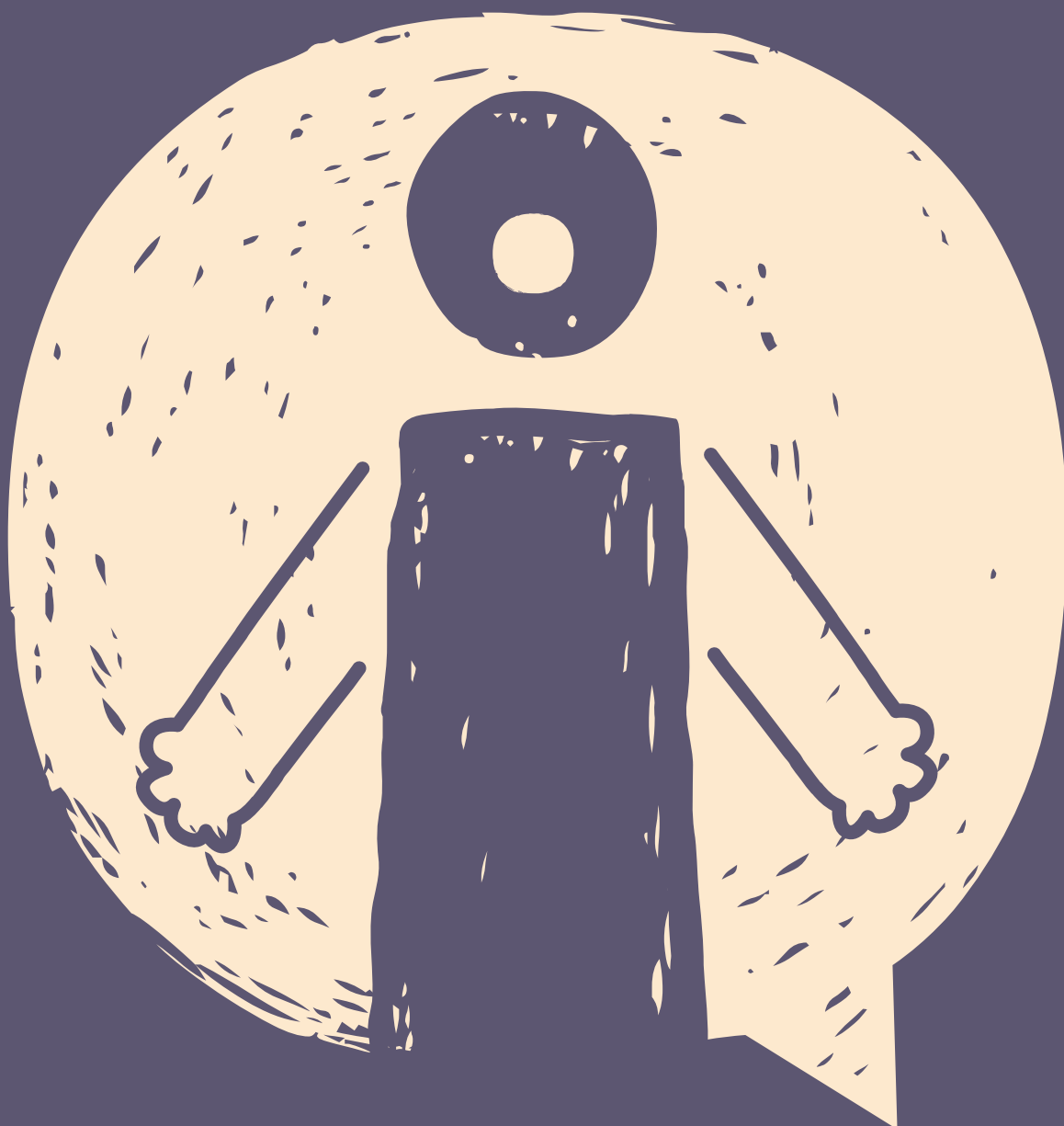


MY VOICE MATTERS

Report on a National
Consultation with Family,
Friends and Carers/Supporters
of Mental Health Service Users

Executive Summary



Seirbhís Sláinte
Níos Fearr
á Forbairt

Building a
Better Health
Service



Mental Health Reform
Promoting Improved Mental Health Services

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Executive Summary

by Pádraig Ó Féich, Kate Mitchell,
Sergio Pérez and Shari McDaid. | **2019**

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List of Abbreviations

ARI	Advancing Recovery in Ireland
CBT	Cognitive Behavioural Therapy
CHO	Community Health Organisation
FFCS(s)	Family, Friend(s) and Carer(s)/Supporter(s)
HSE	Health Service Executive
MHC	Mental Health Commission
MHS(s)	Mental Health Service(s)
TCD	Trinity College Dublin





Foreword



Ireland's national mental health policy *A Vision for Change*, which was published in 2006, set out a blueprint for developing modern, recovery-orientated mental health services (MHSs), which recognised the valuable role of family, friends and carers/supporters (FFCSs). The policy emphasised principles of partnership, with FFCSs being involved in a meaningful way in the planning and delivery of recovery-focused care with the service user. *A Vision for Change* recommended that a partnership approach should be taken to the planning, development, delivery, evaluation and monitoring of MHSs, with the inclusion of all stakeholders. The Vision for Change Expert Group also recognised that, in order to ensure effectiveness, the mental health system should meet the needs of FFCSs, respect FFCSs as individuals and treat them with dignity at every level of service provision. These principles are also affirmed through various national guidelines, including the Mental Health Commission's Quality Framework and the HSE's recent publications on recovery-led services.

Mental Health Reform's *My Voice Matters* national consultation on the experiences of FFCSs of people who use specialist MHSs in Ireland provides an insight into the extent to which FFCSs are experiencing the type of MHSs aspired to within national policy and guidelines. The consultation is the first national, large-scale survey in

recent years to provide in depth and up-to-date feedback on the direct experiences of FFCSs of people who access psychiatry, community and inpatient MHSs.

The findings from Mental Health Reform's national consultation on the experiences of FFCSs are important and timely. They provide key decision makers with national, independent feedback to inform MHS planning and delivery. Giving voice to FFCSs is integral to identifying areas of good practice as well as informing the changes required to effectively meet the needs of FFCSs. These findings are particularly pertinent in the context of the development of a new national mental health policy, due to be published in 2019 and the ongoing absence of a national mental health information system to report on routine data on service delivery, as well as outcomes for FFCSs.

