating the subjective burden of mental illness on the family (Marsh, 2001).

### 9.4.3 Discharge

*In other words, was he being just dumped back on society, dumped back into his family? Because I just felt there was nothing else for him, but to be sent back to his family, and what was there in society? Very little...*

The stage of discharge of persons with mental health problems to their homes was reported to be one of the most difficult periods. Participants reported about unexpected discharges of their relatives to their homes with no information about illness, treatment, or follow-up care provided to the family. They felt that there should have been a designated person that they could contact in case of emergency and, in cases when the person was still unwell at the time of discharge, respite care or supported accommodation should have been provided. Participants experienced difficulties in re-establishing relationships with persons with mental health problems, and felt that in some cases they should not have been discharged back to the family home.

One of the recurrent needs at the time of discharge, voiced by the participants, was a proactive, out-reach follow-up service and approachable contact from the mental health services. They also needed timely information about discharge, including treatment plan and medication. Inclusion of carers in the discharge process and appointing a key worker for the family were included in Recommendation 3.6 of *A Vision for Change*.

Whereas all participants complained about lack of information, family support and follow-up services on discharge, participants who had experiences with both private and public services commented that the discharge from private hospitals was happening on the basis of insurance 'credits' available to the patients, and not necessarily when their health and well-being had

improved. Therefore, persons with mental health problems were often still unwell when discharged back to the family care, which added to the burden on the family and possibly led to relapse. This finding requires further investigation.

#### 9.4.4 Relapse

*And my husband had to commit him, we were both together and I said it's your turn to commit him, it's your turn to sign... And my husband was in floods of tears and I was just stoned<sup>1</sup>...*

The stage of relapse was reported as one of the most difficult periods of family experience, along with the initial encounter. In several cases it was reported that relapse occurred after persons with mental health problems stopped taking medication. Participants experienced grief and frustration similar to the initial encounter, accompanied by disappointment or disillusionment of participants that the illness had not been 'cured' and was enduring. Attempts of suicide, self-harm, or most aggressive outbreaks described by participants occurred at the time of relapse. Participants faced difficulties with placement of participants in an inpatient unit or hospital similar to those during the first admission. Most second admissions were voluntary. In some cases participants had to commit their relatives for the second time, which was associated with another emotional blow for the whole family.

Participants expressed the need for a key worker for a family, information about medication, its side-effects, and the consequences of not taking medication. They felt that continuity of follow-up on discharge could have prevented some of the relapses. Participants felt that support and services provided after discharge and during relapse were different in different catchment areas and in public and private services, with public sector providing more follow-up services than private.

At this stage turning to support groups for help proved to be beneficial to some participants. Marsh (2001) also recommended family consultation during the time of relapse, providing families with professional advice on diagnosis, treatment plan, medication and future goals and actions of family members.

#### 9.4.5 Acceptance

*It's very hard, when they're just diagnosed, to accept it, it takes you a while, but you accept that.*

Participants felt that information about the diagnosis was vital for them in order to accept the illness of their relative and learn as quickly as possible of how to help.

In line with some previous findings (Karp & Tanarugsachock, 2000), this study found that the stage of acceptance of mental illness in the family may be one of most difficult for carers and families. Participants felt that acceptance was a personal, individual matter and provided few comments about this stage. More fathers than mothers found it difficult to accept the illness of their child, with most of them being members of SI. Whereas some participants started to come to terms with illness after learning the diagnosis and 'educating themselves' about the illness, for others, counselling provided by SI made it easier to accept the illness and 'move on' with their lives. More research is needed to provide insight into acceptance of mental illness in the family by individual family members as a means of coping and adapting.

<sup>1</sup> The participant used the word 'stoned' to describe emotional 'numbness', not drug-induced state.

#### 9.4.6 Death of the main carer

*I suppose after my mother died, because the onus was on me then to look after him and look after my father. Yeah, I suppose that time it was difficult.*

The stage of death of the main carer of a person with mental health problems was viewed as most difficult by two siblings who had to take on the caring responsibilities after the death of their parent. Extra responsibilities were added to existing ones, and the siblings felt the most burden of mental illness on the family at that stage. They felt that their relatives needed ongoing support from services and suitable accommodation. Continuity of support and services to persons with mental health illness can alleviate the burden of siblings or children after the death or illness of the main carer.

#### 9.4.7 The turning point

*The programme that they put in place for her has been very effective. I can see my daughter back to me for the first time in probably eight years... I think generally at this stage I'm confident that we really have turned the corner, hopefully.*

The theme of a turning point in experience of mental illness in the family quite unexpectedly emerged from some participants in their answers to the question about the change in their expectations of treatment and rehabilitation of their relative (see Question 5 of Appendix 6), and was associated with a positive change of hopes and aspirations of participants.

The turning point somehow marked the beginning of gradual improvement in mental health and social functioning of persons with mental illness. The turning point was associated with at least two or more events. These events were related but not limited to the improvement of treatment and rehabilitation services, change of medication, adjustment of the person with mental illness to the existing medication, improved relationships with psychiatrists characterised by mutual trust, increased motivation, seeing a psychologist on a regular basis, and encouragement by mental health services of personal and occupational growth. Other events, or factors were associated with relocation to more suitable accommodation, taking on responsibility for own treatment or medication, participation in suitable occupational or training activities, and enrichment of the social circle, starting off at a support group, or treatment and rehabilitation facilities provided by mental health services.

Those participants who mentioned the turning point in the mental health and well-being of their relative were happy with the present state of health of their relative, and satisfied with the services and support provided to their ill relative. This supports some previous findings suggesting that the needs of families are closely connected with their perceived needs of persons with mental health problems and their quality of care (De Haan *et al.*, 2001, Mental Health Commission, 2004). The total scores on the scale of physical assistance and psychological resistance to fulfilling basic daily living tasks (PRADLI) were significantly higher for those persons who were reported as having had a turning point in their health and functioning.

It may be hypothesised that the aforesaid events, associated by the participants of the study with the turning point in the state of health and social functioning of their relative, signalled the beginning of the process of rehabilitation, or recovery, at least in the sense of recovering a meaningful social role, as referred to in *A Vision for Change*. The principle of recovery was defined in *A Vision for Change* as 'the belief that it is possible for all service users to achieve control over their lives, to recover their self-esteem, and move towards building a life where they experience a sense of belonging and participation' (p. 105). It may be beneficial to explore and validate the concept of the 'turning point' as a possible starting point on the road to recovery through further research involving or led by service users.

#### 9.4.8 Views of participants on rehabilitation or recovery of persons with mental health problems

*My expectations are high, but I can't see anything coming of it at the moment. I want things for my son, I want him to be rehabilitated, but it doesn't seem to be part of the scheme of things in psychiatric therapy.*

The question about expectations of treatment and rehabilitation of persons with mental health problems elicited the views of participants on the effectiveness of treatment and care of their relatives, and the improvement, maintenance or deterioration of their mental health, social functioning and quality of life.

Views and expectations of outcomes of successful treatment and rehabilitation were slightly different for individual participants, depending on their own experience with the mental illness of their relative. Although participants were not asked to rate their current level of expectations, more than half of the participants volunteered their own assessment of the level of their current hopes for the future of physical and social functioning of their relative. On the basis of such self-rating, three distinct groups emerged from the analysis: participants with 'low' expectations, participants whose expectations 'had changed' and become 'higher', and participants whose expectations were 'high' at the time of the study. Contrary to some previous findings that the relatives' expectations of treatment and rehabilitation of persons with enduring mental illness were usually readjusted at the time of acceptance of the permanence of mental illness and became somewhat lower (Karp and Tanarugsachock, 2000), participants in this study reported that their expectations had become higher with time, and none reported that their expectations had become lower. Moreover, the change in expectations, reported in retrospect by participants in this study, was not associated with the stage of acceptance of mental illness, but with perceived improvement of psycho-social functioning of persons with mental illness.

