

MY VOICE MATTERS

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



Seirbhís Sláinte
Níos Fearr
á Forbairt

Building a
Better Health
Service



Mental Health Reform
Promoting Improved Mental Health Services

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of Mental Health Service Users

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

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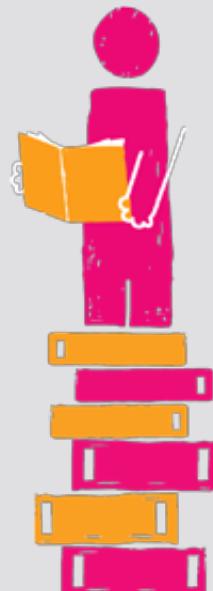
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List of Abbreviations

A&E	Accident and Emergency
ARI	Advancing Recovery in Ireland
CAMHS(s)	Child and Adolescent Mental Health Service(s)
CBT	Cognitive Behavioural Therapy
CHO	Community Health Organisation
DBT	Dialectical Behavioural Therapy
DCU	Dublin City University
DOP	Department of Psychiatry
ECT	Electroconvulsive Therapy
ED	Emergency Department
FFCS(s)	Family, Friend(s) and Carer(s)/Supporter(s)
HSE	Health Service Executive
MDT	Multidisciplinary Team
M	Mean
MHC	Mental Health Commission
MHS(s)	Mental Health Service(s)
OCD	Obsessive Compulsive Disorder
OECD	Organisation for Economic Co-operation and Development
PTSD	Post Traumatic Stress Disorder
REFOCUS	Recovery Experience Forum of Carers and Users of Services
SD	Standard Deviation
SOP	Standard Operating Procedure
SPSS	Statistical Package for Social Sciences
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 FFCSS involvement appear not to be embedded at a systemic level throughout the country. While some FFCSSs 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 FFCSSs 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 FFCSSs.

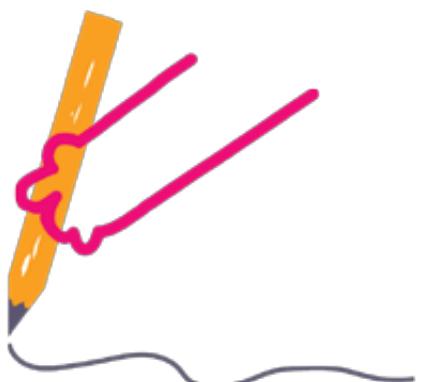
Mental Health Reform's staff and Board of Management look forward to working collaboratively with the relevant stakeholders to support the implementation of the recommendations set out in this report. I would like to thank HSE Mental Health for their foresight and commitment to funding the national consultation. 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.

About the Authors

Pádraig Ó Féich, PhD,
is the Research Officer
in Mental Health Reform.

Kate Mitchell, LLM,
is the Senior Policy and Research Officer
in Mental Health Reform.

Sergio Pérez, BA,
is the Research Assistant
in Mental Health Reform.

Shari McDaid, PhD,
is the Director of
Mental Health Reform.

EXECUTIVE SUMMARY





INTRODUCTION

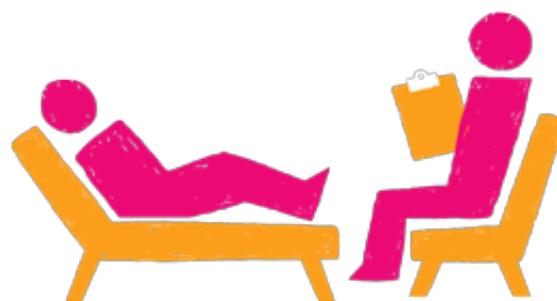
This report describes the key findings from Mental Health Reform's *My Voice Matters* national consultation with family, friends and carers/supporters (FFCSs). Note that, for the purposes of this report, the term 'FFCS' is used to refer to those individuals who support a person who has accessed/continue 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.

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.

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.

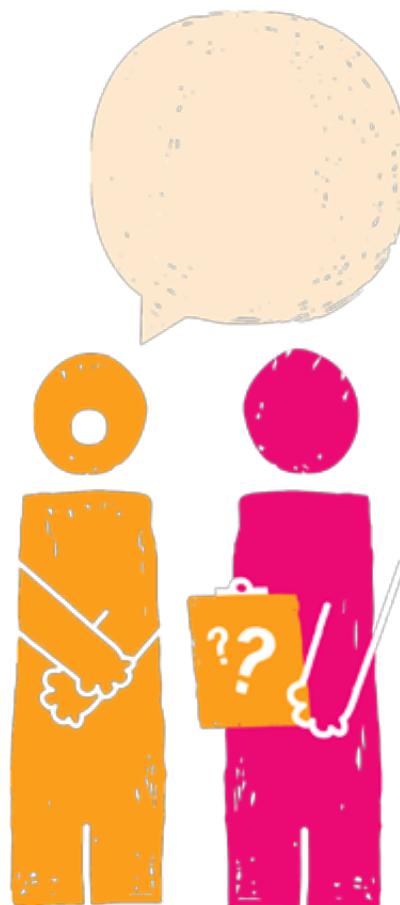


3 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office.
4 Department of Health. (2012). *National Carers' Strategy*. Dublin: Department of Health.

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. See appendix C for the survey. A brief summary of the methodology used is outlined below. For more detail, see chapter two of this 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.

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.

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 this report.



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

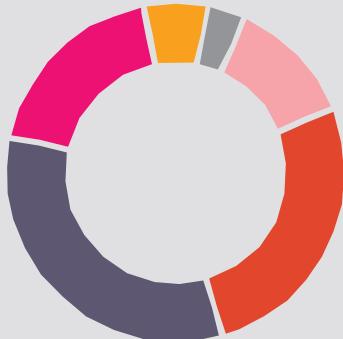
PARTICIPANTS

46.3 yrs

AVERAGE AGE

18-79 yrs

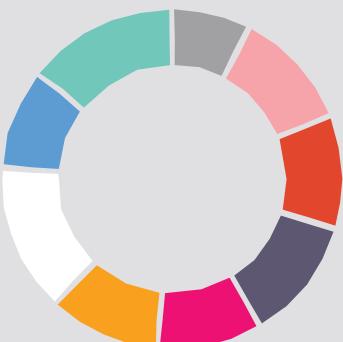
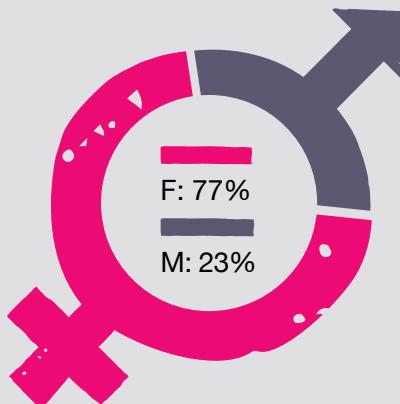
AGE RANGE



AGE GROUPS:

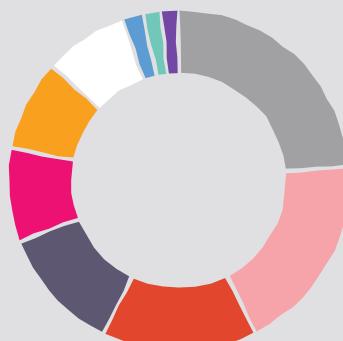
18-25:	3.8%
26-34:	12.2%
35-44:	26.7%
45-54:	32.8%
55-64:	18.5%
65+:	6.0%

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 this 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.

**THREE-QUARTERS
(75.9%)**

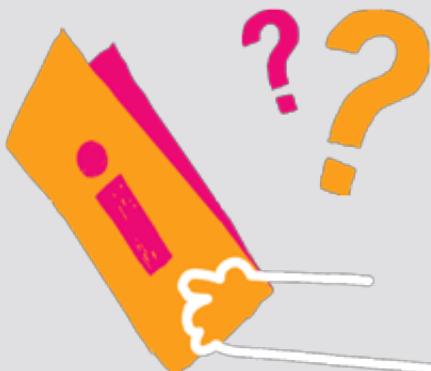
DISAGREED that the HSE MHSs **EXPLAINED HOW TO SUPPORT THE PERSON IN THE LONGTERM**. One in ten (9.9%) agreed, while 14.2% neither agreed nor disagreed.