The evidence from the national consultation shows that there is variation in the experiences of FFCSs, with considerably high levels of dissatisfaction with the MHSs more generally. Significant efforts must be made to involve FFCSs at all levels of MHS provision, as envisaged in national mental health policy more than a decade ago. It is imperative that change is implemented in a standardised manner to ensure consistency in MHS delivery across all parts of the country. Notwithstanding the valuable work that

..The My Voice Matters report captures, to a large extent, the current experiences of family, friends and carers/supporters in Ireland and its findings and recommendations provide a firm platform for implementing the change required to ensure the appropriate services and supports are available for family, friends and carers/supporters..

has been undertaken by HSE Mental Health¹ and many local MHSs, mental health staff and communities over the years, as the findings indicate, effective practices of FFCS involvement appear not to be embedded at a systemic level throughout the country. While some FFCSs may be experiencing services consistent with aspects of national policy and guidelines, many are not.

The *My Voice Matters* report captures, to a large extent, the current experiences of FFCSs in Ireland and its findings and recommendations provide a firm platform for implementing the change required to ensure the appropriate services and supports are available for FFCSs.

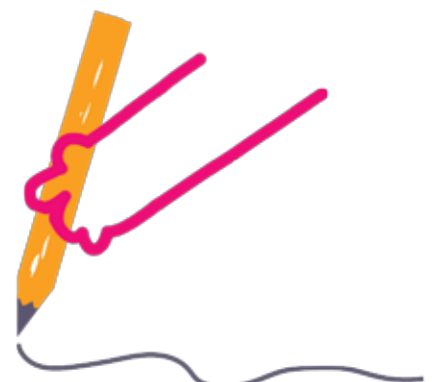
Mental Health Reform's staff and Board of Management look forward to working collaboratively with the relevant stakeholders to support the implementation of the recommendations set out in this report. I would like to thank HSE Mental Health for their foresight and commitment to funding the national consultation. I would also like to thank Dr. Shari McDaid and the team of staff at Mental Health Reform for producing this valuable and informative report. Special thanks goes to the peer researchers and the other stakeholders involved, including Mental Health Reform's membership for supporting the delivery of the national consultation.

Finally, I would like to extend a thanks to all those who took the time and effort to complete the survey and share their experience and thoughts with us.



Professor Agnes Higgins
Chairperson
Mental Health Reform

¹ HSE Mental Health operates at national level and has responsibility for all mental health services, including in planning, operations, quality and service improvement.





Acknowledgements

Mental Health Reform would like to thank everyone who assisted in carrying out the *My Voice Matters* project. Most importantly, we would like to thank each person who took the time to complete the survey and share their views and experiences of the mental health services in Ireland. Mental Health Reform aims to ensure that the findings from the *My Voice Matters* project not only inform our work going forward but also help to shape the development of mental health policy, law and practice in Ireland.

We would also like to thank sincerely all those who have worked on the project in the past two years. Thanks to all the members of the research team, past and present, who worked tirelessly to bring this project to completion.

We would like to acknowledge the work of Dr Esther Murphy in developing the initial design of the survey and of Oscar James for his role in refining the survey design, data collection and initial data analysis. Thanks also to the peer research assistants, Dr Mike Watts, Sharon Uí Chonghaile and Anthony O'Callaghan who helped to recruit and collect data from participants, and to the Steering Group for their assistance during the design of this project.

We also acknowledge the support and advice of those who provided feedback

on drafts of this report. These include Mental Health Reform's Chairperson Agnes Higgins, Professor in Mental Health, School of Nursing & Midwifery, Trinity College Dublin (TCD), Kevin Cullen, Director of the Work Research Centre, Dr Louise Doyle, Associate Professor, School of Nursing & Midwifery, TCD, members of Mental Health Reform's Grassroots Forum and Health Service Executive (HSE) Mental Health Services senior staff.

A special thank you to Mental Health Reform's member organisations for promoting the survey. We would also like to thank those organisations and individuals external to Mental Health Reform's membership who helped to bring the project to the attention of individuals accessing their services.

Finally, we would like to acknowledge the support of the HSE for this project. Although the *My Voice Matters* project was conducted independently by Mental Health Reform, it would not have been possible without the funding provided by HSE Mental Health. The HSE's financial support for this national consultation of mental health service users and their family, friends and carers/supporters (FFCSs) shows a commitment to service improvement and to listening to the voices of people who use the mental health services.

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EXECUTIVE SUMMARY





INTRODUCTION

This report describes the key findings from Mental Health Reform's *My Voice Matters* national consultation with family, friends and carers/supporters (FFCSs). Note that, for the purposes of this report, the term 'FFCS' is used to refer to those individuals who support a person who has accessed/continue to access mental health services (MHSs).² The report focuses on feedback from people with experience of supporting a person who has used secondary and/or tertiary MHSs. A complementary report details feedback from people who have themselves used the MHSs (referred to throughout as 'service users').

This research aimed to explore the views and experiences of FFCSs with regard to their support for a person with direct experience of using secondary and/or tertiary MHSs in Ireland.

The views of FFCSs are central to developing MHSs in Ireland. The Government, the Health Service Executive (HSE) and all staff working in MHSs can benefit from receiving national, independent feedback on a regular basis from FFCSs that can help to shape service planning priorities. It is Mental Health Reform's intention that the *My Voice Matters* reports will assist the Government and the HSE in their efforts to improve Ireland's mental health system.

*A Vision for Change*³ specifically recommends that FFCSs should be involved in every aspect of MHS development and delivery. In addition, the National Carers' Strategy⁴ sets out a number of recommendations to ensure that carers are recognised and respected as key care partners and included in decisions relating to the person they support. Mental Health Reform is aware that there have been numerous actions at local and national level to promote the involvement of FFCSs, many of which have stemmed from the HSE's Advancing Recovery in Ireland (ARI) programme and the establishment of the HSE Mental Health Engagement Office. The recent publication of the HSE's family guidance document acknowledges the contribution that families make to the care and recovery of service users. It provides practical advice for the MHSs on supporting families to enable them to make their contribution.

2 Mental Health Reform acknowledges that there are different views on the terms used to describe a person who supports someone who uses the MHSs. While there has been an emphasis in recent years on terms such as "family member" "family supporter" "supporter" there are many who still relate to the term "carer" and consensus is yet to be reached on the language used to describe this large group of people. For this reason, Mental Health Reform sought to include a term that would capture all individuals who support or care for a person who uses the MHSs in Ireland i.e. family, friends and carers/supporters (FFCSs). This term is used throughout the report.