Participants who reported that their expectations were low at the time of the study felt that there was little rehabilitation forthcoming from mental health services, and were concerned about the deterioration and low functioning levels of their relatives. They did not seem to believe in recovery of persons with mental health problems. Their expectations of treatment and rehabilitation could be compared to those characteristic of the programme of 'ward closure', which equated rehabilitation with 're-settlement and maintenance' (Department of Health and Children, 2006, p.105). However, participants whose expectations had become higher, and who felt that the psycho-social functioning of their relative had improved, wanted their relative to have a more 'normal' life, including independent living in suitable accommodation, meaningful occupation during the day and integration into the community.

It is worth mentioning that the word 'recovery' did not emerge directly from the individual contributions of the participants and the word 'rehabilitation' was mostly used. Those participants who mentioned recovery had learnt the word from other sources, such as SI or AWARE support groups, brochures, or other written information, or from service users speaking at SI conferences. The finding seems to confirm that of *A Vision for Change*, which stated that service users and their carers should not be considered a homogenous group, 'although there are many issues which are common to both groups' (Department of Health and Children, 2006, p.24). However, such concepts as 'encouragement', 'responsibility', 'motivation', 'holistic approach', and such like, mentioned by some participants, seemed to be related to such underlying principles of recovery as 'empowerment', 'recovering self-esteem', 'belonging and participation', described in *A Vision for Change*. It is necessary to carry out further research involving service users to validate the findings of this study and to explore the processes and the desired outcomes of recovery.

Overall, the views of participants on the effectiveness of treatment and rehabilitation of persons with mental illness were very similar to those of service users described by *A Vision for Change*. They included greater access to psychological therapies, gaining new skills and qualifications, a holistic approach to service provision, integration into the community, suitable housing and availability of ongoing support services in the community.

Participants also valued their own contribution to the treatment and rehabilitation of their relatives, and felt that they should be more involved, unless their relative did not wish them to be so. They also commented that such involvement was beneficial for their own sense of well-being, as it helped them to feel useful. As stated in *A Vision for Change*, services provided by community mental health teams should include greater practical support for carers, as well as greater involvement in care planning, with the agreement of service users, and inclusion in the discharge process. Recommendation 3.9 of *A Vision for Change* states that ‘service users and carers should participate at all levels of the mental health system.’ (p. 31).

## 9.5 Support resources available, their utilisation and further supports needed

*That's another thing with the mental health services: it depends on where you are living.*

As reported by all participants, there was a lack of formal support resources specifically designed for families with enduring mental illness. The families relied on informal supports available in the area as heavily as on formal family support resources. Informal supports included friends, other relatives and neighbours, and individual information resources, such as books, television and the Internet. In cases when community psychiatric nurses or social workers were providing services to persons with health problems, they served as an additional informal type of family consultation and crisis management resource for carers and relatives. Participants felt that nurse and social worker services were understaffed and ‘overworked’, and that there should be more formal support resources designed specifically for families, such as a key worker, or family counselling.

Most formal family support resources, i.e., resources designed specifically to provide support to families with mental illness, used by the participants, were provided by voluntary organisations such as SI and AWARE. Only two family education programmes were provided by mental health services in two specific catchment areas of County Dublin. Fewer family support resources were available in the MHS area, and fewer recruits of MHS were aware of SI family support groups available in their catchment area.

A higher percentage of MHS recruits reported having a specific approachable contact with mental health services compared to participants recruited via SI. The type of contact was also different, with MHS recruits relying more on nurses and care workers, and participants of SI reporting more contacts with psychiatrists. One of the explanations for this finding emerged from SI participants who had experience of both public and private services, who felt that there were fewer nurses and care-workers available to their relatives in the private sector than in the public, and psychiatrists were too pressed for time and overworked to be approachable for family consultation. There is more research needed on the reasons for such perceived differences in service provision between the public and private sectors.

Regardless of their source of referral to the study, participants commented that there was no consistency across the country in service provision either to service users, or to their carers. Qualitative and quantitative data collected by this study suggest that the quality of services and support provided to families with mental health problems varied dramatically in different

catchment areas, in individual hospitals or units, in community residencies, in private and public sectors of mental health services, and in various counties of Ireland. There is a need for further research and better planning of support services in order to ensure high quality of services everywhere in Ireland.

For most of the study participants, SI seemed to be the one and only available, known and used support facility. One of the criticisms of participants of mental health services included the lack of information about family support resources, including information about SI. Information and support resources used by the participants had to be sought out via friends, other relatives or primary health care services.

In agreement with previous findings, some of the barriers to utilisation of existing resources were lack of time and lack of flexibility of existing services (Biegel *et al.*, 2004). In addition, some of the participants reported that they were at the stage when they did not need formal support resources as much as they had needed them during the initial encounter, discharge, relapse, and other most difficult stages of their experience. The need for formal support resources such as counselling, educational programmes, or psycho education seemed to have decreased for those participants whose relative's health and well-being had improved. However, such needs as a key worker for the family, or mediator between persons with mental health problems and their families, information about treatment and care of their relatives, and approachable contact from mental health services were reported as ongoing by participants, regardless of the stages of their experience with mental illness.

Family support groups were also seen as valuable resource when available, and served different purposes at different stages of experience of the participants: from social and information contact at the early stages, to advocacy of persons with mental health problems, helping other families with mental health difficulties, and information about recovery at the stage of improvement of health and well-being of persons with mental health problems. In addition to developing new coherent resources suitable for individual carers and relatives of service users at various stages of their experience, there is a need to support existing resources, such as SI, and benefit from their expertise in developing multi-functional and proactive support resources in Ireland.

### 9.5.1 Views of participants on the future

*I just hope to live as long as possible to be of service, to be of help to my daughter and the others.*

In agreement with previous findings (see, e.g., MHC, 2005), this study has shown that most of the perceived future needs of carers and families of persons with mental illness were associated with the quality of services and the well-being of their relative. As found by this study, in line with some previous studies, some of the families' worries about the future included suitable accommodation, employment, and legal status of persons with mental health problems after the carers were gone (see, e.g., Marsh, 2001). One of the unexpected findings of the study was that despite the worries, most of the participants were relatively optimistic about the future well-being of their relatives, and expressed hopes for the improvement of their quality of life in the future.

Participants with a slightly shorter experience of mental health problems, or those whose relative's health and well-being had not improved were more pessimistic about their own and their relative's future. A worrying finding was that most of these with more pessimistic views on the future well-being of their relative and themselves were using private mental health services at the time of the study. There is a need to do more research and evaluation of quality of private mental health services offered to families with mental illness.



## 9.6 Satisfaction of participants with services and support provided to persons with mental health problems and their carers and families

*If his needs are met, my needs are met.*

A higher percentage of carers and relatives of persons with mental health problems who took part in this study were dissatisfied or very dissatisfied with the services and support provided to both themselves and their relative, than that suggested by previous findings on satisfaction of carers in Ireland (see, e.g. De Haan *et al.*, 2001). Half of the participants were dissatisfied or very dissatisfied with the services provided to their relative, and 60% with the services and support provided to themselves, as compared to 44% of dissatisfied or very dissatisfied carers of persons with the first episode of psychosis in the survey carried out by EUFAMI in 2001 (De Haan *et al.*, 2001). The results of this study support previous evidence that carers were less satisfied with services provided to themselves than with those provided to their ill relative (MacDonald *et al.*, 1990), and also that the needs of families and their satisfaction with services to carers were interrelated with the needs of persons with mental health problems and their satisfaction with services provided to service users (Mental Health Commission, 2005).