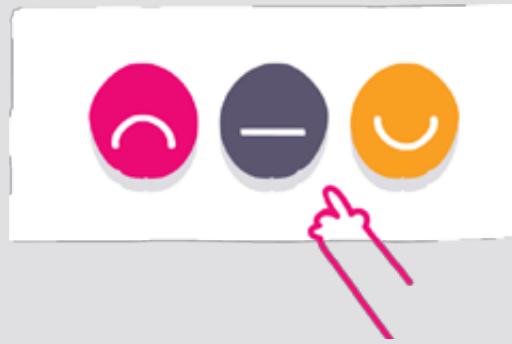
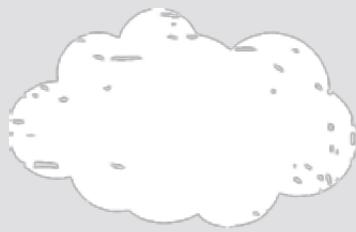
Approximately **TWO-THIRDS
(65.6%)**

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.

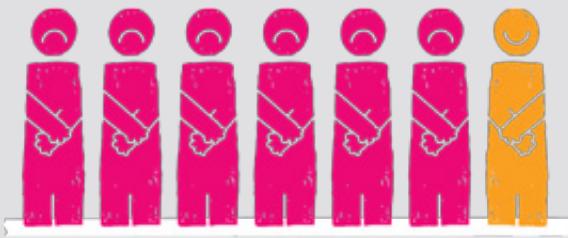
**FOUR IN EVERY FIVE
(81.8%)**

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).





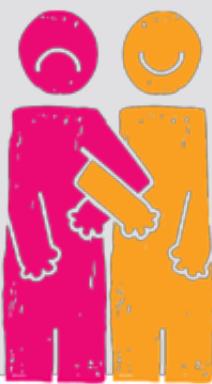
INVOLVEMENT IN MHS PLANNING



ONE IN EVERY SEVEN

(14.5%)

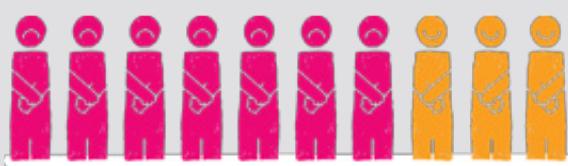
participants indicated that most (8.9%) or all (5.6%) of **THEIR VIEWS HAD BEEN INCORPORATED** into the recovery/care plan of the person they support. Over one-third (35.6%) indicated that some of their views had been incorporated.



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.



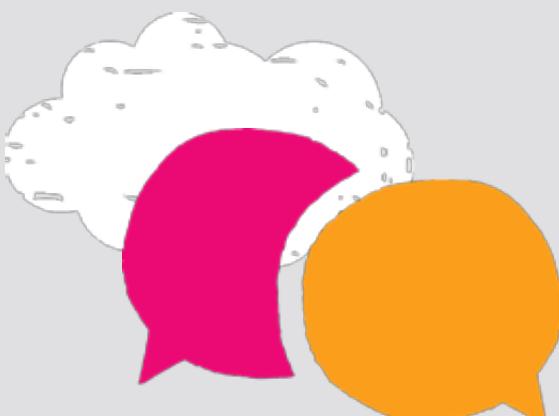
**ALMOST THREE-QUARTERS
(74.0%)**

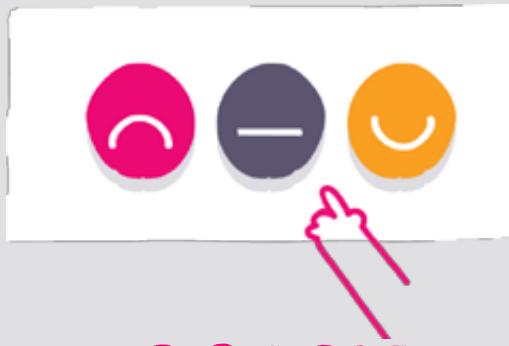
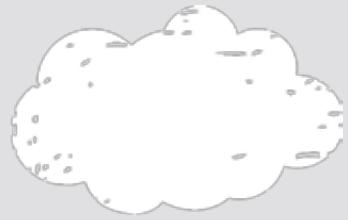
of participants reported that they **DID NOT HAVE THE CONTACT DETAILS** of a key worker in the HSE MHSs. While approximately one in four (26.0%) indicated that they did have key worker contact details.

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%)

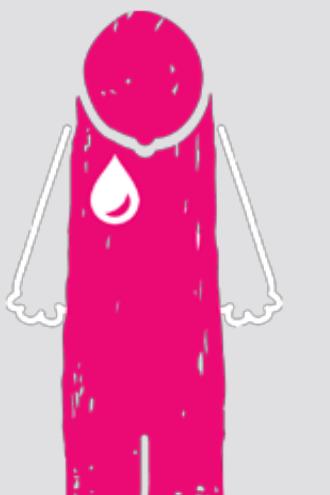
of participants reported **LOW LEVELS OF SATISFACTION** with the **QUALITY OF SERVICE** received by the person they support. More than one in four (28.5%) reported moderate levels of satisfaction and one in six (15.8%) reported high levels of satisfaction.

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 FFCSSs. Some highlighted a need for formal peer supports in the form of group therapy with other FFCSSs. 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 FFCSSs and service users.



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



Qualitative Feedback: Unavailable Services

"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.





Qualitative Feedback: Positive Experiences

"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"

"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"

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

"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"

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

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

"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"

"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"

"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"

"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"

"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.



Qualitative Feedback: Additional Findings

"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 FFCSs 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 FFCSs 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 FFCSs 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 FFCSs 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 FFCSs, and the challenge of respecting service users' confidentiality, the evidence shows that many FFCSs 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* FFCSs report represents one way of giving voice to FFCSs 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 FFCSSs 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 FFCSSs 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 FFCSSs of all those who use MHSs.



..Mental Health Reform's *My Voice Matters* consultation of FFCSSs 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 FFCSSs 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 FFCSSs 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 FFCSSs 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 FFCSSs in individual care plans and in the discharge planning process. Where it is not possible to incorporate the views of FFCSSs, a full explanation should be provided to FFCSSs by a member of the HSE MHSs.
4. HSE MHSs should formally assess and address the support needs of FFCSSs. In particular, the support needs of FFCSSs 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 FFCSSs 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 FFCSS 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 FFCSSs to participate in service improvement initiatives.
8. The Government should ensure that independent advocacy is available for FFCSSs 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 FFCSSs' 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 FFCSSs 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.

INTRODUCTION



1. INTRODUCTION

This report details the key findings from Mental Health Reform's national consultation on family, friends and carers/supporters (FFCSs) experiences of the mental health services (MHSs) in Ireland. 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/continues to access MHSs.¹⁵ 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').

The overall aim of this survey was to explore the views of FFCSs who have supported a person with direct experience of using secondary and/or tertiary MHSs in Ireland. The survey addressed the following themes: information provision for FFCSs, supports for FFCSs (e.g. the appointment of key workers), and opportunities provided by the MHSs for FFCSs to be involved in the care and treatment of the person they support. The survey also sought FFCSs' views on the care provided to the person they support. See appendix C for the survey.

Owing to the lack of comparable research, the extent of progress in recent years in implementing FFCS involvement in the mental health care and treatment of the person they support is unknown. Mental Health Reform is aware that there have been numerous actions at local and national level to promote such involvement, many of which have stemmed from the Health Service Executive's (HSE) Advancing Recovery in Ireland (ARI) programme and the establishment of the HSE's Mental Health Engagement Office. Under the ARI programme and its predecessor, FFCSs have participated in the cooperative, triologue-approach leadership training at Dublin City University (DCU) since 2008. The HSE's Mental Health Engagement Office has led to the appointment of Area Leads to consult with and present the views of service users and FFCSs through engagement and partnership. The Area Leads participate in decision-making at area management level. Local area structures are also being developed to allow for the involvement of service users and FFCSs in the planning, design, implementation and evaluation of MHSs. Other initiatives have included the introduction of the EOLAS programmes^{16,17} in some HSE services (which aims to empower FFCSs through information provision), the emergence of recovery colleges (which recognise the importance of recovery of the family member) and the introduction on a pilot basis of family peer support workers.

15 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.