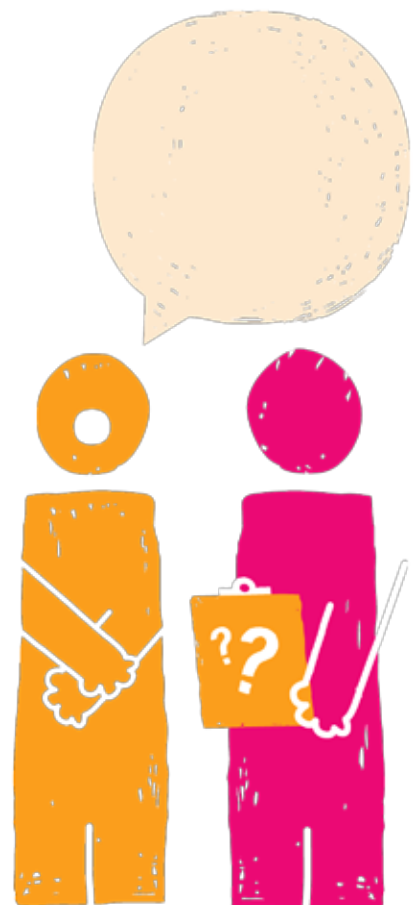
3 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office.

4 Department of Health. (2012). *National Carers' Strategy*. Dublin: Department of Health.

Valuable feedback from FFCSSs has been collected through consultations carried out as part of the development of *A Vision for Change*⁵ and the Mental Health Commission's (MHC) Quality Framework for MHSs.⁶ However, in recent years, there has been no comprehensive, national survey focussed specifically on the experiences of FFCSSs of people engaged with MHSs in Ireland.

The extent of progress on involving FFCSSs in the mental health care and treatment of the person they support is unknown. To what extent are FFCSSs provided opportunities to become involved in the care of the person they support? To what extent are their views taken on board in recovery/care planning? Are their own support needs addressed by the MHSs?

As a result, Mental Health Reform identified the need for an independent, national, large-scale survey to provide in depth and up-to-date feedback on the experiences of people who provide support to individuals accessing psychiatry, community and inpatient MHSs. Below is a brief summary of this research.



5 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office.

6 Mental Health Commission. (2007). *Quality framework: Mental health services in Ireland*. Dublin: Mental Health Commission.



METHODOLOGY

As part of this research, individuals with experience of supporting a person who has used MHSs were asked to complete a survey. A brief summary of the methodology used is outlined below. For more detail, see chapter two of the main FFCS report.

Survey design:

Survey design was carried out in a phased manner. Initial survey questions were developed based on a literature review of similar past research and Mental Health Reform's previous consultations carried out between 2011 and 2015. A first draft of the survey was tested through cognitive interviews⁷ with 10 individuals, and a second draft was tested with focus groups. The final draft survey was reviewed by external researchers with expertise in survey design.

Who took part?

Only individuals over the age of 18 years with experience of supporting a person who had accessed psychiatry, community or inpatient MHSs in Ireland in the last two years were eligible to take part. In total 786 participants who met these inclusion criteria were recruited using several methods of recruitment. For more information on recruitment and the sample, see section 2.3 of the main FFCS report.

Collecting the data:

Survey responses were collected over a six-month period between November 2017 and April 2018. A large majority of participants completed the survey online through SurveyMonkey, while a minority completed paper versions of the survey and returned them by post.



7 The cognitive interviewing approach is used to evaluate sources of response error in survey questionnaires, see: Willis, G.B. (1999). *Cognitive interviewing: A "how to" guide*. Presented at the 1999 Meeting of the American Statistical Association. Research Triangle Park, NC: Research Triangle Institute.

For more information on cognitive interviewing, see: Memon, A., Meissner, C.A., & Fraser, J. (2010). The Cognitive Interview: A meta-analytic review and study space analysis of the past 25 years. *Psychology, Public Policy and Law*, 16(4), 340-372. doi:10.1037/a0020518



786

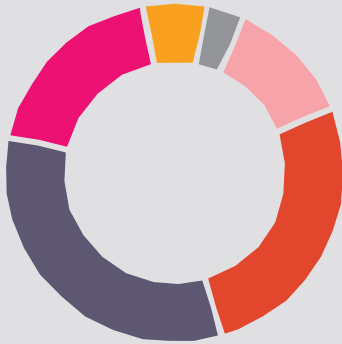
PARTICIPANTS

46.3^{YRS}

AVERAGE AGE

18-79^{YRS}

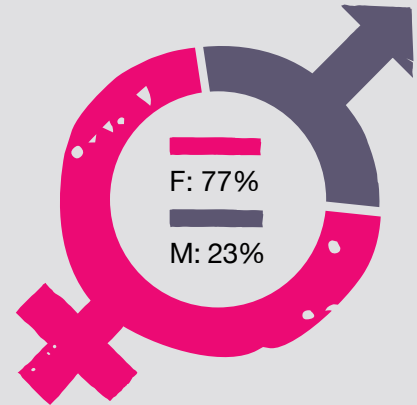
AGE RANGE



AGE GROUPS:

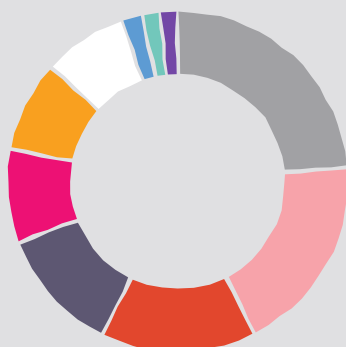
18-25:	3.8%
26-34:	12.2%
35-44:	26.7%
45-54:	32.8%
55-64:	18.5%
65+:	6.0%

GENDER:



COMMUNITY HEALTH ORGANISATION (CHO) AREA:

CHO1: 7.7%	CHO4: 11.7%	CHO7: 14.1%
CHO2: 11.3%	CHO5: 10.1%	CHO8: 9.6%
CHO3: 10.9%	CHO6: 10.5%	CHO9: 14.2%



MAIN DIAGNOSIS OF PERSON BEING SUPPORTED⁸:

Depression: 23.8%	Bi-polar disorder: 12.0%	Post-traumatic stress disorder (PTSD): 1.9%
Schizophrenia / Schizoaffective disorder: 18.9%	Personality disorder: 8.7%	An eating disorder: 1.8%
Anxiety disorder: 14.7%	Other: 8.6%	Prefer not to say: 1.5%
	Not been given a diagnosis: 8.1%	

⁸ Mental Health Reform understands that not everybody agrees with the mental health diagnosis they have been given, or with the biomedical approach to mental health.