This study did not support previous findings that such factors as gender of carers, patients' age, and overall duration of enduring mental illness were positively correlated with the satisfaction of families with service provision to their relative (see, e.g., Stengard *et al.*, 2000). The approximate duration of untreated illness, calculated in this study, also did not have any significant effect on the satisfaction of families with the services provided to service users, or on their relative's perceived level of functioning at the time of the study. Contrary to some previous findings (Chen & Greenberg, 2004), neither age nor gender of family members, nor their socio-economic status, had any significant effects on the level of satisfaction with the services and support provided to themselves and their relative. Moreover, the results of the study were not supportive of the finding of Chen and Greenberg (2004), claiming that living with the relative with mental illness was associated with higher levels of 'care-giving gains' for carers and helped their constructive adaptation to mental illness in the family.

The residential status of persons with mental health problems had a significant negative effect on the level of satisfaction of participants with services and support provided both to their relative and to themselves. Families of service users, who were living elsewhere outside their family homes at the time of the study, were more satisfied with the support and services provided to the family, than those who were living in the same accommodation as the service users. This finding partially supports that emerging from the stakeholder consultation reported in *Quality in Mental Health – Your Views* (Mental Health Commission, 2005), whereby families voiced the need for better housing planning for service users in order to alleviate the burden of caring on the family. An additional explanation of this finding emerged from the qualitative data, whereby participants felt that it was not beneficial for the mental health of service users to stay in their family homes and that they should have been 'moved on' to more independent and, preferably supported, accommodation in order to avoid relapses occurring in the same circumstances as the original onset of mental illness, and to ensure their rehabilitation or recovery progress. This finding requires further investigation and validation by service users.

The finding that participants residing in the same accommodation with their relative were less satisfied with the services and support provided to them and their relative, is also supportive of the needs of new service users with severe and complex mental health problems, highlighted in *A Vision for Change*. The approximate duration of illness reported by the participants whose relatives were living at home at the time of the study was significantly lower than that of service

users who were residing elsewhere at the time of the study, and who could have been affected by mental health problems since the beginning of the de-institutionalisation programme. As reported by participants and supported by the findings of *A Vision for Change*, ‘they may never had been in a long-stay ward, but some will have had multiple admissions to acute wards... Some may have never been admitted to hospital...’ (p.106). Persons with mental illness who had never been admitted to hospital or unit, or had been re-admitted to acute wards several times but were still unwell at the time of the study, were living at home with participants. In most cases, as reported by the participants, they were resistant to treatment and medication offered by mental health services. The burden of caring for these persons was perceived as quite heavy by the participants, who were also least satisfied with supports provided to the family. The needs of such families should be addressed in an urgent fashion, particularly due to the high risk to such persons of becoming homeless or spending time in prison mentioned in *A Vision for Change* (Department of Health and Children, 2006).

The gender of persons with mental health problems was found to be significant to the level of satisfaction of participants with services and support provided to service users, with participants whose relatives were male being less satisfied with the services. The study found no evidence to suggest that the nature of the illness and the improvement of health and well-being in females were significant factors in the level of satisfaction with services; a relatively equal proportion of males and females were reported to ‘have improved’ by participants. This finding is quite worrying, considering the fact that young men are more at risk of attempting suicide and self-harm due to their feelings of entrapment and hopelessness, as suggested by *A Vision for Change*, and need special consideration by planning authorities and service-providers.

The finding that participants whose relatives had medical cards were more satisfied with the services and support provided to services users and their families indirectly validates some of the qualitative data in this study, suggesting that there may be more family support resources available for families in the public, than in the private sector. Whereas both holders and non-holders of medical cards were reported to use the services of psychiatrists quite often, a higher proportion of medical card holders used in-patient and out-patient services, services of mental health nurses, and psychologists. As reported by study participants, only service users with medical cards used services of psychologists. *A Vision for Change* recommends that at least two clinical psychologists be represented in a liaison mental health team in order to provide an effective daytime service for secondary care needs serving local populations. It would be beneficial to ensure that these recommendations were adhered to in both public and private sectors.

The finding that participants who felt that their relatives had good personal relationships with their psychiatrists were significantly more satisfied with the services and support provided to service users supports the views of services users on quality of care highlighted in the report of stakeholder consultation *Quality of Health – Your Views* (Mental Health Commission, 2005). A sympathetic and caring relationship between service users and service providers was one of the needs of service users voiced at the consultation.

The finding that participants who knew whom to contact from the mental health service of their relatives for help and advice were significantly more satisfied with the services and support provided to service users supports the need for partnership and improved communication between all stakeholders, highlighted in *A Vision for Change*.

Participants whose relatives’ health and well-being had improved and who were happy with their present state of health and functioning were significantly more satisfied with the services and support provided to their relative. This finding restates how closely the needs of carers and families are connected with the needs of service users (Department of Health and Children, 2006). The scale of ability or psychological resistance of persons with mental health problems to fulfil basic daily living tasks (PRADLI) served as an indirect but helpful tool for measuring

the health and well-being of persons with mental health problems at the time of the study. The scores on the PRADLI scale calculated on the basis of ratings by participants were significantly higher for service users whose health and well-being were reported as have improved after a certain turning point in their lives, and were positively correlated with the level of satisfaction of participants with the services and support provided to both them and their relatives.

## 9.7 Advice of participants to other families with mental illness, to policy-makers and to the general public

The questions in the interview schedule dealing with the advice provided by participants to other families, to policy-makers and to the public (Questions 11, 12, Appendix 6) were designed in order to support and validate the previous qualitative findings on experiences, needs, and support requirements of families with mental illness, and to serve as first-hand guidance for recommendations to policy-makers and society in general. Recommendations will be outlined in Chapter 10 of this study.

### 9.7.1 Advice of participants to other families with mental illness

*Remember that it's the illness, not the person, and this will pass. It will be better, it will improve. Don't be afraid.*

Some of the advice provided by participants to other families with mental illness restates the needs of carers presented earlier in this study and supporting previous findings, such as the need of information on mental illness and treatment (Department of Health and Children, 2006). The need of family support groups, and quick-action service in case of emergency were highlighted by the Mental Health Commission in the report of the stakeholder consultation on the quality of mental health services (MHC, 2005).

Narratives of constructive adaptation of families to enduring mental illness provided information on individual coping mechanisms and underlined the need for individualised, person-centred family support resources. Gender differences in the effects of mental illness in the family and coping mechanisms used by males and females were highlighted by such issues important to female carers, as blame, need for support from other family members and acceptance of mental illness as a crisis in the family. Male participants, in agreement with previous findings (Pickett-Schenk, 2003), restated their perceived need to stay in control of the situation as their way of coping. Such mechanisms of adaptation of family members to illness in the family need to be taken into consideration in designing suitable support resources.

The issue of public services offering more support to service users and carers than private, emerging from participants who had the experiences of both, indirectly validated the findings of the study discussed in previous sections of this Chapter. The perception of the private sector of being more equipped and offering higher quality care emerged from one participant who had no family experience of private sector services. The differences in resources of private and public sectors need to be further investigated in order to ensure equal standards of care.

Such advice of participants for other families, as the relative 'will improve', 'it depends on the patient', and 'new medication is working' are consistent with participants' narratives pertaining to the stage of a turning point in the state of health and well-being of their relatives and the possibility of their recovery.