16 Higgins, A., Hevey, D., Gibbons, P., O'Connor, C., Boyd, F., McBennett, P., & Monahan M. (2017). A participatory approach to the development of a co-produced and co-delivered information programme for users of services and family members: the EOLAS programme (paper 1). *Irish Journal of Psychological Medicine*, 34 (1), 19-27.

17 Higgins, A., Hevey, D., Gibbons, P., O'Connor, C., Boyd, F., McBennett, P., & Monahan, M. (2017). Impact of co-facilitated information programmes on outcomes for service users and family members: the EOLAS programmes (paper 2). *Irish Journal of Psychological Medicine*, 34 (1), 29-37.



The Expert Group on the national mental health policy *A Vision for Change* made a clear recommendation that the involvement of service users and their carers/supporters should be a feature of every aspect of service development and delivery. The Group recognised that “there are times when the information needs of carers and families may conflict with the service user’s wish for privacy. While the rights of privacy and confidentiality for the user must be respected [in line with national and international law], a way forward should be agreed to ensure that the needs of the carer and family are also met”.¹⁸ In addition, the National Carers’ Strategy¹⁹ sets out a number of actions to ensure that carers are recognised and respected as key care partners and included in decisions relating to the person that they are caring for. These actions should be considered in progressing the involvement of FFCSs in MHS delivery.

Recent efforts to adhere to national policy principles of ‘partnership’, whereby service users and FFCSs are involved in the planning and delivery of MHSs, must be welcomed. However, to date, there has been no comprehensive gathering of feedback on the experiences of FFCSs of the MHSs in Ireland. To what extent are FFCSs 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? Concerns raised at Mental Health Reform regional consultations over a five-year period suggest a perceived marginalisation from the MHSs among FFCSs. In Mental Health Reform’s public consultation meetings in 2015, participants reported a lack of consistency across the MHSs in FFCS involvement.

18 Department of Health. (2006). *A Vision for Change. Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office, p.30.

19 Department of Health. (2012). *National Carers’ Strategy*. Dublin: Department of Health

To date, there has been a limited amount of research published on the experiences of FFCSs supporting people who use the MHSs in Ireland. As part of the development of *A Vision for Change*²⁰, a consultation was facilitated in 2004 to allow service users and FFCSs to describe their experiences of MHSs and to articulate their views of the changes required to provide effective, more user-friendly MHSs. Similarly, in 2005, the Mental Health Commission (MHC) launched a report which highlighted the views and perspectives of all stakeholders, including FFCSs, as to what constitutes quality in MHS provision.²¹ This feedback has informed the development of the MHC’s Quality Framework for MHSs.²²

After that, the National Service User Executive Second Opinion Reports in 2009²³ and 2011²⁴, which reported on satisfaction levels among services users of the HSE MHSs, also sought the views of family members on their involvement in MHSs. More recently, throughout 2014, the HSE Mental Health Division held a series of listening meetings across the country to consult with service users and FFCSs on their views of the MHSs for the purpose of informing service planning and improvement. However, none of these consultative processes engaged in a dedicated survey of FFCSs.

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

21 Mental Health Commission. (2005). *Quality in mental health - Your views: Report on stakeholder consultation on quality in mental health services*. Dublin: MHC.

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

23 National Service User Executive. (2009). *Summary report of the NSUE survey of members on Vision for Change: Have your voice heard... for a change*. Dublin: NSUE.

24 National Service User Executive. (2011). *Summary report of the NSUE survey of members on Vision for Change: Have your voice heard... for a change*. Dublin: NSUE.

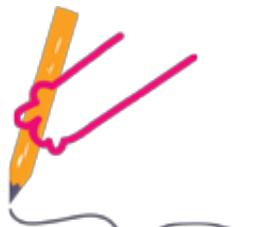
Other organisations such as the Recovery Experience Forum of Carers and Users of Services (REFOCUS) group, made up of FFCSSs and service users, and hosted by the College of Psychiatrists, have produced reports identifying the needs of FFCSSs and setting out specific measures for supporting them in their role as a carer/supporter.²⁵

In addition, Mental Health Reform facilitated its own independent public consultations in different parts of the country between 2011 and 2015 on people's experiences of the MHSs. Such forums were attended by a range of key stakeholders including FFCSSs.

Notwithstanding the valuable feedback collected through these consultations, Mental Health Reform identified a need for a national, large-scale survey to provide in depth and up-to-date feedback specifically on the experiences of people who provide support to individuals accessing a range of MHSs.

The *My Voice Matters* national consultation was conducted independently by Mental Health Reform, from study and survey design, through to data collection, analysis and report writing. The research was funded in whole by HSE Mental Health.²⁶ This support by HSE Mental Health is very encouraging in that it demonstrates a commitment among senior management to listen to the views of people using MHSs in order to inform service improvement. Preliminary findings of the research were presented to HSE Mental Health, in addition to an advance copy of the report being provided to the team prior to publication.

The Government, the HSE and all staff working in mental health and related support services can benefit from receiving national, independent feedback from FFCSSs on a regular basis, to facilitate priority setting in terms of service planning. The availability of feedback from FFCSSs is integral to the process of identifying areas for service improvement, given their direct experience of the services. In particular, it is necessary for HSE MHSs to be aware of the extent to which community mental health teams are addressing the specific support needs of FFCSSs as per national policy. In the absence of a national mental health information system, which collects routine data on service delivery, as well as outcomes for service users and FFCSSs, the availability of feedback provided through consultations such as the *My Voice Matters* study becomes increasingly important. It is Mental Health Reform's intention that the *My Voice Matters* Project will assist the Government and the HSE in their efforts to improve Ireland's mental health system.



..The MY VOICE MATTERS national consultation was conducted independently by Mental Health Reform, from study and survey design, through to data collection, analysis and report writing..

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

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

METHODOLOGY



SECTION
2

2. METHODOLOGY

2.1: Study Design

This research employed a survey design which included closed and open-ended questions. FFCSSs with experience of supporting a person with direct experience of specialist MHSs in Ireland in the last two years were asked to complete the survey.

2.2: Survey Design

The FFCSSs' survey was designed in a phased manner. Following a detailed literature review, initial survey questions were developed based on a variety of prominent studies of carers' experiences of the MHSs, e.g. the Caring for Carers survey.²⁷ Where necessary, questions were tailored to the Irish context. Additional survey questions were developed based on information gathered from Mental Health Reform's previous consultations on people's experiences of the MHSs, which were carried out across Ireland between 2011 and 2015. Proposed themes for the survey were then discussed with the project Steering Group.²⁸ On foot of this, questions were further developed and organised by theme into sections to develop a working draft of the survey.

Next, in order to test each of the survey questions, a series of cognitive interviews²⁹ were conducted with 10 individual FFCSSs. Changes were made in accordance with the feedback received. Two focus groups with FFCSSs were then conducted to gather further feedback on the updated survey. After further revision, the survey was reviewed by external researchers with survey design expertise before undergoing a final in-house review by Mental Health Reform staff. Once finalised, the survey was prepared in two formats: hardcopy and online versions.

This process resulted in the final survey, which consisted of 58 questions in total. These included multiple choice questions, Likert-scale questions³⁰, several 'tick all that apply' questions and a number of open ended questions which facilitated more in depth feedback from FFCSSs.



- 27 European Federation of Families of People with Mental Illness and KU Leuven. (2015). *Experiences of family caregivers for persons with severe mental illness: An international exploration*. Retrieved from http://www.eufami.org/c4c/c4c_reports/c4c_global.pdf
- 28 The Steering Group for the project consisted of two representatives from the HSE Mental Health Division Engagement Office, two staff members of Mental Health Reform, one expert by experience and one family carer/supporter. This steering group was only involved during the design phase of the project.

- 29 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
- 30 Used to measure people's' attitudes by asking respondents to indicate their feelings towards a statement on a scale ranging between two poles, e.g. strongly agree to strongly disagree.



2.3: Study Population and Sample

The target population was FFCSSs of people with experience of accessing secondary or tertiary MHSs³¹ in Ireland in the last two years. Only individuals over the age of 18 with the relevant experience met the inclusion criteria. Those who took part in the survey are referred to as participants throughout this report.