KEY QUANTITATIVE FINDINGS

This is a selection of key findings from the FFCS survey. For a more detailed presentation of the findings, see chapter three of the main FFCS report.

INFORMATION AND ADVICE

TWO-THIRDS

(66.5%)

of participants reported being **DISSATISFIED** with the **INFORMATION & ADVICE** they received when the person they support first came into contact with HSE MHSs. 16% were satisfied and 17.5% neither satisfied or dissatisfied.

Approximately **TWO-THIRDS**

(65.6%)

reported that they had **NOT RECEIVED INFORMATION** on what to do in case of a crisis. One third (34.4%) reported they were given information of this nature. Of those who had been given information on what to do in case of a crisis, less than half (47.6%) found it useful.

THREE-QUARTERS

(75.9%)

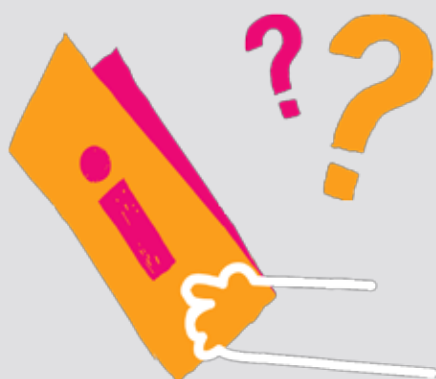
DISAGREED that the HSE MHSs **EXPLAINED HOW TO SUPPORT THE PERSON IN THE LONGTERM.**

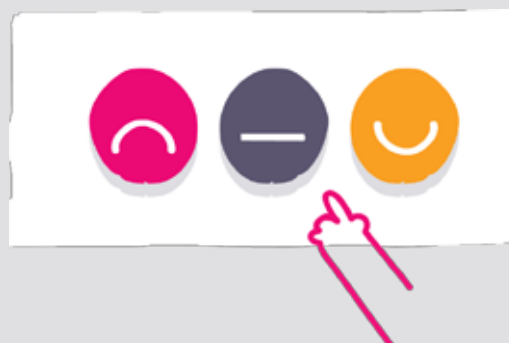
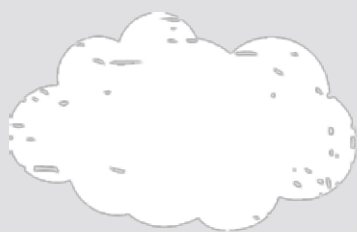
One in ten (9.9%) agreed, while 14.2% neither agreed nor disagreed.

FOUR IN EVERY FIVE

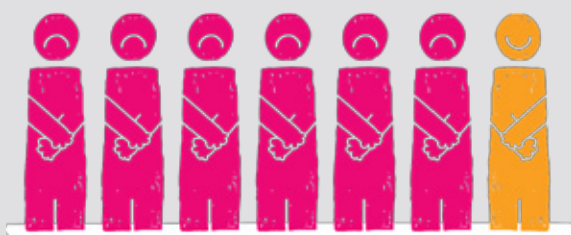
(81.8%)

reported that **THEY HAD NOT BEEN LET KNOW HOW TO MAKE A COMPLAINT ABOUT HSE MHSS** by someone in the MHSs. 6.4% had been let know, while 11.8% reported that they found the information displayed in MHS facilities (clinic, leaflets, website).





INVOLVEMENT IN MHS PLANNING



ONE IN EVERY SEVEN

(14.5%)

participants indicated that most (8.9%) or all (5.6%) of **THEIR VIEWS HAD BEEN INCORPORATED** into the recovery/care plan of the person they support. Over one-third (35.6%) indicated that some of their views had been incorporated.



APPROXIMATELY HALF

(49.8%)

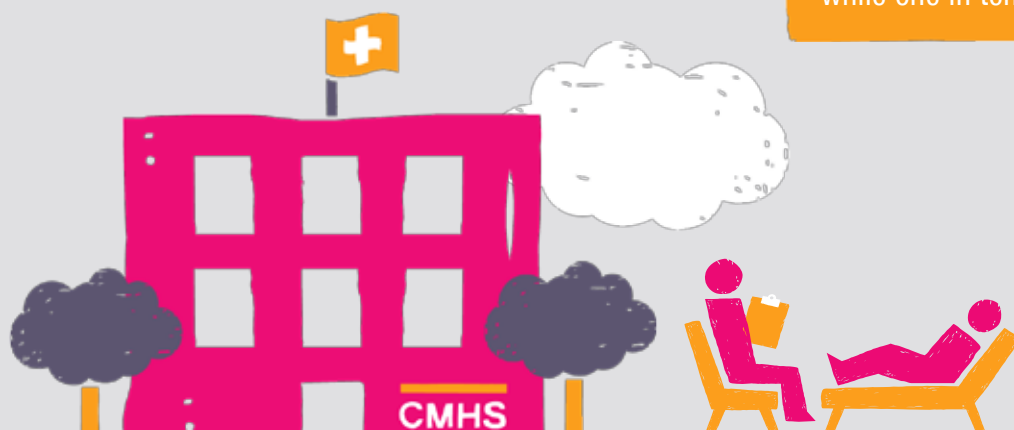
indicated that **NONE OF THEIR VIEWS** had been incorporated into the recovery/care plan of the person they support.



MORE THAN SEVEN IN TEN

(72.2%)

DISAGREED that they had had the opportunity to **PROVIDE FEEDBACK TO THE MHSs** to inform service improvement in the last two years, while one in ten (10.7%) agreed.





SUPPORT NEEDS AS A CARER/ SUPPORTER

Approximately **SEVEN IN EVERY TEN**

(71.7%)

participants were **DISSATISFIED** with the extent to which the HSE MHSs had **CONSIDERED THEIR SUPPORT NEEDS**. Approximately one in ten were satisfied (10.6%), while 17.7% were neither satisfied nor dissatisfied.