### 9.7.2 Advice of participants to policy-makers

*Obviously put more money into the services, build accommodation, accommodation is terribly, terribly important and different type of hostels are required, high support, medium support, low support...*

More funding for mental health services, more supported housing of different levels of support, more family support services, and ensuring continuity of care were the main four requirements of participants, supporting the needs voiced by service users and carers in *A Vision for Change*. In agreement with the results of the consultation of the Expert Group, participants highlighted that persons with mental health problems were more at risk of homelessness, suicide, or drug addiction than other groups in the general population, and that investing funds in coherent and community-based mental health services will save government funds in the future. In agreement with service users consulted by the Expert Group, participants raised the issue of service users' right to respect and dignity. An issue of lack of staff and resources in current service provision, and recognition of the current contribution of some services to the health and well-being of persons with mental health problems and their families, despite the 'appalling conditions', also emerged from the participants.

### 9.7.3 Advice to the general public

*If something different happened to him, I think he would be good in society, but if nobody has any interest in him outside his mother and father, how can you move forward?*

Advice provided by participants to the public supported the need for a wider partnership between all mental health stakeholders and the wider community highlighted by *A Vision for Change*. Participants felt that improvement in the health and well-being of persons with mental illness was possible not only with improvement of mental health services, but also with involvement and support by society in general. More advocacy, more education, and awareness-raising campaigns aimed at tackling the stigma surrounding mental illness were viewed by participants as actions that needed to be carried out by policy-makers, the public, and families with mental illness. Participants felt the need to advise the public that persons with mental illness were no more violent than the general population, and in most cases more sensitive and shy due to their emotional problems. The need to challenge the 'myths' surrounding persons with mental health problems and their families in society emerged from the interviews with participants.

## 9.8 Limitations of the study

A more representative sample of various subgroups of relatives is required to validate and further explore the identified individual needs of such relatives, as sisters, brothers, spouses, and offspring of persons with mental health problems. However, as the findings of the study support some of the previous international findings on the needs and support requirements of individual family members, they can be viewed as a stepping stone towards exploring the needs of the whole family unit, and developing more effective, user-sensitive and efficient support resources for families with enduring mental illness.

The inclusion criterion for participation in the study was having a relative with enduring mental illness of two or more years' duration, which required contact with mental health services at least twice within one year. This study did not take into account experiences of families with mental illness whose members were using mental health services in a less frequent fashion.

Selection and invitation of potential participants to the study were outside the direct control of the researcher and therefore did not allow for the analysis and comparison of participants and non-participants of the study. Such analysis would have benefited understanding of contextual and individual differences of participants and further added to the generalisability of study results.

The semi-structured approach to gathering data on stages of family experience used in this study in order to collect information on various stages of service provision did not allow for a proper ground theory approach to data analysis, therefore content analysis was performed on the data. The stages described in this study need be further defined and validated by an open-ended and data-driven ground theory approach in order to collect more ad hoc and authentic descriptions of the stages of family experience with mental illness in Ireland.

Due to the small numbers of participants whose relatives had been diagnosed with bi-polar disorder, and to the lack of information from some participants about the nature of illness of their relative, diagnosis did not prove to be a significant tool of analysis of experiences, needs, and support requirements of families with mental illness in this study. Findings of this study provide more insight into the experiences, needs, and support requirements of families affected by schizophrenia, than of those affected by other mental illness. Research involving more diagnostic groups is needed in order to explore experiences of relatives and carers with other types of enduring mental illness.

The sample of the study can be considered as sufficiently representative of the population of families with enduring mental illness residing in the city and county of Dublin. Though several participants of the study had experience with mental health services elsewhere in Ireland, caution should be exercised in drawing conclusions about the rest of the country. More research into the needs and support resources of families with mental health problems in other areas of Ireland is needed to validate the findings of this study.

It would have been beneficial to involve service users in the design or analysis of the study in order to validate some of the experiences of carers and relatives with service provision and rehabilitation. This study explored experiences and needs of one group of stakeholders in the mental health area and cannot be viewed as an evaluation of mental health service provision in Ireland.

The sample of the study might have been biased due to the higher proportion of participants recruited via support groups of SI, and less representative of the population of families not availing of support groups. Participants recruited via support groups might have been influenced by the views of other families and health professionals attending such groups. However, the number of participants recruited via MHS was sufficient for the exploratory nature of the study and the in-depth analysis of individual experiences of relatives of persons with enduring mental health problems.

## 9.9 Conclusions

The aim of the study was to explore experiences, needs, and support requirements of families with enduring mental illness in Ireland. While more research on the experiences of families in different areas of Ireland is needed, one of the findings of the study was the lack of uniformity of services and supports provided both to carers and families of persons with mental health problems and to service users themselves. There is no reason to assume that such lack of uniformity is not representative of other regions in Ireland. Therefore, recommendations outlined in Chapter 10 will apply to services and support provided to families with enduring mental illness in Ireland.

### **9.9.1 The role of carers and relatives in treatment and rehabilitation of persons with mental health problems**

In line with previous studies, this study confirms that carers and relatives play an important role in treatment and rehabilitation of their relatives with mental health problems. Most of the participants of this study remained the first resort of care at the onset of mental health problems, sought help and access to treatment when the relative was unwell, provided care and support on discharge, and supported their relatives' rehabilitation. Their current and future hopes and aspirations were associated with health, well-being and quality of life of their relative. To the best of their abilities, they struggled to ensure that the best available treatment and care, accommodation, occupation, and environment were provided to their relative. Carers and families acted as advocates of mental health, promoted integration of their relative into the wider community, and in some cases remained the only source of social support for their relatives. The caring, supporting, and proactive role of families in the treatment and rehabilitation of service users needs to be fully recognised and appreciated by all mental health professionals and stakeholders.

### **9.9.2 The impact of enduring mental illness on the family and support resources available and needed**

The experiences of carers and relatives of persons with mental illness suggested that mental illness had a substantial negative affect on health and psychosocial well-being of the whole family and its individual members. In most cases the onset of illness occurred during the school years, and the burden of illness added to parental and marital problems of family members and reduced the social functioning of the family. The burden of illness, though ongoing due to its enduring nature, seemed to be heavier on the family at the initial stages, and less so as the family adapted to the phenomenon of mental illness.

Parents, and especially mothers, experienced the most of the burden of mental illness on the family, and needed more support resources than other kinship groups. The burden of mental illness on the family, and the stigma associated with mental illness in society in some cases led to complete disintegration of the family, leaving mothers or parents to their own devices in caring, and dramatically reducing their support networks.

Whereas support groups for parents, especially mothers, offered by such voluntary organisations as SI and AWARE seemed to be meeting their needs, support resources were lacking for siblings, spouses, and children, which may have resulted in further emotional problems experienced by these kinship groups. Lack of support resources for other kinship groups may have led to reducing the family network of persons with mental illness and cutting them short of family support during their reintegration into the community. It is therefore necessary to develop efficient support resources for the whole family, capable of meeting the family needs from the early stages of mental health problems.

### **9.9.3 Support services and resources needed at different stages of family experience with enduring mental illness**

Support resources for families seemed to be lacking at the most difficult stages of family experiences with mental illness, such as the initial encounter, the first encounter with mental health service provision, getting the diagnosis, discharge, and relapse. On top of the heavy emotional burden of the perceived loss of a family member to illness, relatives of persons with mental health problems experienced logistical difficulties in getting help and information from mental health services on admission, treatment, care and, in extreme cases, protection of the family from the disruptive behaviour of the person with mental health problems.