Snowball sampling was used to recruit the majority of the sample. This is a sampling technique where a “sample is constructed from a base of initial contacts, who are asked to provide introductions to their associates, who, in turn, are asked to refer others”.³² Wright and Stein³³ note that it is particularly useful when recruiting hidden, difficult to access or stigmatised populations. Since FFCSSs of MHS users can experience stigma due to their supporting role, FFCSSs therefore constitute a hard-to-reach population. Snowball sampling was therefore considered an appropriate sampling method for this survey.

Note that snowball sampling has been criticised because the final sample can be influenced by the initial participants. To combat this, rather than starting with a single group and allowing the sample to snowball from there, Mental Health Reform drew on its extensive network of over 70 member groups, as well as organisations and individuals external to Mental Health Reform, in an effort have as large and diverse a starting group as possible.

Mental Health Reform member organisations, Mental Health Reform advisory groups (including its Grassroots Forum), non-governmental organisations external to Mental Health Reform’s membership, primary care centres, employability companies, independent professionals and members of the Oireachtas were contacted and asked to bring the national consultation survey to the attention of people accessing their services.

In addition, radio advertisements and an extensive social media campaign also increased awareness of the survey and facilitated recruitment.

In total, 794 participants responded to the survey. Twelve participants were excluded either because they were under the age of 18 or because the person they support had not accessed psychiatry, community or inpatient MHSs in Ireland in the last two years. In total, 782 FFCSSs who met the sampling criteria³⁴ completed the survey (mean age: 46.27; age range: 18–79). There was a female to male gender ratio of over 3 to 1³⁵ (female: 77.0%; male: 23.0%). No participant self-identified as a gender other than male or female. A wealth of socio-demographic information was gathered, e.g. Community Health Organisation (CHO) area and relationship to the person being supported. This is outlined in table 2.1.

31 At various levels, e.g. community mental health services, inpatient service and/or contact with a psychiatrist.

32 Wright, R., & Stein, M. (2005). Snowball sampling. In K. Kempf-Leonard (Ed.), *Encyclopedia of social measurement* (Vol.3) (pp. 495–500). Boston, MA: Elsevier, p. 495.

33 Wright and Stein. (2005). Snowball sampling. In K. Kempf-Leonard (Ed.), *Encyclopedia of social measurement* (Vol.3) (pp. 495–500). Boston, MA: Elsevier.

34 Only individuals aged 18 years or older with experience of supporting a person accessing MHSs in Ireland in the last two years were eligible to take part.

35 Although there is a gender imbalance, nationally, more carers are female (60.5%) than male (39.5%; CSO, 2016), while gender ratios in previous research with carers was broadly similar, e.g. 82% female and 18% male, see: O’Brien, F. (2009). *Family carers health survey*. Dublin: College of Psychiatrists of Ireland.

Table 2.1: Socio-demographic profile of the FFCSS survey sample.

Age Group	%	n*
18-25	3.8%	29
26-34	12.2%	94
35-44	26.7%	205
45-54	32.8%	252
55-64	18.5%	142
65 or older	6.0%	46
Gender	%	n
Female	77.0%	598
Male	23.0%	179
Educational Attainment	%	n
No formal education/primary education only	1.2%	9
Lower secondary	3.5%	27
Upper secondary	11.1%	86
Third level non-degree	23.2%	180
Third level degree	28.6%	222
Post graduate qualification	32.6%	253
Ethnic/Cultural Background	%	n
Irish (including Irish Traveller)	91.3%	709
English/Scottish/Northern Irish/Welsh	4.8%	38
Other ethnic/cultural background ³⁶	3.9%	29
Sexuality/Sexual Identity ³⁷	%	n
Straight/Heterosexual	92.7%	725
Lesbian/Gay	2.8%	46
Bisexual	2.2%	17
Other Sexual Identity ³⁸	1.2%	9

³⁶ Although a variety of different responses were given (e.g. African, Indian, etc.), all categories with less than 1.0% were combined within the ‘other’ category.

³⁷ Participants could tick all options that applied to them. It was therefore possible to choose multiple sexual identities.

³⁸ ‘Other’ was included as a response option so that individuals did not feel forced to respond within a paradigm that they do not agree with. Other sexual identity could include, but is not limited to, asexual, demisexual or pansexual.



Work/Employment Status	%	n*
Paid full or part-time employment	69.1%	535
Looking after the family home	9.8%	76
Retired	7.2%	58
Unemployed	4.0%	31
Student	3.6%	28
Unable to work due to chronic illness/disability	3.5%	27
Other	2.7%	21
Do you have a Chronic Illness/Disability? ³⁹	%	n
Yes	20.6%	158
No	79.4%	609
What is your Community Health Organisation catchment area?	%	n
CHO Area 1 (Donegal, Sligo/Leitrim/West Cavan, Cavan/ Monaghan):	7.7%	60
CHO Area 2 (Galway, Roscommon, Mayo):	11.3%	88
CHO Area 3 (Clare, Limerick, North Tipperary/East Limerick):	10.9%	85
CHO Area 4 (Kerry, North Cork, North Lee, South Lee, West Cork):	11.7%	91
CHO Area 5 (South Tipperary, Carlow/Kilkenny, Waterford, Wexford):	10.1%	79
CHO Area 6 (Wicklow, Dun Laoghaire, Dublin South East):	10.5%	82
CHO Area 7 (Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West):	14.1%	110
CHO Area 8 (Laois/Offaly, Longford/Westmeath, Louth/Meath):	9.6%	75
CHO Area 9 (Dublin North, Dublin North Central, Dublin North West):	14.2%	111

**Note that the column listing the number of participants in each category does not sum to 782, the total number of participants who took part. Instead, this column sums to the total number of participants who answered each of the questions listed, reflecting the valid percent.*

FFCSs were also asked questions about the person they support. These questions concerned things like diagnosis, type of MHS(s) utilised, and access to private MHSs, etc. Their responses to these questions are outlined in table 2.2.

39 Participants were presented with a list of illnesses and disabilities and asked to tick all that applied to them. The most common were as follows: 'other' (8.3%); difficulty with basic physical acts (4.1%); difficulty with pain and/or breathing (4.0%); and difficulty remembering/concentrating (3.6%).

Table 2.2: Characteristics relating to the person being supported.

Who is the Person You Support to You?	%	n*
Child (including adult child)	37.8%	295
Sibling	18.1%	141
Spouse/Partner	16.0%	125
Parent	9.4%	73
Friend	5.0%	39
Other relative	2.7%	21
Other	11.0%	86
Do you live with the person you support?	%	n
Yes	44.1%	344
Sometimes	11.4%	89
No	44.5%	347
If the person you support has a diagnosis of their mental health difficulty, please select the closest to their main diagnosis ⁴⁰ :	%	n
Depression	23.8%	185
Schizophrenia (including schizoaffective disorder)	18.9%	147
Anxiety disorder	14.7%	114
Bi-polar disorder	12.0%	93
Personality disorder	8.7%	68
Other ⁴¹	8.6%	67
'Have not been given a diagnosis'	8.1%	63
Post-Traumatic Stress Disorder (PTSD)	1.9%	15
Eating disorder	1.8%	14
'Prefer not to say'	1.5%	12
Has the person you support had contact with the following services in the last two years? (tick all that apply)	%	n
Psychiatrist	79.8%	624
Community mental health services	72.5%	567
Inpatient MHSs ⁴²	48.3%	378

40 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.

41 'Other' represents any respondent who selected 'other' as the option under the diagnosis question.

42 Of those reporting that the person they support has accessed inpatient services in the last two years, 58.4% reported services were accessed voluntarily, 21.4% reported services were accessed involuntarily and 20.3% reported that the person they support had accessed these services both voluntarily and involuntarily.



Does the person you support have access to any of the following private mental health care services?	%	n*
Private psychiatrist	17.5%	126
Private therapist/counsellor	29.6%	217
Private community mental health services	13.3%	90
Private inpatient mental health care	17.2%	121
Access to some form of private care ⁴³	42.2%	325
No access to private care of any kind	57.8%	445
How long has the person you support been in contact with HSE MHSs?	%	n
Less than one year	13.3%	104
One to five years	40.4%	316
Six to 10 years	14.2%	111
More than 10 years	26.1%	204
'No longer in contact with HSE MHSs'	5.1%	40
Don't know/can't remember	0.9%	7
Does the person you support have a long-term physical health diagnosis, as well as a mental health difficulty?	%	n
Yes	25.7%	201
No	74.3%	580

**Note that the column listing the number of participants in each category does not sum to 782, the total number of participants who took part. Instead, this column sums to the total number of participants who answered each of the questions listed, reflecting the valid percent.*

43 This is the proportion of participants who indicated access to one or more of the private MHSs listed.

2.4: Data Collection

Data collection took place over a six-month period between November 2017 and April 2018. The primary method for data collection was through SurveyMonkey, an online survey tool; however, paper versions of the survey were available to any participant on request.