ALMOST THREE-QUARTERS

(74.0%)

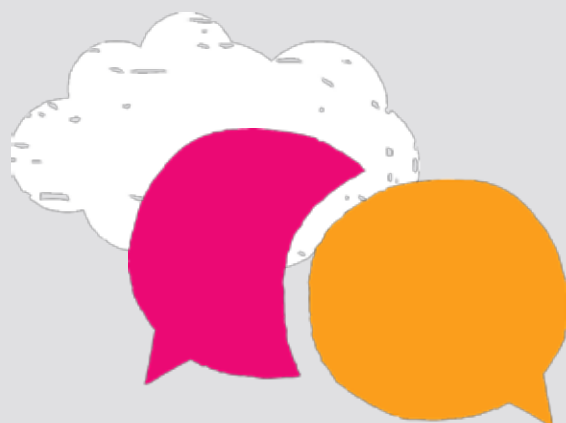
of participants reported that they **DID NOT HAVE THE CONTACT DETAILS** of a key worker in the HSE MHSs. While approximately one in four (26.0%) indicated that they did have key worker contact details.

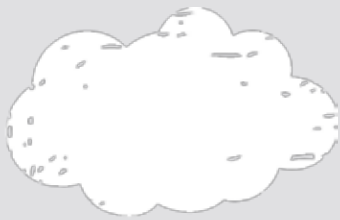
INDIVIDUAL COUNSELLING was by far the **MOST COMMON SUPPORT** accessed by participants, with approximately **ONE IN FOUR**

(26.6%)

accessing this type of support in the last two years.

ADVOCACY SERVICES were the **LEAST COMMON SUPPORT** accessed by participants, with one in 20 (5.2%) accessing this type of support.





VIEWS AND EXPERIENCES OF INPATIENT CARE

ALMOST HALF

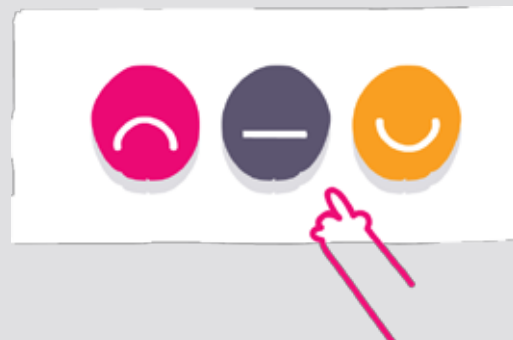
(49.0%)

of participants **DISAGREED** that they '**FELT LISTENED TO BY HOSPITAL STAFF**', while under a third agreed (30.2%).

Similarly, **ALMOST HALF**

(47.4%)

agreed that they **FELT THAT THE HOSPITAL EXPECTED THEM TO BE RESPONSIBLE** for the recovery of the person they support, while 30.5% disagreed.



VIEWS ON CARE PROVIDED TO SERVICE USERS

MORE THAN HALF

(55.7%)

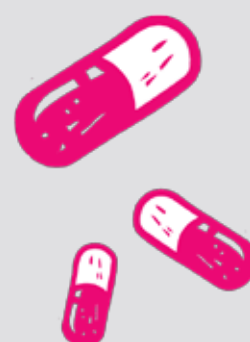
of participants reported **LOW LEVELS OF SATISFACTION** with the **QUALITY OF SERVICE** received by the person they support. More than one in four (28.5%) reported moderate levels of satisfaction and one in six (15.8%) reported high levels of satisfaction.

Participants were also asked **HOW SATISFIED** they were that HSE MHSs had provided the individual with supports that adequately targeted their needs.

SIX IN EVERY TEN

(60.1%)

reported **LOW LEVELS OF SATISFACTION**, one in four (26.5%) reported moderate levels of satisfaction and less than one in seven (13.3%) reported high levels of satisfaction.





SUMMARY OF QUALITATIVE FEEDBACK

As part of the survey, participants were asked a number of open-ended questions, which gave them the opportunity to express their views and answer in greater detail than did the closed-ended questions on the survey.⁹ This section outlines the results of a content analysis of the participants' responses to these open-ended questions. This analysis was carried out in accordance with the guidelines set out by Erlingsson and Brysiewicz¹⁰ (see section 2.5 of the FFCS main report for more detail).

Note that all quotes are presented as written by participants and are therefore authentic to the writer. Quotes were only altered if potentially identifiable information (e.g. names or locations) were conveyed or where additional clarity was needed. For example, where a participant referred to 'the recommendations of a Vision for Care', [Change] was added to clarify for readers that this participant was referring to the recommendations of *A Vision for Change*. Similarly, where participants used abbreviations, these abbreviations were clarified, e.g. 'CBT [cognitive behavioural therapy]'. This was done to increase the accessibility for the reader by avoiding the excessive use [sic.]. All edits or additions to quotes are marked using squared brackets, e.g. [names a place].

Table 1: Beneficial services that were unavailable.

Question:	Is there any service that was not available to you that you would have benefitted from?
Additional support services for FFCSs	Some participants expressed that supports for FFCSs are lacking and more are needed, e.g. online supports, the support of a key worker and/or social worker, or supports geared towards developing their coping and self-care skills. Others simply described what they perceived as a complete lack of support for FFCSs.
Information, advice and education services	Some participants indicated that they felt 'lost', 'overwhelmed' and even 'fearful' that they might 'do more harm than good' in their role as carer/supporter, and that more information, advice and education would help them better cope with, understand and help the person they support.
Talking therapy	Some participants sought talking therapies for themselves, e.g. personal counselling, family or couple's therapy. Many expressed a need for access to any/more talking therapy for service users.

9 Closed-ended questions are questions where participants are asked to pick from a selection of fixed response options, while open-ended questions require participants to respond in their own words.

10 Erlingsson, C., & Brysiewicz, P. (2017). A hands-on guide to doing content analysis. *African Journal of Emergency Medicine*, 7(3), 93-99. doi:10.1016/j.afjem.2017.08.001

Out of hours / Crisis services	Out of hours services were described by many participants as needed, e.g. specialist 24/7 crisis services and a service or person that could be contacted at any time in case of, or leading up to, a crisis. Some highlighted the need for non-crisis services to be available after working hours and at weekends and for more respite services.
Services for service users	Some participants chose to respond by highlighting what they perceived as gaps in the services provided to the person they support. Examples of these included a lack of services targeted towards particular mental health difficulties, or the unavailability of specific types of mental health professionals (e.g. a psychologist or a key worker).
Mediator/ Communication service	Some participants expressed a need for a mediation service that could facilitate better communication between themselves and members of the mental health team of the person they support.
Peer support services	Some participants expressed a desire for more peer support services for FFCs. Some highlighted a need for formal peer supports in the form of group therapy with other FFCs. Others believed that having the opportunity to simply talk to someone who has experienced difficulties similar to their own would have been very beneficial.
Community-based/local support services	Some participants conveyed that community-based local MHSs were lacking, often resulting in the person they support having to travel, sometimes long distances, to access necessary services. They sought more and/or improved community based services and home visits.
No additional services required	Some participants responded to this question simply with 'no', 'none', or some variation of this.
Other Services	Some participants reported other services that may have been of benefit to them. These included (but were not limited to) supports to facilitate/encourage the social inclusion of the person they support, e.g. housing supports, and employment supports. Some mentioned the need for follow-up services by mental health teams for both FFCs and service users.