Participants in the study felt that if timely help at the **onset** of mental health problems had been available from primary health care and professional mental health services, some of the ‘breakdowns’ of their relatives, and their unnecessary and damaging committals could have been avoided. It is necessary to clarify guidelines on access to treatment and various treatment options available to families with mental health problems.

Information and advice about the nature of the illness, its treatment, and how family members should deal with it were reported as lacking at the times of **admission, and discharge**, which led to further emotional distress of relatives and carers, deterioration of their personal relationships with service users, and in some cases, to relapse. The lack of follow-up services and an approachable contact in case of emergency often left the families helpless in crises and in some cases led to further committals of their relative and further deterioration in family relationships.

Information about **diagnosis** was viewed by participants as essential for provision of proper care to their relatives, and for their own psychological well-being and constructive adaptation to mental illness in the family. Participants needed clear explanations on the nature of the illness, its **treatment, medication**, and prospect of **recovery**, delivered in an individualised and sensitive manner.

Participants felt that **family consultation** with mental health services on the treatment and rehabilitation plan of their relative and individual or family **counselling** would have been beneficial at the stages of admission and getting a diagnosis from mental health services.

Educational programmes or family support groups were viewed as effective at these stages by some participants, and too overwhelming and threatening by others. Several participants expressed the need to developing their caring, coping, and crisis intervention skills on a more individualised basis. This kind of training is sometimes referred to in literature as psycho-education (Marsh, 2001) and has been shown to be effective by some studies at the stages of first admission, discharge, or relapse.

The need for participation in support groups seemed to increase at the time of **relapse**. Such participation helped carers and families to accept that the illness had become enduring.

At the stages of improvement, and **rehabilitation or recovery** of persons with mental health problems, family support groups served as an advocacy network. Participants with more experience with mental illness considered it important to share their experience and provide hope to other families at earlier stages of enduring mental illness in the family.

The findings of this study suggest that not only are formal and comprehensive family support resources lacking, but also that the existing support resources are not consistent and vary dramatically across catchment areas, public and private sectors, individual hospitals, units, and community residencies, and various parts of the country.

#### 9.9.4 Views of participants on rehabilitation and recovery of persons with mental health problems

Participants in the study felt that there was a lack of services and support for their relative at the rehabilitation stage, whereby few encouragement, motivation, and integration resources were available. However, several participants felt that rehabilitation services had improved over the last few years, which could have resulted in the improvement in the psycho-social functioning. Participants who felt that their relatives’ health had improved had a vision of recovery similar to that of service users. The reasons behind this improvement and the turning point in psycho-social functioning of their relative, reported by some participants, need to be further explored and validated by research directly involving service users.

Accommodation of various degrees of support, meaningful occupation or employment during the day, and social integration were viewed by most participants as serving a double function of effective rehabilitation tools, and outcome measures of such rehabilitation or recovery.

### **9.9.5 Private versus public mental health services**

As reported by the participants, more personalised and approachable contacts for families, information and follow-up services were forthcoming from the public than from the private mental health sector. The slightly greater diversity of support and rehabilitation resources available to persons with mental health problems who had medical cards indirectly validates this finding.

However, participants also reported a lack of consistency of support and rehabilitation resources in the public sector. As reported by participants, the non-consultant hospital doctors changed every six months, which could have affected the build-up of trusting relationships with service users and their treatment and rehabilitation.

Perceived lack of services of community nurses, psychologists, and social workers emerged from all participants in the study regardless of the use of public or private services by their relative.

### **9.9.6 Satisfaction of participants with services and support provided to their relative and to themselves**

Participants whose relatives had medical cards, were female, whose health and social functioning had improved, and who were happy with the current state of health of their relative were more satisfied with the services and support provided to their relative.

Participants who were more satisfied with the services and support provided to their relatives were also more satisfied with the services and support provided to themselves.

Participants whose relatives resided outside their family homes, had medical cards, and had higher PRADLI scores of daily functioning were more satisfied with the services and support provided to themselves and their families.

### **9.9.7 Support from society**

Participants in the study felt that, without support from the wider community, rehabilitation or recovery of service users would be difficult. The fact that mental health problems had been hidden in the family for too long due to the stigma associated with mental illness led to the creation of such 'myths' about service users, as that they were violent and dangerous to society and could not recover their social and occupational functioning. Participants felt that the myths surrounding mental illness needed to be challenged by the media, research and advocacy networks. This would help to ensure greater public support for the integration and recovery of persons with mental health problems.

It is hoped that this study will challenge some of such myths, and help to bring about more support for families with enduring mental illness in Ireland.







# Chapter 10

## Recommendations

As highlighted in *A Vision for Change* (Department of Health and Children, 2006), and supported by the findings of this exploratory study, provision of coherent and effective mental health services aimed at the rehabilitation or recovery of service users would be most effective and efficient in the context of partnership between mental health services, service users, their carers and families, primary care services, educators, voluntary organisations, local authorities and the general public.

Whereas **family involvement** in care is often appropriate and beneficial in service provision (Department of Health and Children, 2006), it can only be effective with the **consent of service users**, unless there are exceptional circumstances in which the judgement of service users is viewed as impaired, and family involvement as clinically essential by mental health services. **Support for family members** who can and wish to become involved in the care of service users needs to be provided.

The recommendations below concentrate on a framework for provision of services and support to families at various stages of their experience with mental illness, family-tailored support services, general family support resources, and directions for further research.

### **A framework for provision of family services and supports at various stages of family experience with enduring mental illness**

Figure 10.1 presents a framework for the provision of family supports and services at various stages of family experience with mental health problems, such as the onset of illness, first treatment contact or admission to in-patient services, arriving at diagnosis, discharge, rehabilitation or recovery of service users, and relapse.

#### **Family support at the onset of mental health problems**

- 1 Since mental health problems during the onset of illness are often voiced at primary care level, **the training and education of GPs** need to include recognition and early detection and appropriate responses to, mental health problems. Such information should be part of the training and education of primary health care practitioners.
- 2 **Communication** between primary health care services and mental health services should be improved in order to facilitate timely and appropriate responses to mental health problems and early intervention.
- 3 In order to assist early intervention, the public needs clear and accessible information on **how and where to access professional mental health services**. Mental health services need to provide such information in health clinics, general hospitals, schools and community facilities and the Internet.
- 4 **Information** about mental health, recognition and prevention of mental health problems, and tackling of stigma associated with mental illness should be included in **teacher training programmes, and school curricula**. This will help to ensure prevention, early detection and appropriate responses to mental health problems.
- 5 Information about **existing family support resources**, with a brief description of the types of services offered, and associated contact details, need to be made available at schools, health clinics, mental health services, general hospitals, community and civic offices, the Internet, and telephone directories. Such lists need to be **updated** at least once a year.