A large majority of participants completed the survey online. Research has found that online surveys have several advantages over traditional survey methods^{44, 45, 46, 47} including

- ❖ online surveys can reach more potential participants quickly
- ❖ they can reduce bias and measurement error⁴⁸ as a result of questions relating to stigmatised topics (like mental health) and
- ❖ they can enhance participation of stigmatised populations.

Research has also found that the quality of the data gathered via online surveys is at least as good as traditional survey methods.^{49, 50}

- 44 McCabe, S. E. (2004). Comparison of web and mail surveys in collecting illicit drug use data: A randomized experiment. *Journal of Drug Education*, 34(1), 61-73. doi:10.2190/4HEY-VWXL-DVR3-HAKV
- 45 McCabe, S. E., Boyd, C. J., Couper, M. P., Crawford, S. D., & D'Arcy, H. (2002). Mode effects for collecting alcohol and other drug use data: Web and U.S. mail. *Journal of Studies on Alcohol*, 63, 755-762. doi:10.15288/jsa.2002.63.755
- 46 Rhodes, S. D., Bowie, D. A., & Hergenrather, K. C. (2003). Collecting behavioural data using the World-Wide Web: Considerations for researchers. *Journal of Epidemiology and Community Health*, 57, 68-73.
- 47 Trau, R. N., Härtel, C. E., & Härtel, G. F. (2013). Reaching and hearing the invisible: Organizational research on invisible stigmatized groups via web surveys. *British Journal of Management*, 24(4), 532-541.
- 48 The difference between the measured value of a quantity and its true value, see Dodge, Y. (2003). *The Oxford Dictionary of Statistical Terms*. Oxford: Oxford University Press.
- 49 Gosling, S. D., Vazire, S., Srivastava, S., & John, O. P. (2004). Should we trust web-based studies? A comparative analysis of six preconceptions about Internet questionnaires. *American Psychologist*, 59, 93-104. doi: 10.1037/0003-066X.59.2.93
- 50 Whitehead, L. (2011). Methodological issues in Internet-mediated research: a randomized comparison of internet versus mailed questionnaires. *Journal of medical Internet research*, 13(4). doi: 10.2196/jmir.1593

Online data collection was therefore considered an appropriate and potentially effective method of data collection in this context.

Paper versions of the survey were made available to a large number of organisations to meet the needs of people who are not comfortable using computers. Participants who requested a paper version of the survey were provided with a survey pack including a consent form, an information sheet (see appendix A) and a stamped addressed envelope to return their completed survey.

All participants were instructed to read an information sheet about the *My Voice Matters* project. They were required to indicate that they had read the information sheet and that they consented to take part by ticking a box.

2.5: Data Analysis

Survey data were exported from the SurveyMonkey platform to Statistical Package for the Social Sciences (SPSS), the statistical analysis software (version 25). Data were then cleaned and ineligible participants (e.g. individuals under the age of 18 or those who indicated that the person they support had not accessed MHSs in the last two years) were excluded from the final data set. A descriptive analysis of the data was carried out using SPSS. Valid percentages⁵¹ are reported throughout this report. However, where missing cases exceed 5% of responses, this is noted. Note that all figures are rounded to the nearest tenth and may not add to exactly 100%.

The sample for each question (n) was only reported for the purpose of follow-up questions, when participants who responded

51 Valid percent is the percent when all missing responses are excluded from calculations. For example, if 500 participants answered a question (missing responses=282), the missing cases would be excluded from calculations and the 500 responses would equal 100%.



in a particular way to one question were asked a follow-up question. For example, the number of participants who reported that the person they support presented at an emergency department for their mental health difficulty was reported because these participants were then asked a follow-up question, did the person they support receive support that adequately addressed their needs as a result? The sample for a question was also reported where the number of responses differed considerably from the total sample. For example, a number of questions included a ‘not involved’ response option. Participants who indicated that they were ‘not involved’ were excluded from the figures reported for these questions, resulting in a smaller sample for these questions. Cases like this are footnoted throughout the findings chapter.

Participants were also asked two open ended questions as part of the survey. These questions were as follows:

- ★ Is there any service that was not available to you that you would have benefitted from?
- ★ What positive experiences have you experienced of HSE MHSs?

Due to the large number of responses (454 codable responses to the former and 493 codable responses to the latter), a conventional content analysis⁵² was considered the most appropriate method of analysis. This was carried out in accordance with the guidelines outlined by Erlingsson and Brysiewicz⁵³:

- ★ First, the responses were read and re-read to become familiar with the data and to note initial ideas for codes

52 A content analysis aims to reduce large amounts of text into a systematically organised summary of key results based on the frequency with which particular codes and categories are evident in the data.

53 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.

- ★ Second, primary codes were formulated⁵⁴
- ★ Third, due to the large number of primary codes, these codes were collated into subcategories
- ★ Finally, these subcategories were collated into categories. Note that a response could have been assigned to several categories simultaneously.

2.5.1: Unavailable Service That Participants Would Have Benefitted From:

Responses were coded independently by two members of the research team. There was an agreement (intercoder reliability) rate of 88.7%. All disagreements were resolved by another member of the research team. Note that not all participants responded to this question and not all responses were codable.⁵⁵ In total, 454 responses to this question were deemed codable (codable response rate: 58.1%).

2.5.2: Positive Experiences of HSE MHSs:

Again, responses were coded independently by two members of the research team. There was an agreement (intercoder reliability) rate of 80.3%. All disagreements were resolved by another member of the research team. Again, not all participants responded to this question and not all responses were codable. In total, 493 responses to this question were deemed codable (codable response rate: 63.0%).

54 In formulating primary codes to analyse interviews, an additional step may be required. One can divide the text into smaller parts referred to as meaning units, see Erlingsson and Brysiewicz (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. These meaning units are then collated to develop primary codes. However, the majority of responses to the open ended questions included in the FFCS report were short, therefore dividing responses into smaller meaning units was deemed unnecessary.

55 Responses were deemed not to be codable if a response lacked sufficient information to be accurately coded or was unintelligible in the context of the question asked, e.g. in response to the question relating to beneficial services that were unavailable, responses that could not be coded included ‘Bobe’, ‘don’t know’, ‘ok’, or ‘R’.

Note that the qualitative and quantitative findings are reported together where relevant. For example, responses provided by participants on crisis out-of-hours services through open-ended questions are reported alongside the quantitative, or closed ended questions on out-of-hours services (see section 3.1.1.).

Also, many participants responded to the open ended questions with feedback that was not specific to the questions asked. These responses were coded and categorised along with the question specific responses and are reported in the qualitative feedback sections in chapter three.

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].

2.6: Ethical Considerations

Full ethical approval was granted from the research ethics committee in Waterford University Hospital. Among the key ethical issues considered were the following: ensuring fully informed consent; confidentiality and anonymity of survey participants; and data protection.

To ensure fully informed consent, detailed information about the project was made available in a variety of ways in the lead up

to and during the recruitment process. As part of the recruitment campaign, posters, leaflets and information sheets (see appendix A) were made available to individuals and organisations to ensure that potential participants had all relevant information. Importantly, before filling in the survey, all participants were required to read information about the project and indicate the following by ticking a box:

- ✖ they understood the purpose of the study
- ✖ they understood that their responses would be confidential
- ✖ they understood that no identifiable information would be collected to ensure their anonymity
- ✖ and that they freely consented to take part.

Steps like these ensured that potential participants were able to access detailed information about the project and its benefits before they gave consent and took part.

Confidentiality and anonymity were central to the approach taken by this project. No identifiable information was collected as part of the survey. For example, as noted above, rather than requiring a signature to indicate consent, participants were simply required to tick a box. Also, when cleaning the data, steps were taken to ensure that any data that was potentially identifiable was anonymised.