..Out of hours services were described by many participants as needed...

"To this day there is no support at all for my family"

"More support as the carer. The carer is often forgotten about"

"Availability of practical advice, every day is a guessing game, never sure if you've done it right"

"A massive information gap is about what to do after you tell yourself and the person that's it's Ok to not be Ok.... what next???!!! We were all at a loss after the initial bit and there's no information about what to do next"

"A service which helps to provide the family with information on how to best treat the ill person...never was I given any advice on how to deal with his episodes of rage and self-harm. how to support, how not to enable while also not making things worse etc."

"Counselling and support for parents regarding how to manage his anxiety"

"More support locally"

"A functional all-hours A&E service for mental health would make life indescribably easier for both of us"

"Care Plan for individuals who need to access the Mental Health Services from the beginning of engagement particularly for those most vulnerable"

"CBT [cognitive behavioural therapy] course or weekend activities based around mental fitness and ability to cope. Once a week counselling does not work for people who are in a severe state of anxiety"

"A mediation role is missing to provide a link between families and the support team in mental health. It could allow family members to give background and context to help explain and support a patient's behaviour and to help support teams understand"

"Support of a peer group going through the same as me"

"Local hospital in a crisis - had to go to Dublin (based in [names Irish county])"



Table 2: Positive experiences of HSE MHSs.

Question:	What kind of positive experiences have you experienced from HSE MHSs?
Positive experiences of staff	Positive experiences of staff were by far the most common type of positive experience reported by participants. These participants often wrote positively about individual staff members that had been 'helpful', 'positive' or 'supportive' both to the person they support and to themselves as well.
Therapies and facilities	Some participants described how particular therapies and/or facilities had had a positive impact on the person they support.
Direct access to services	Positive experiences where the person they support accessed services and supports in a timely manner.
Crisis MHSs	Positive experiences of HSE MHSs crisis care, e.g. positive experiences of emergency department services or a key worker who was accessible out of hours.
Support for family members	Positive experiences of supports received from HSE MHSs, e.g. family counselling and/or individual counselling for family members or practical supports like information on how to support the service user.
Recovery	Positive experiences whereby HSE MHSs facilitated/supported the recovery of the service user.
Involvement of families in the service user's care	Positive experiences whereby HSE MHSs facilitated and even encouraged their involvement in the care and treatment of the person they support.
Follow-up and outreach MHSs	Positive experiences of HSE Follow-up and outreach MHSs, e.g. home visits and access to a community psychiatric nurse.



"Dr [names doctor] is a wonderful support to us the family including my son. She goes above and beyond phoning us after her clinics meeting us when we request a meeting and is honestly interested in our sons mental health"

"We participated in a communication course given by the social worker involving a number of weeks given in our home with the whole family present"

"I have learned valuable coping tools to manage my daily life"

"Psychologist I see at present is very motivated and patient centred. She does not endorse medication as the only way forward and supports positively while also challenging me when necessary"

"CAMHS psychiatrist extremely helpful. Considerate. Takes account of all views and info given. Has been knowledgeable and supportive regarding my views on some meds side effects amongst other issues"

"An understanding worker whom I rang when things were at crisis with my husband...she helped just by listening"

"I am now seeing changes due to me attending appointments when my son could not. I think the team see me as important now, because I showed them how difficult it can be to care for someone with mental health issues"

"Current psychiatrist has stayed in contact over weekends and late in evening on a couple of crisis"

"A family therapist who focused on supporting me enabling me to support my child"

"After my partner was back home from psychiatric hospital, he had nurses coming to the house to make sure she is ok while I was in work"

"Done a Family Connections Course which I found very good"

"Found the family therapy arranged some time following hospital time extremely helpful"

"Community nursing staff that came to the house after leaving hospital were excellent"



Although participants were asked specific open-ended questions, many took the opportunity to share their views and experiences more broadly, even when not specific to the questions asked. Without prompt, many chose to share negative experiences they had, or to raise what they perceived as important issues relating to the provision of MHSs in Ireland. Table three lists the issues most prominent in these comments.

Table 3: Additional issues raised without prompt by participants.

Involvement of FFCSSs	Some participants used the open-ended questions to express their dissatisfaction with the level of their involvement in the treatment and care planning of the person they support.
Mental health system	Some participants conveyed a negative view of the Irish mental health system. Participants wrote of what they perceived as a 'flawed', 'broken' or 'faulty' system. Others wrote more specifically about an 'under resourced system' with staff shortages, funding shortages and/or poor facilities.
Access issues	Some participants described difficulties accessing the services and supports required by themselves and/or the person they support. These included difficulties with hospital admissions and accessing specific mental health professionals or therapies. Participants wrote about the lack of locally available MHSs. However, the most common barrier to accessing MHSs raised by participants was excessive waiting times. Participants wrote about the detrimental effect waiting times/lists can have, while others felt they were compelled to access the services they required through private MHSs because of the longer waiting times for public MHSs.
Issues with MHS staff	Some participants took the opportunity to raise issues they had experienced with MHS staff, e.g. poor communication between staff (at various levels) and FFCSSs, a lack of time for both service users and their supporters, and a lack of consideration of the support needs of FFCSSs.
Continuity of care	Some participants expressed frustration at what they perceived as excessive staff rotation and the potentially detrimental effect this can/did have on the person they support. Other issues raised included the lack of continuity of care received by the person they support when transitioning from child to adult MHSs, and/or the lack of follow-up care provided to the person post discharge from inpatient MHSs.
Other issues	A variety of other issues were raised by participants in response to these open-ended questions, e.g. an excessive focus on medication at the expense of alternative treatments and therapies; a perceived lack of a holistic approach to mental health; and the stresses and strains, be they physical, mental or financial, experienced by participants as a result of their caring role.