<b>Family services and supports:</b>	<ul style="list-style-type: none"> <li>- Training of GPs and college staff</li> <li>- Information on how and when to access MHS</li> </ul>	<ul style="list-style-type: none"> <li>- Information about service provision</li> <li>- Information about available services and support resources</li> </ul>	<ul style="list-style-type: none"> <li>- Family consultation:               <ol style="list-style-type: none"> <li>1) Family needs analysis</li> <li>2) Information about diagnosis;</li> <li>3) Treatment and care plan;</li> </ol> </li> <li>- Key-worker for the family</li> <li>- Family-tailored support services<sup>1</sup></li> <li>- General support resources<sup>2</sup></li> </ul>	<ul style="list-style-type: none"> <li>- Family consultation:               <ol style="list-style-type: none"> <li>1) Aftercare plan</li> <li>2) Reassessment of family needs</li> <li>3) Out-patient, home, and respite care options</li> </ol> </li> <li>- Key-worker</li> <li>- Family-tailored support services<sup>1</sup></li> <li>- General support resources<sup>2</sup></li> <li>- Alternative accommodation for service users if necessary</li> </ul>	<ul style="list-style-type: none"> <li>- Independent or supported accommodation for service users</li> <li>- Support with occupation and employment of service users</li> <li>- Advocacy</li> <li>- Public awareness campaigns</li> <li>- Evaluation of efficiency of family support services and resources</li> </ul>	<ul style="list-style-type: none"> <li>- Family consultation:               <ol style="list-style-type: none"> <li>1) Revision of treatment and care plan</li> <li>2) Reassessment of family needs</li> </ol> </li> <li>- Family-tailored support services<sup>1</sup></li> <li>- General support resources<sup>2</sup></li> </ul>
<b>Stages of family experiences:</b>	<b>Onset of illness</b>	<b>First Treatment Provision, or First Admission</b>	<b>Diagnosis</b>	<b>Discharge</b>	<b>Rehabilitation and/or recovery</b>	<b>Relapse</b>
<b>Stakeholders Involved:</b>	<ul style="list-style-type: none"> <li>- Persons with mental health problems</li> <li>- Families</li> <li>- Primary health services</li> <li>- Educators</li> <li>- Local community</li> <li>- Voluntary organisations</li> <li>- General Public</li> <li>- MHS</li> </ul>	<ul style="list-style-type: none"> <li>- Service users</li> <li>- Families</li> <li>- MHS</li> <li>- Voluntary organisations</li> <li>- Community Groups</li> </ul>	<ul style="list-style-type: none"> <li>- Service users</li> <li>- Carers and families</li> <li>- MHS</li> <li>- Voluntary organisations</li> </ul>	<ul style="list-style-type: none"> <li>- Service users</li> <li>- Carers and families</li> <li>- MHS</li> <li>- Voluntary organisations and community groups</li> <li>- Local authorities</li> </ul>	<ul style="list-style-type: none"> <li>- Service users</li> <li>- Carers and families</li> <li>- MHS</li> <li>- Voluntary organisations</li> <li>- Local authorities</li> <li>- General public</li> <li>- Social services</li> <li>- Adult education authorities</li> </ul>	<ul style="list-style-type: none"> <li>- Service users</li> <li>- Carers and families</li> <li>- MHS</li> <li>- Voluntary organisations</li> </ul>

**Figure 10.1** A framework for provision of family supports and services at various stages of family experience with mental health problems

<sup>1</sup> See page 205.

<sup>2</sup> See page 205.

### Mental health service provision in partnership with families

- 6 At the time of the **first contact with mental health services** by their relatives, or at the **first admission**, most carers need information, empathy, and support. **Basic information** should be offered to families, including the available **services**, the time and manner of their operation, time needed on average for arriving at diagnosis, and confidentiality issues. Concerned relatives should also be provided with a **list of support resources** available to the family, a brief description of the types of services offered, and associated contact details (see Figure 10.1).
- 7 **Family consultations** should be carried out by mental health services at the stage of identifying the nature of the illness (**diagnosis**), prior to **discharge**, and after **relapse or readmission** (see Figure 10.1). Such family consultations should be open to participation by service users and by their families who can and wish to become involved in treatment and care.
- 8 With the agreement of service users, during family consultations carers and relatives should be provided with information about the **diagnosis** or the general nature of mental illness, the **treatment and care plans**, including but not limited to prescribed **medication and its side-effects**.
- 9 Individual **needs** of family members and suitability of various **family support resources** should be discussed at family consultations, outlined in the care plan of service users, and reviewed on a regular basis. This will facilitate planning of future supports for the family, and evaluation of their effectiveness for service provision.
- 10 **Out-patient, home-based, and respite** care options should be discussed and agreed during family consultations with home carers, and outlined in the care plan.
- 11 If the discharge of persons with mental health problems to their family homes is not considered to be in the best interests of either service users or their families, a **suitable form of other accommodation** needs to be offered to service users. It should not be acceptable that persons with mental health problems are discharged back in their family care if they are still unwell, or if their carers are unwell, or if relationships between carers and service users are of an unhealthy nature.
- 12 A **key worker** should be assigned to each **service user** by the community mental health team, as outlined in *A Vision for Change*. In order to promote communication and partnership between stakeholders, it is recommended that such key worker will also be **available to the family** for advice and contact, with the consent of the service user.
- 13 If the key worker is unavailable to the families, **another mental health professional** involved in service provision to persons with mental health problems should be available for consultation with carers and families in case of emergencies.

### Rehabilitation or recovery of service users

- 14 All services, supports, and information provided to service users and their families at all stages of family experience with mental illness should be aimed at **rehabilitation or recovery**. The findings of this study, following *A Vision for Change*, suggest that a recovery-oriented approach may improve the psychological well-being of both service users and their families, and their satisfaction with service provision.
- 15 Persons with mental health problems who are on the waiting lists for public housing may need **guidance and support from mental health services** on how to avail of such accommodation. Communication between mental health services and local authorities should be improved.

- 16 Assessment of individual **occupational needs, skills, and abilities of service users** need to be carried out by social services in partnership with adult education authorities and rehabilitation teams, in order to facilitate ‘place and train’ modules suggested by *A Vision for Change*.
- 17 **Awareness campaigns** focusing on mental health, mental illness, the effects of bullying and stress on mental health, treatment, recovery, and tackling of stigma associated with mental illness should be carried out by statutory and non-statutory organisations and community groups for **schools, colleges, and the general public**, in partnership with service users and their families.

#### Family-tailored support services

- 18 Family-tailored support services should include **family education, individual and family counselling, and family psycho-education**, involving service users and their family members. Such services should be developed in all catchment areas on the basis of the **needs** of service users and their families, highlighted during the **family consultations** and documented in the **care plans**.
- 19 More **individual-based and user-friendly** support services need to be developed and offered by mental health services for **parents, spouses, siblings, and children** of persons with mental health problems. Such programmes should be developed according to evidence-based best practice, piloted within an Irish context, and made available to families in all catchment areas.
- 20 Voluntary organisations have many years of experience in the development and provision of family support resources in Ireland, and their **expertise** should be used for the development of new, and improvement of existing, family support resources provided by mental health services.
- 21 **Cost-effectiveness and efficiency** of professional family support resources should be **evaluated** by mental health services. Outcome measures of such evaluation can include the satisfaction of service users, and their carers and families with the quality of support and services provided to families with mental illness.

#### General family support resources

- 22 General family support resources include services of **voluntary organisations and community groups**. General family support resources could be effectively used by family members throughout **all stages** of their experience with mental illness (see Figure 10.1). Adequate **funding** of existing family support resources need to be secured on a long-term basis to ensure continuation of their use by families with mental health problems.
- 23 More **family support groups** need to be made available for service users and their families in all catchment areas. Such family support groups could be developed in partnership with service users and family carers.
- 24 More **mental health information centres**, available for information, advice, and counselling of service users and their families, could be developed by voluntary support resources, community groups, or mental health services. Such centres could be located in the premises used by voluntary organisations, community groups, or mental health services. The general public should have easy access to such centres.

- 25 Extension of working hours of **helplines** for persons experiencing mental health problems and their family members should be considered by voluntary organisations and community groups, in order to provide continuous support for families with mental health problems.
- 26 Development of new, and improvement of existing, mental health information centres, family support groups, and helplines should involve partnerships of service users and their families. This would provide additional **occupational and training opportunities** for recovering service users and promote **advocacy** for families with mental illness.
- 27 **Cost-effectiveness and efficiency** of voluntary family support resources should be **evaluated** independently or in partnership with mental health services. Some of the additional outcome measures of such evaluations could be the level of satisfaction of service users and their carers and families with the quality of support and services provided to families with mental illness.