Finally, a number of steps were taken to ensure that the data were securely stored and only accessible to Mental Health Reform’s research team working on the project. As noted above, survey responses were gathered using an online survey platform. These data were only accessible via a password protected account. When these data were exported to SPSS for detailed analysis, they were stored in a password protected folder to which only the Mental Health Reform research team had access. All completed paper versions of the surveys were stored in a locked cabinet in a locked office until entered into SPSS, after which they were destroyed.

FAMILY, FRIENDS AND CARERS/ SUPPORTERS' SURVEY FINDINGS



3. FAMILY, FRIENDS AND CARERS/SUPPORTERS' SURVEY FINDINGS

In this chapter, findings from the FFCSs' survey are outlined. Findings are organised into two sections. The first section focuses on FFCSs' own experiences of MHSs in Ireland. The second section focuses on the FFCSs' views of the care provided to the individual they support.

3.1: FFCS Experience

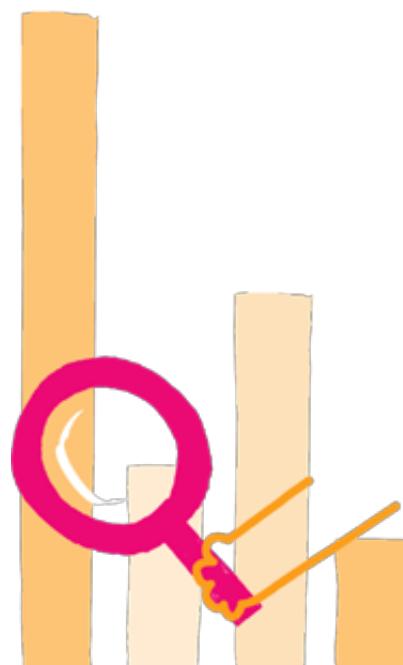
This section outlines findings relating to FFCSs' own experiences of MHSs in Ireland and is organised into four subthemes: information and advice; involvement in mental health service planning; FFCSs' support needs; and experiences of inpatient MHSs.

3.1.1: Information and Advice:

Participants were presented with a series of questions relating to the information and advice they have received from the MHSs in their role as a FFCS.⁵⁶ The findings relating to these questions are outlined below.

Participants were asked to indicate the extent to which they were satisfied with the information and advice they received when the person they support first came into contact with HSE MHSs. Two-thirds (66.5%) reported being dissatisfied with the information and advice they received at that time, while over one in six (16.0%) indicated that they were satisfied. Some 17.5% indicated that they were neither satisfied nor dissatisfied (see figure 3.1).

On average, participants were dissatisfied with the information and advice received when the person they support first came into contact with MHSs ($M=2.12$; $SD=1.22$).^{57, 58}



⁵⁷ M stands for the mean or average score of the sample. SD stands for standard deviation, which indicates the amount of variation in participant responses. A low SD indicates that most responses are grouped close to the mean or average, while a high SD indicates that there is more variation in responses. Note that reporting the median and mode for a Likert scale is considered more accurate by some (see the following for more detail: Carifio, L. & Perla, R. (2008). Resolving the 50-year debate around using and misusing Likert scales. *Medical Education*, 42(12), p.1150–1152.); however, the M and SD are reported throughout this report as they are more accessible for readers. See appendix B for the medians and modes for each of the Likert scale questions.

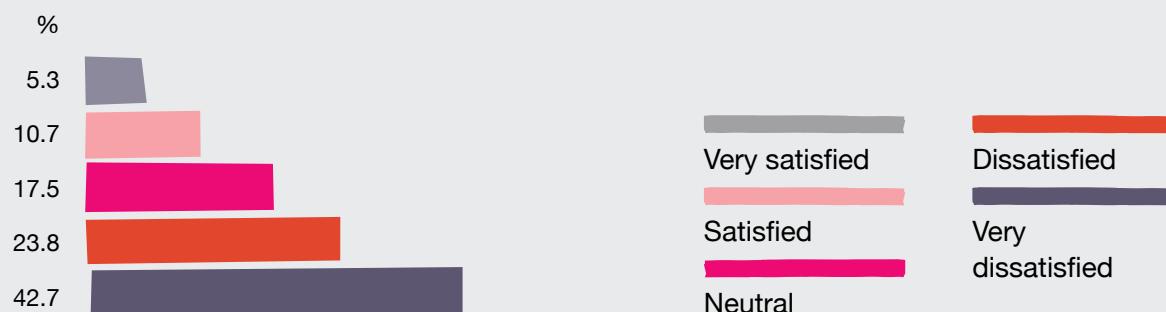
⁵⁸ This M and SD are based on a five-point rating scale ranging from one (very dissatisfied) to five (very satisfied). There was one additional response option: one in ten (10.0%) indicated that they were 'not supporting the person when they first came into contact with HSE MHSs'. These and the missing responses were excluded from the figures reported here, resulting in $n=702$.

⁵⁶ Mental Health Reform acknowledge that permission to provide FFCSs with specific information about treatment and care must be granted by the person accessing the services. However, all questions relating to information and advice included in this survey related to general information and advice and therefore can be provided to FFCSs without consent.



Figure 3.1: Satisfaction with information and advice at first contact with HSE MHSs.

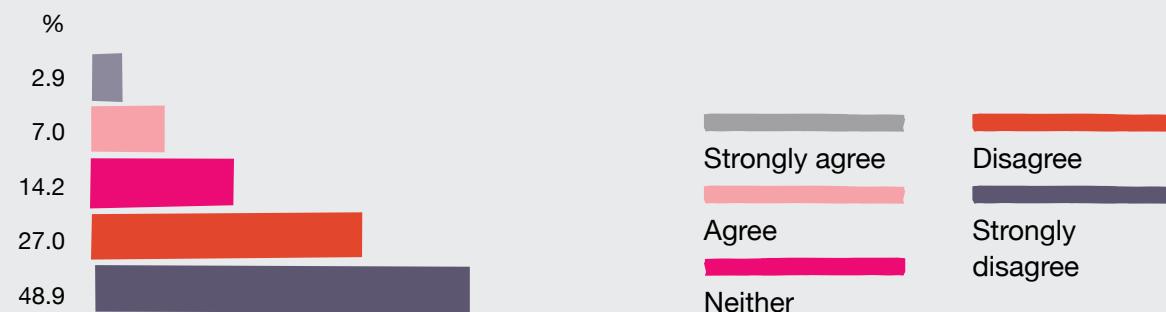
WERE YOU SATISFIED WITH THE INFORMATION AND ADVICE YOU RECEIVED FROM THE HSE MENTAL HEALTH SERVICES WHEN THE PERSON YOU SUPPORT FIRST CAME INTO CONTACT WITH THE SERVICES?



Participants were asked if they agreed that HSE MHSs explained how to support the person in the long-term. Three-quarters (75.9%) disagreed that the HSE MHSs explained how to support the person in the long-term. One in ten (9.9%) agreed, while 14.2% neither agreed nor disagreed (see figure 3.2). On average, participants disagreed that the HSE MHSs explained how to support the person long-term ($M=1.88$; $SD=1.08$).⁵⁹

Figure 3.2: Levels of agreement that HSE MHSs explained how to support the person in the long-term.