"I have never been consulted or given opportunity to be part of plan"

"Being able to talk to team involved to give a more rounded picture which would help with overall understanding"

"Individual committed staff in a dysfunctional uncaring system"

"About half of the staff are magnificent despite the shocking levels of under staffing and under resourcing"

"When I was trying to contact nurses or therapist to express the worries about my partner, I was completely ignored"

"Access to service when needed, not months down the line when things had deteriorated"

"The waiting lists for all services are too long"

"The community team do not even answer phone calls. A voicemail machine for a team is diluting accountability and no use in a crisis"

"To be effective there has to be a holistic approach to mental health not an over reliance on drug therapy"

"I never seem to be able to deal with the same psychiatrist twice and everyone is always too busy to talk"

"A written Care Plan, as outlined in the recommendations of the Vision for Care [Change] plan. I have requested this written Care Plan several times over several years, and none has been forthcoming. While the efforts of the nursing staff have on the whole been excellent, I feel that there are issues with the Leadership in this area"

"More communication between all organisations"

"I found that other counties had support groups such and more services available for myself as her carer and for her as the patient, but that was because we live in [an Irish county] and it's rural"

"I think the service is way too drug based"

"My own mental health has really suffered"

"I received no service support ... Family groups, Wellness sessions, counselling, online support from HSE, nothing. They don't understand the stress on families I felt"



CONCLUSIONS

Since 1984¹¹, national mental health policy has firmly embedded the role of FFCs in the delivery of MHSs in Ireland. More recent policy¹² and guidance¹³ has advanced this principle of FFCs involvement at all levels of the mental health system and provides specific, practical recommendations on how FFCs can be effectively supported by the MHSs.¹⁴

Until now, there has been little independent evidence from the perspective of the individual FFCs that shows how well national mental health policy has been fulfilled. Mental Health Reform's *My Voice Matters* consultation of FFCs is the first national, large-scale survey in recent years to provide in depth and up-to-date feedback on the direct experiences of those supporting people who access a range of MHSs. The *My Voice Matters* results provide broad-based evidence of the extent of FFCs involvement in the mental health care of the person they support.

Findings indicate that some FFCs are experiencing opportunities for participation in the care process for the person they support. Some participants documented how they had been facilitated and encouraged by the MHSs to be involved in the care and treatment of the person they support. Half of participants reported that their views were incorporated in individual recovery/care plans of the person they support, at least to some extent.

Notwithstanding efforts made by HSE MHSs to improve the experiences of FFCs, and the challenge of respecting service users' confidentiality, the evidence shows that many FFCs are not experiencing the quality of service set out in national policy and guidance. Approximately half of participants reported having none of their views incorporated into recovery/care plans. Between two-thirds and four-fifths of participants reported dissatisfaction with the quality of information and guidance provided by the MHSs. Three-quarters of participants reported that they did not have the contact details of a key worker. Seven in every ten participants reported dissatisfaction with how the MHSs had considered their support needs.

The publication of the *My Voice Matters* national consultation is very timely; the Minister-appointed Oversight Group preparing a refreshed mental health policy is expected to complete its report in early 2019. The *My Voice Matters* FFCs report represents one way of giving voice to FFCs in the development of updated mental health policy, which in turn will inform service delivery at all levels and cross sections of the mental health system. The results provide a basis for building on recent initiatives and increasing the momentum of the HSE's progress achieved thus far.



11 Department of Health and Children. (1984).

Planning for the future. Dublin: The Stationery Office.

12 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office.

13 Mental Health Commission (2007). *Quality framework: Mental health services in Ireland*. Dublin: Mental Health Commission.

14 HSE Mental Health Services. (2017). *Family recovery guidance document 2018 - 2020: Supporting a national framework for recovery in mental health 2018-2020*. Dublin: HSE MHS.



The findings detailed in this report can aid the Oversight Group to develop recommendations focussed on areas that FFCs currently experience as unsatisfactory. In addition, the findings can inform the Department of Health's deliberations on mental health policy and its monitoring of the HSE's MHS delivery. Ultimately, we hope that the findings will lead to policy and service delivery that will enhance supports for FFCs and more fully recognise their important role in enabling the recovery of many service users.

Accountability at all levels of the system, starting with the Minister with responsibility for mental health, will be required to implement the key recommendations set out in this report.

The availability of regular, national, independent feedback on people's experiences of the MHSs can support transparent monitoring of national mental health policy.

Mental Health Reform will disseminate this report and bring the findings and recommendations (outlined below) to the attention of key stakeholders, including the HSE Mental Health Services, the Department of Health, the Minister with responsibility for mental health, the MHC and relevant professional associations. Mental Health Reform will advocate for and monitor the timely and effective implementation of the report's recommendations in the hope that their fulfilment will lead to services that adequately involve and support FFCs of all those who use MHSs.



..Mental Health Reform's *My Voice Matters* consultation of FFCs is the first national, large-scale survey in recent years to provide in depth and up-to-date feedback on the direct experiences of those supporting people who access a range of Mental Health Services..