#### Directions for further research

- 28 Research on the **experience and needs of service users** at various **stages** of their mental health problems should be carried out in order to provide further recommendations for improvement of support for service users and their families.
- 29 Research on **psychosocial factors** associated with the **onset** of mental illness should be carried out in order to identify and explore further factors involved in the onset or recurrence of mental health problems, and to tailor service provision to the individual recovery needs of service users.
- 30 Research on the **duration** between the **first contact for help** and **referral** to treatment, and between the **referral** and the **first treatment provision** need to be carried out in order to identify and explore further factors associated with duration of untreated illness, which may affect early intervention.
- 31 Research on the **processes and outcomes of recovery** need to be carried out, which would facilitate establishing measures of successful outcomes and effectiveness of treatment and care provision.
- 32 **Needs analysis of general practitioners and educators** at the stage of the onset of mental health problems should be carried out in order to facilitate early recognition and prevention of mental health problems.
- 33 **Needs of mental health professionals at various stages of service provision** should be assessed in order to improve planning of service delivery as outlined in *A Vision for Change*.
- 34 More research on **public perceptions** of such enduring mental illness as schizophrenia and depressive disorders is needed in order to identify the nature and origin of the stigma associated with mental illness. This will help to provide specific **guidelines** for challenging myths and misconceptions surrounding mental health problems.



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# Appendices

## Appendix 1 Information Letter for Participants



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 E [ykartalova@hrb.ie](mailto:ykartalova@hrb.ie)

June 7<sup>th</sup>, 2005

### Family Support Study:

**Are you getting the support you need to cope with mental illness in your family?**

*Dear Sir/Madam,*

The Health Research Board is carrying out a study to find out what type of support is available for families with a mentally ill relative and how their life is affected by their relative's illness. This is being done so we can give good advice to the people who plan services so that better support can be given to the people who need it most.

The study aims to find out the needs and experiences of people who have a relative with enduring mental illness in Ireland. "*Enduring mental illness*" means a person has had mental health problems that have lasted for *two or more years*, and they need to be in contact with mental health services at least once a year. An example of enduring mental illness could be serious depression or schizophrenia.

#### **What has this got to do with you?**

In order to provide good advice on your needs it is important to know what type of support, if any, you are getting and what type of help you think would be useful. The HRB would also like to hear about your personal experiences with mental illness in the family, what difficulties you have had at different times during your relative's illness, and what helped you to go through them.

#### **How do you tell us about your needs, experience and ideas?**

You are invited to have a private interview with Yulia Kartalova-O'Doherty, who is an HRB researcher. The interview will be completely *anonymous*, this means that no-one else will find out what you have said, and no personal information (e.g. personal names, addresses, organizations, etc) will be recorded. It is also entirely *voluntary*, so *if you feel like stopping at any stage* you can do so.

**To be involved you need to contact us:**

If you want to find out more or are willing to help with this study, or even if have questions or comments, please phone Yulia Kartalova-O'Doherty

- Phone 01-676-1176 extension 144 between 9.30am and 5.30pm, Monday to Friday.
- Phone 087-670-4312 at all other times
- E-mail [ykartalova@hrb.ie](mailto:ykartalova@hrb.ie) .

**What will be involved in the interview?**

- The interview will take between 45 and 90 minutes.
- It will be arranged in a place that suits you.
- The information you share with us during the interview will be available to the research team only.
- Any records of the interview will be destroyed after the study is published.
- If you take part in this study you are covered by an approved policy of insurance in the name of the Health Research Board.

If you know any other persons who have relatives with enduring mental illness and who might be interested in the study, please feel free to give them the contact details.

With your help, the findings of the study will be published between December 2005 and February 2006. We appreciate your time and effort, your experience is very important to us.

Yours faithfully,



Rosalyn Moran  
Head of the Mental Health Research Division

## Appendix 2 Consent Form for Participants



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### Family Support Study:

#### Consent Form for Participants (Interviewees)

Please tick boxes

- |  |                          |
|--|--------------------------|
| I have read the information letter on the above project  | <input type="checkbox"/> |
| I understand why I am being asked questions  | <input type="checkbox"/> |
| I agree to answer questions about my experiences, needs and support requirements   | <input type="checkbox"/> |
| I understand that only the Health Research Board research team will know the answers I give                                | <input type="checkbox"/> |
| I agree to allow the interviewer to audio tape the interview   | <input type="checkbox"/> |
| I understand that the notes and the tape of the interview will not be disclosed to anyone other than the HRB research team | <input type="checkbox"/> |
| I know how to contact the research team if I need to, as provided in the information letter                                | <input type="checkbox"/> |
| I understand that participation in the research is voluntary and I am free to withdraw at any time                         | <input type="checkbox"/> |

Date \_\_\_\_\_

Signed \_\_\_\_\_

Print \_\_\_\_\_

## Appendix 3 Questionnaire for relatives of persons with enduring mental illness



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### Family Support Study:

#### Questionnaire for relatives of persons with enduring mental illness

**Gender:** Male ( ) Female ( )

**Age:** \_\_\_\_\_

**Marital status:** Single ( ) Married / cohabiting ( )  
 Separated / Divorced ( ) Widowed ( )

What is your **relation** to the person with mental illness?  
 (e.g., brother, sister, mother, father, wife, husband, uncle, partner, etc)\_\_\_\_\_

**Education:** Some primary ( ) Completed Primary ( )  
 Some Secondary ( ) Completed Secondary ( )  
 Some Post Secondary ( ) Certificate / Diploma ( )  
 One or more University Degrees ( )  
 Other \_\_\_\_\_

**Current employment status:** Employed full-time ( ) Employed part-time ( )  
 Unemployed ( ) Homemaker ( )  
 Study ( ) Retired ( )  
 Training ( )  
 Other \_\_\_\_\_

**Occupation** (if unemployed or retired what was previous occupation)  
 \_\_\_\_\_



Please describe the **area** you live in:

urban ( )

suburban ( )

town ( )

countryside ( )

farm ( )

other \_\_\_\_\_

How many **hours of contact** per week on average have you had with your relative for the last 12 months? (or per month if resides elsewhere) \_\_\_\_\_

Do you participate in any **family support programme(s)**?

Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, what programme(s)? \_\_\_\_\_

Do you have a Medical card? ( ) Tick if yes

Do you have medical insurance: VHI, BUPA etc.? ( ) Tick if yes

Are you and/or any member of your family in receipt of carers' allowances?

How **satisfied** or **dissatisfied** are you with the quality of services and support offered to **you and your family**?

Very dissatisfied ( ) Dissatisfied ( )

Satisfied ( ) Very satisfied ( )

Neither satisfied nor dissatisfied ( )



Where does your relative **reside** at the moment?

At home with you/other relatives ( )

In their own accommodation ( )

In an in-patient unit ( )

In a community residence ( )\*please see below:

\*(if in a community residence, do you know if it is high ( ), medium ( ), or low ( ) support?)

Other (please specify) \_\_\_\_\_

What **services** does your relative use at least once a year?

In-patient care ( ) Out-patient care ( )

Respite care ( ) Day care ( )

Nurse ( ) Psychiatrist ( )

Psychologist ( ) Support programme(s) ( )\*

Other (please specify) \_\_\_\_\_

\*If your relative uses **support programme(s)**, what are they?

Does your relative have a **Medical card**? ( ) Tick if yes

Does your relative have **medical insurance: VHI, BUPA etc.**? ( ) Tick if yes

Is your relative in receipt of **disability allowances**?