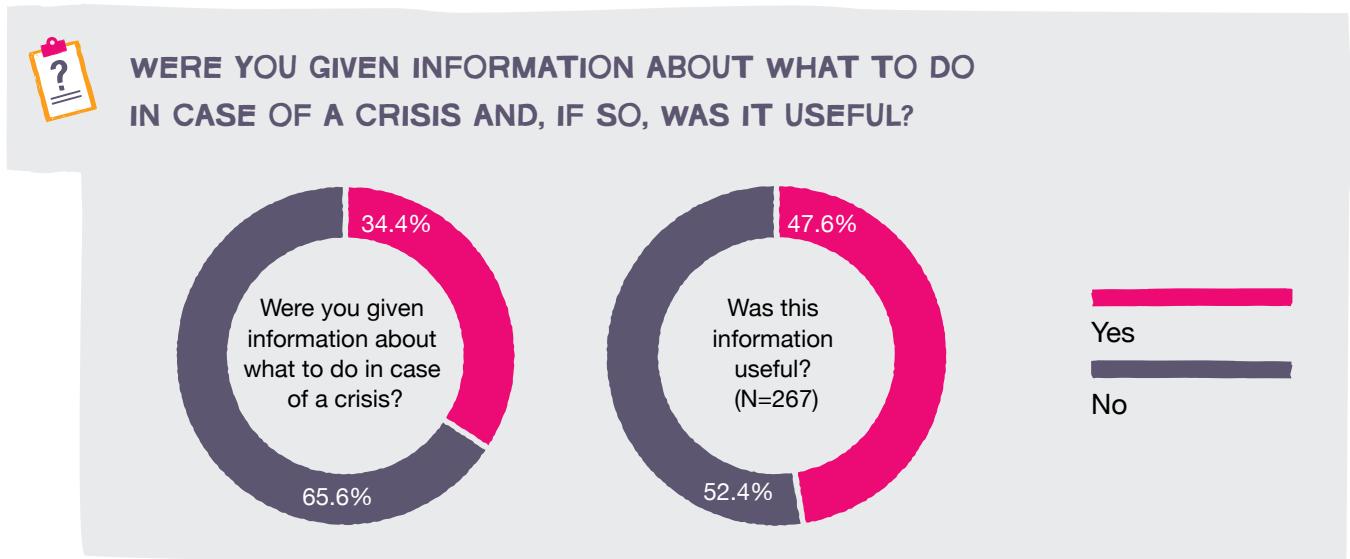
THE HSE MENTAL HEALTH SERVICES EXPLAINED HOW TO SUPPORT THE PERSON LONG-TERM



⁵⁹ This M and SD are based on a five-point rating scale ranging from one (strongly disagree) to five (strongly agree). There were two additional response options: 6.2% indicated that they were not involved 'by choice of the person I support' and 4.1% indicated that they were not involved 'by my choice'. These and the missing responses were excluded from the figures reported here, resulting in n=697.

Participants were also asked whether they had been given any information about what to do in the event of a crisis. Approximately one-third (34.4%) reported that they had received information on what to do in case of a crisis, while two-thirds (65.6%) reported that they were not given information of this nature. Of those who were given information about what to do in case of a crisis (n=267), fewer than half (47.6%) found the information useful (see figure 3.3).

Figure 3.3: Information on what to do in case of a crisis.



Related Qualitative Feedback:

When asked whether there were any services that were unavailable to them that they feel they would have benefitted from, the need for accessible 24/7 crisis orientated services was frequently reported in participant responses. Often describing crisis situations that they had found very difficult, many participants expressed a desire for specialist 24/7 crisis services, better support and advice for FFCSSs on what to do in the case of a crisis, and a service or professional that could be contacted at any time in case of, or leading up to, a crisis (also see section 3.1.3.1 for further examples).

“Family support is low on the agenda. Especially when you are the main carer and you are faced with your loved one in crisis and supports are not available at 3am in the morning. Also waiting in a crowded a &e waiting room when the person is again unwell is stressful for both my sibling and us as family members”

“Emergency intervention team”

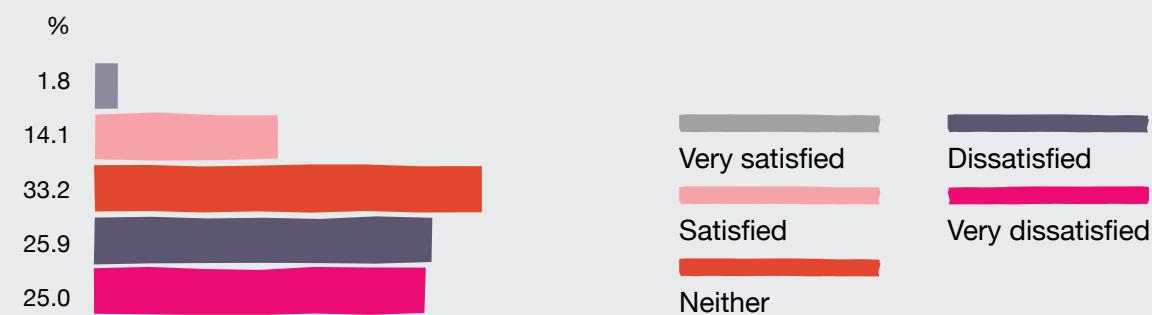
“A home carer, personal carer for my daughter at home when she’s in crisis - I can’t take care of her 24/7 sometimes I think I’ll end up in hospital myself”



Participants were asked to indicate the extent to which they were satisfied with the information about MHSs given on the HSE website. Of those who indicated that they had accessed the HSE website, half (50.9%) reported that they were dissatisfied, one in six (15.9%) reported that they were satisfied, and one-third (33.2%) reported that they were neither satisfied nor dissatisfied with the information about MHSs given on the HSE website (see figure 3.4). On average, participants were dissatisfied with the information given about MHSs on the HSE website ($M=2.42$; $SD=1.07$).⁶⁰

Figure 3.4: Satisfaction with information about MHSs on the HSE website.

HOW SATISFIED ARE YOU WITH INFORMATION GIVEN ABOUT MENTAL HEALTH SERVICES ON THE HSE WEBSITE?



When asked about the information they had received in relation to available support groups in the community for FFCSSs, one in six (17.4%) reported that they had been given information about available support groups (on request: 7.2%; without prompt: 10.2%), while approximately four in five (82.6%) reported that they had not been given this information (see figure 3.5).⁶¹

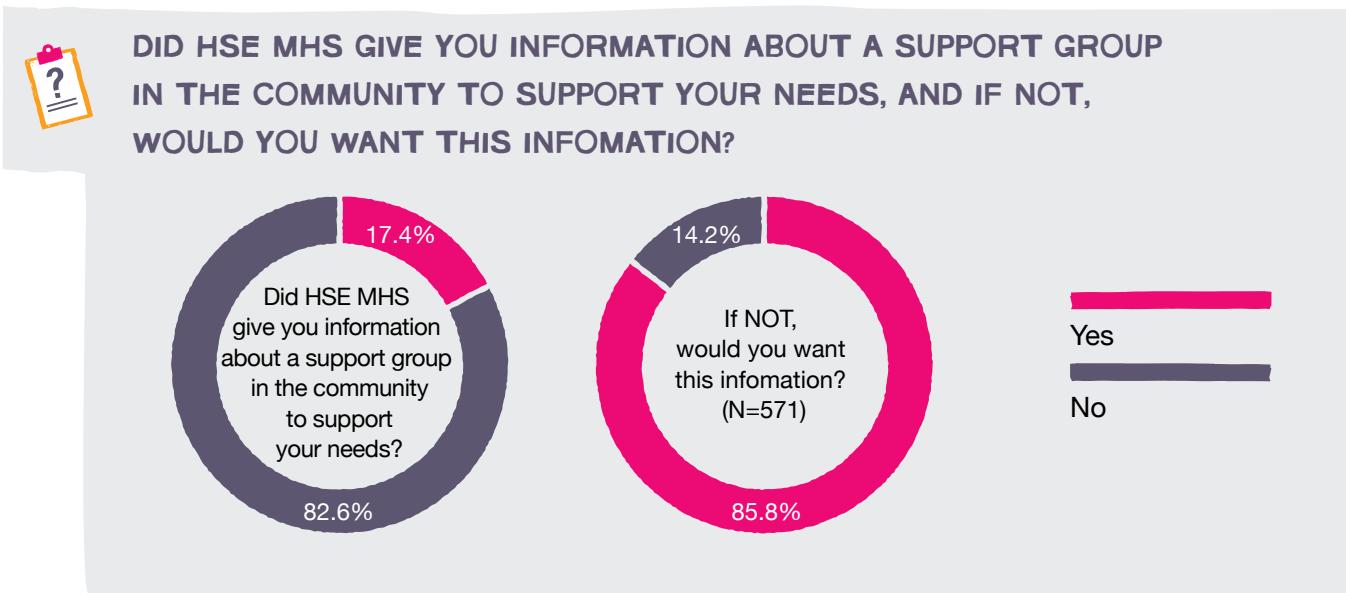
Of those who were given information on available support groups ($n=120$), 69.1% found it useful, while 30.9% did not find it useful.⁶² Of those who reported that they had not been given information about a support group ($n=571$), 85.8% would have liked to receive such information, while 14.2% reported that they would not have wanted such information (see figure 3.5).