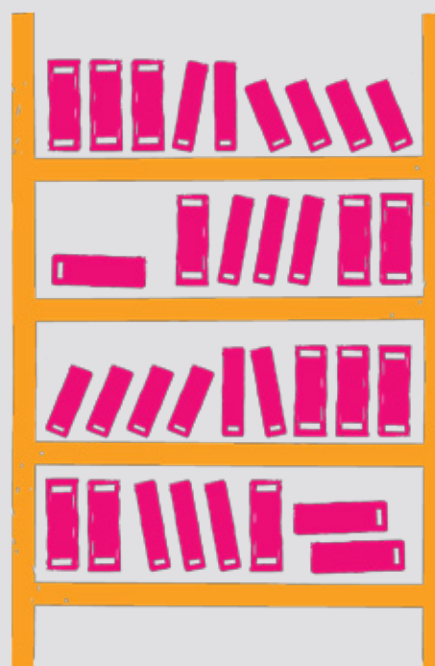
RECOMMENDATIONS

1. HSE MHSs should provide FFCs with information of a general nature, including information on how to provide long-term support to the individual concerned, information and advice on what to do in a crisis, information about support groups in their local communities, and guidance on how to make a complaint about the MHSs.
2. All HSE MHSs should work with FFCs at local level to develop high quality information that adequately meets their needs, taking into account the literacy and language barriers experienced among certain groups.
3. HSE MHSs should encourage and facilitate opportunities for FFCs to be involved in the assessment, care and treatment of the person they support, except where the individual does not consent. This includes incorporating the views of FFCs in individual care plans and in the discharge planning process. Where it is not possible to incorporate the views of FFCs, a full explanation should be provided to FFCs by a member of the HSE MHSs.
4. HSE MHSs should formally assess and address the support needs of FFCs. In particular, the support needs of FFCs should be assessed and appropriately addressed during the discharge planning process.
5. HSE Mental Health should invest through development funding in a range of supports for FFCs in their local community, including individual talk therapy, peer support groups and peer workers, family talk therapy, family mental health information and education, online and/or listening supports and advocacy services.
6. HSE MHSs should ensure that every FFC is appointed a designated key worker following contact with the MHSs, and for the duration of the time the person they support is engaged with the services.
7. HSE Mental Health should ensure that mechanisms are established and widely publicised at local, regional and national level to provide opportunities for FFCs to participate in service improvement initiatives.
8. The Government should ensure that independent advocacy is available for FFCs to support their engagement with HSE MHSs.
9. To ensure a smooth transition for service users and their families from child to adult MHSs, formal collaboration processes between CAMHSs and adult MHSs must be established. This should include the appointment of a key worker for the child/young person and their family member during the transition period.
10. This consultation on FFCs' experiences of the MHSs should be repeated every two years to ensure that the HSE and other key stakeholders are receiving national independent feedback from FFCs on a regular basis. This would not only demonstrate progress but would facilitate priority setting by the Minister with responsibility for mental health, the Department of Health and the HSE for annual service plans.
11. HSE Mental Health should produce a time-lined action plan in 2019 to implement these recommendations. A senior staff member in HSE Mental Health should be assigned responsibility for overseeing the development and implementation of the action plan.
12. The Minister with responsibility for mental health should ensure accountability in the implementation of these recommendations through ongoing monitoring and evaluation.



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RESPONSE OF THE GRASSROOTS FORUM

Mental Health Reform's Grassroots Forum (GRF) is made up of people with experience of the MHSs and FFCSSs.¹⁵ The GRF is core to Mental Health Reform's work. We are consulted on all new Mental Health Reform policy positions, and our views are incorporated in the development of these positions. In recent years we have fed into Mental Health Reform's policy submissions on the review of *A Vision for Change*, the national mental health policy and MHR's analysis on reform of the Mental Health Act, 2001. We have also met with key decision-makers to voice our concerns about challenges faced by people with mental health difficulties and their FFCSSs.

Overall, Mental Health Reform's national consultation has been very valuable in facilitating FFCSSs to share their experiences of the MHSs in Ireland. It is encouraging that some FFCSSs reported positive experiences of the MHSs, including with mental health staff, crisis supports and follow-on services. However, there was also a lot of variation among the experiences of FFCSSs, with a high level of dissatisfaction among the survey participants.

Based on the national consultation findings, there appears to be little communication between mental health staff and FFCSSs about how the service user is doing, next steps in care and how they can help going forward, including when the person is discharged. The findings highlight a need for high quality, accessible and useful information for FFCSSs. Training and education programmes should be available to FFCSSs to help them cope, practise self-care and support the service user. We believe that these programmes should be

delivered in all communities and should address a range of mental health difficulties. Service users and FFCSSs should also be provided with training and information on how to engage, and where relevant, live in the same home with each other.

Furthermore, it appears that many FFCSSs are dissatisfied with their level of involvement in the mental health care planning and delivery of the person they support. They want more involvement and communication with the MHSs. In our view, it is important for mental health staff to seek input from FFCSSs in order to avail of valuable information that may be useful to the CMHT and which they may not otherwise receive from the service user. This may involve meeting with the consultant psychiatrist and/or other members of the team on their own and/or with the service user. In our experience, there are some MHSs that facilitate and even encourage family involvement; however, this is not standard practice and there are many services that do not accommodate this type of involvement.

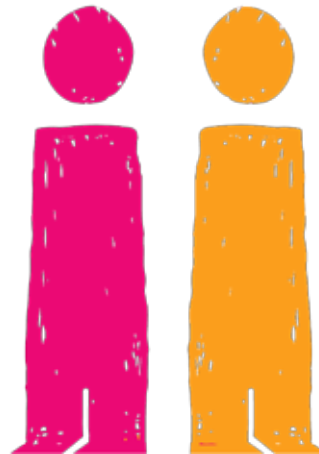
A standardised approach which encourages FFCSS involvement, where the service user consents, should be implemented across the MHSs. This should include increased involvement in the service users' individual recovery/care plan. We recognise the ongoing challenges with balancing the service users' right to privacy and the benefits of involving FFCSSs in mental health service planning. The GRF recommends approaching confidentiality as an ongoing process, whereby it is continuously discussed with the service user and pieces of information can be shared with FFCSSs over time. It is also necessary for MHSs to establish a process for engaging with family members who reside outside of Ireland.

¹⁵ Members of the Forum are nominated by MHR member organisations and participate as nominees of their organisation. Currently, there are approximately 15 active members.



It is also important to note that the role FFCSS carry out in supporting people who use the MHSs can take a toll on their own health, which can often deteriorate rapidly. The findings from the national consultation show that there is a lack of supports for FFCSS to promote their own mental health and well-being. In our view, MHSs have a responsibility to care for FFCSS as well as service users and more supports should be made available to FFCSS across the country. These supports should include training and information on self-care and coping strategies; the appointment of a key worker or family liaison worker; care/recovery plans for FFCSS; out-of-hours crisis supports e.g. a phone line; support groups; respite services and child/youth focussed supports for family members under the age of 18. We recognise the importance of supports for FFCSS and acknowledge how isolated individuals can feel when these are not provided. The HSE MHSs should ensure that FFCSS are made aware of all available supports in their communities.

While the positive experiences reported by FFCSS through the national consultation should be acknowledged, there are many survey participants who reported poor experiences of the MHSs. These experiences are not acceptable and highlight the need to improve the quality and consistency of FFCSS involvement in mental health service delivery across the country. This will require a system wide cultural change that can support practical measures, e.g. the implementation of clear standards for MHSs on working with FFCSS. This national consultation has been hugely important in giving voice to the views of FFCSS who support people who use the MHSs in Ireland. There is, however, a need for an ongoing consultation process to ensure FFCSS have a key role in improving the MHSs through collaborative service planning.



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Mental Health Reform
Promoting Improved Mental Health Services





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