How **satisfied** or **dissatisfied** are you with the services and support offered to your ill relative?

Very dissatisfied ( ) Dissatisfied ( )

Satisfied ( ) Very satisfied ( )

Neither satisfied nor dissatisfied ( )

Use PRADLI instrument (see next page) to assess **ability and willingness** of your ill relative to undertake **daily living tasks**.

## Appendix 5 PRADLI Scale

### Family Support Study:

Psychosocial Resistance to Activities of Daily Living Inventory (PRADLI<sup>1</sup>).

In the last 30 days, to your knowledge, have your relative been impaired and needed assistance, or displayed resistance in performing basic daily living tasks, such as eating, taking medication, or getting in or out of bed?

Yes\* \_\_\_\_\_ No \_\_\_\_\_ Don't know \_\_\_\_\_

\*If yes, please circle applicable numbers on the scale from 1: maximum impairment (maximum assistance required), and non-cooperative to 7: No impairment (no assistance required), and motivated

NA – Not Assessed/Not Known

<sup>1</sup> Clifford, P.A., Ciper, D.J. & Roper, K.D. (2003). Assessing Resistance to Activities of Daily Living in Long-Term Care. American Medical Directors Association, November/December 2003, pp. 313-319.

Up time: <i>Total hours out of bed</i>	NA	1 Inactive < 1 hour	2 1-2 hours	3 2-4 hours	4 4.5-5 hours	5 5.5-7 hours	6 7.5-9 hours	7 Active >9.5 hours
<b>Eating habits:</b> <i>Ability and willingness to eat at a level to maintain appropriate weight</i>	NA	1 Maximum impairment/ Non-cooperative	2 Maximum impairment/ Cooperative	3 Moderate impairment/ Sometimes eats with hands	4 Moderate impairment/ Constant cueing	5 Minimum impairment/ Resistant	6 Minimum impairment/ some cueing	7 No impairment/ Motivated
<b>Dressing/Changing Clothes</b> <i>for a necessary reason</i>	NA	1 Maximum impairment/Non-cooperative	2 Maximum impairment/ Cooperative	3 Moderate impairment/ Resistant	4 Moderate impairment/ Constant cueing	5 Minimum impairment/ Resistant	6 Minimum impairment/ some cueing	7 No impairment/ Motivated
<b>Toileting:</b> <i>Going to the toilet when necessary and independently</i>	NA	1 Maximum impairment/Non-cooperative	2 Maximum impairment/ Cooperative	3 Moderate impairment/ Resistant	4 Moderate impairment/ Constant cueing	5 Minimum impairment/ Resistant	6 Minimum impairment/ some cueing	7 No impairment/ Motivated
<b>Bathing:</b> <i>Ability and willingness to bathe appropriately</i>	NA	1 Maximum impairment/Non-cooperative	2 Maximum impairment/ Cooperative	3 Moderate impairment/ Resistant	4 Moderate impairment/ Constant cueing	5 Minimum impairment/ Resistant	6 Minimum impairment/ some cueing	7 No impairment/ Motivated
<b>Medical Compliance:</b> <i>Ability and willingness to receive and digest prescribed medication</i>	NA	1 Maximum impairment/Non-cooperative	2 Maximum impairment/ Cooperative	3 Moderate impairment/ Resistant	4 Moderate impairment/ Constant cueing	5 Minimum impairment/ Resistant	6 Minimum impairment/ some cueing	7 No impairment/ Motivated
<b>Restorative Care:</b> <i>Including but not limited to walking, exercising as part of functional rehabilitation</i>	NA	1 Maximum impairment/Non-cooperative	2 Maximum impairment/ Cooperative	3 Moderate impairment/ Resistant	4 Moderate impairment/ Constant cueing	5 Minimum impairment/ Resistant	6 Minimum impairment/ some cueing	7 No impairment/ Motivated
<b>Social/Recreational Participation:</b> <i>Personal hygiene and social/recreational activities</i>	NA	1 <b>Inactive</b> No personal & social activities	2 1-2 hours Personal Activities (e.g., TV, music, etc)	3 2-4 hours Personal activities e.g., TV, music, etc)	4 2-5 hours Personal activities e.g., TV, music, etc)	5 5.5-7 hours Personal and Social activities	6 7.5-9 hours Personal and Social Activities	7 <b>Active</b> 9.5 hours Personal and Social activities

## Appendix 6 Interview Schedule for relatives of persons with enduring mental illness



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### Family Support Study:

#### Interview schedule for relatives of persons with enduring mental illness

1. **First of all, tell me a little bit about your experience with your relative's mental illness. When and how did you realize that your relative was unwell?**  
 Would you remember how long had your relative been unwell before treatment was sought?  
**What kind of support you had and needed at that time?**  
 What happened then? How long did it take from the onset of illness to first admission? Was it voluntary or involuntary admission? And so on.
  
2. **Tell me a little bit about your first encounter with mental health services.**  
**What kinds of information and/or support were given to you?**  
 When did you learn about the diagnosis (if known,) or what kind of illness it was?  
 Treatment plan?
  
3. **What about discharge? What kind of information and/or support were you given at the time of your relative's discharge?**  
 Where was your relative discharged?  
 What kind of support was given to your relative and family after discharge? **What else would have helped?**

4. **What happened after discharge? Did you relative stabilize, or was there a relapse? Approximately when did it happen?**  
  
What did you need at that time, what support did you have and what did you wish you had?
  
5. **What are your expectations now of treatment and rehabilitation of your relative? Have they changed? How and when?**
  
6. **Are you satisfied with the extent of your involvement in your relative's care?**  
  
Do you feel that your experience and knowledge can be of help for your relative's treatment and recovery?  
  
Is your knowledge and experience utilized by mental health services? How? What else could you offer?  
  
**If you wanted to talk to somebody from mental health services about your relative's health and treatment progress, how could this be arranged?**  
  
**Who would be your main contact if you wanted some information** (*nurse, psychiatrist, social worker, friend, Internet, support group – prompt only if necessary*)?  
  
Would you be aware of your relative's treatment plan? (If not: would you like to be aware of that?)
  
7. **What support resources and/or services are available to you in your household and area?** (*Prompt regarding knowledge and use only if necessary: mental health support groups e.g. AWARE; helpline; educational programmes; respite care; public health/psychiatric nurse; social worker, counsellor, other relatives/friends etc.*)  
  
**Which of them are most helpful and why? What are the barriers (if any) of their utilization?** [How does this relate to service provision, access to services or willingness to use services?]
  
8. **What other resources would you need now?** Please feel free to raise any issues that are important to you.  
  
What supports are available to others in your family? What else would they need?
  
9. **What were the most difficult periods (or period) of your experience with mental illness in the family? What helped you to cope? What made you feel better and why? What could have helped even more?**  
  
*(Prompt also if needed: What was your initial reaction to your relative's mental illness and has it changed? When and how? What are your feelings now about your relative's mental illness?)*
  
10. **How do you think mental illness of your relative influenced you and your family in general? Who became the main carer(s)/concerned relative, how and why?**

11. What advice would you give to somebody whose relative has just been diagnosed with an enduring mental illness?
12. If you were advising the government or society about families with mental illness, what would you tell them?
13. What about the future? How do you see yourself in several years?
14. Any other issues that come to your mind?

Many thanks again for your time and participation, which was very helpful. In case that you think of any other issues or comments please contact Yulia Kartalova-O'Doherty at 01-676-1176 extension 144, or e-mail at [ykartalova@hrb.ie](mailto:ykartalova@hrb.ie).







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