60 This M and SD are based on a five-point rating scale ranging from one (very dissatisfied) to five (very satisfied). There was one additional response option: 29.6% of participants reported that they had not accessed the HSE website. These and the missing responses were excluded from the figures reported here, resulting in $n=548$.

61 There were two additional response options: 5.8% indicated that they were not involved 'by my choice' and 5.4% indicated that they were not involved 'by choice of the person'. These and missing responses were excluded from the figures reported here, resulting in $n=691$.

62 Although only valid percentages are reported here, note that this item had a high proportion of missing values (8.3%).

Figure 3.5: Information about community support groups for FFCSSs.



Participants were asked whether anyone in the HSE MHSs let them know how to make a complaint about the MHSs. Approximately eight in 10 (81.8%) reported that no one had let them know how to make a complaint, while approximately one in ten (11.8%) reported that they had found the information displayed in MHS facilities (clinic, website, leaflets, etc.). Some 6.4% reported that they had either been let know how to make a complaint once (3.7%) or more than once (2.7%).

3.1.2: Involvement in Mental Health Service Planning:

Participants were presented with questions relating to their involvement in the care and treatment of the person they support and the extent to which their views were taken into consideration by the MHSs. They were also asked about their involvement in the design and delivery of MHSs in Ireland. Findings relating to these questions are outlined below.

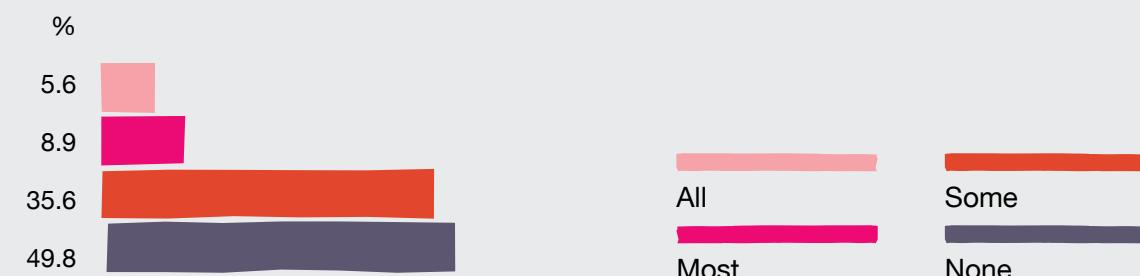
When asked if their views were incorporated into the recovery/care plan of the person they support⁶³, one in seven (14.5%) indicated that most (8.9%) or all (5.6%) of their views had been incorporated, over one-third (35.6%) indicated that some of their views had been incorporated, while half (49.8%) indicated that none of their views had been incorporated into the recovery/care plan of the person they support (see figure 3.6).

⁶³ Some 16.8% reported that they were not involved either ‘by my choice’ (5.7%) or ‘by the choice of the person they support’ (11.1%). These and missing responses were excluded from the figures reported here, resulting in n=640.



Figure 3.6: Extent to which the views of participants were incorporated into the recovery/care plan of the person being supported.

EXTENT TO WHICH THE VIEWS OF PARTICIPANTS WERE INCORPORATED INTO THE RECOVERY/CARE PLAN OF THE PERSON BEING SUPPORTED



Related Qualitative Feedback:

As noted in section 2.5, many participants responded to the open ended questions with feedback that was not specific to that question. Among the issues raised without prompt by participants was their level of involvement in the treatment and care of the person they support. Participants expressed a desire for more involvement in the treatment of the person they support.

"Let the family be involved in their care and ongoing treatment"

Some participants described how their views were '*not taken on board*', '*ignored*' or '*not appreciated*', while others described how they had had little or no contact with the person's mental health team and/or had received no information from them, e.g. on the progress of the person they support or on how best they could help to support their recovery.

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

"My opinion or the insight I had with regard to my wifes condition was not asked for or wanted"

"I don't count. I don't exist as my son is over 18"

Some participants also expressed a belief that increased involvement of FFCSs in this regard would benefit not only the person being supported but the mental health team supporting them, as the FFCS could provide '*insight*' or '*background*' into the person and what may work for them.

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

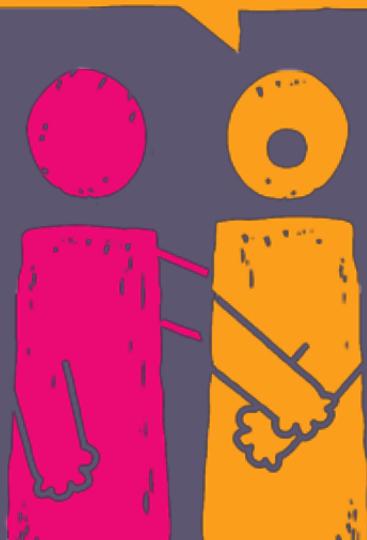


"It could allow family members to give background and context to help explain and support a patient's behaviour and to help support teams understand"

Highlighting the positive impact increased FFCS involvement can potentially have, when participants were asked about their positive experiences of HSE MHSs, some described how HSE MHSs had facilitated and even encouraged their involvement in the care and treatment of the person they support. These participants wrote about how staff gave them the opportunity to get involved and to contribute their views on the care and treatment of the person they support.

"On the whole, in my experience, I have been dealt with well, and been included in my sons evaluations and recovery plans etc."

"The psych reg [registrar] in the hospital she attended via A&E was absolutely wonderful. She was so compassionate and caring and most importantly she took the time to speak to me to get the background as to the build up to the suicide attempt"



Quantitative finding: Participants were asked whether confidentiality between the mental health team and the person they support had ever been a barrier to their views being taken into account by the MHSs. Over four in ten (43.6%) reported that confidentiality had 'never' been a barrier, less than four in 10 (38.1%) reported that this was sometimes the case, while approximately one in five (18.3%) reported that this was 'always' the case.

Qualitative feedback indicated that confidentiality was perceived by some participants as a barrier to their involvement in the treatment and care of the person they support.

"Confidentiality sometimes proves to be a barrier"

"Communication, as [the] person is 22 We were not informed of condition. re patient confidentiality. left in dark"

"The nurses are much more willing to engage with you as a support person although the issue of confidentiality is very unhelpful and frustrating"

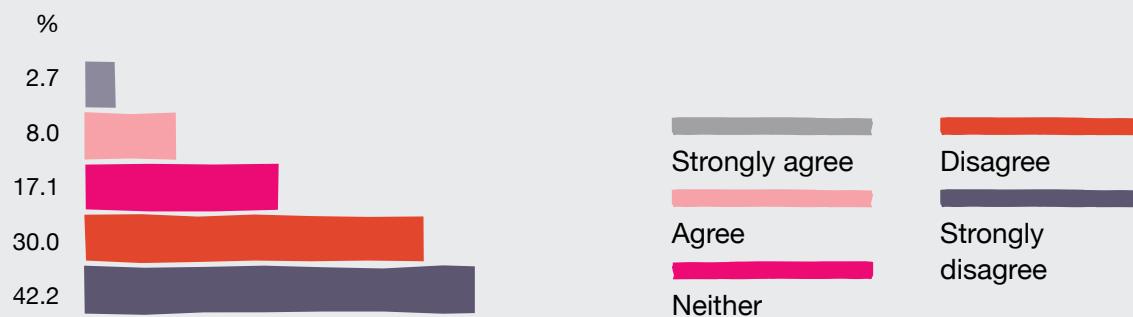
Quantitative finding: Participants were asked to indicate the extent to which they agreed that, in the last two years, they had had the opportunity to provide feedback to the MHSs to inform service improvement. More than seven in ten (72.2%) disagreed, while one in ten (10.7%) agreed (see figure 3.7). On average, participants disagreed that they had had the opportunity to provide feedback to the MHSs to inform service improvement ($M=1.99$; $SD=1.08$).⁶⁴

⁶⁴ This M and SD are based on a five-point rating scale ranging from one (strongly disagree) to five (strongly agree).



Figure 3.7: Opportunity to provide feedback to inform service improvement.

IN THE LAST TWO YEARS, I HAVE HAD THE OPPORTUNITY TO PROVIDE FEEDBACK TO THE MENTAL HEALTH SERVICES TO INFORM SERVICE IMPROVEMENT.



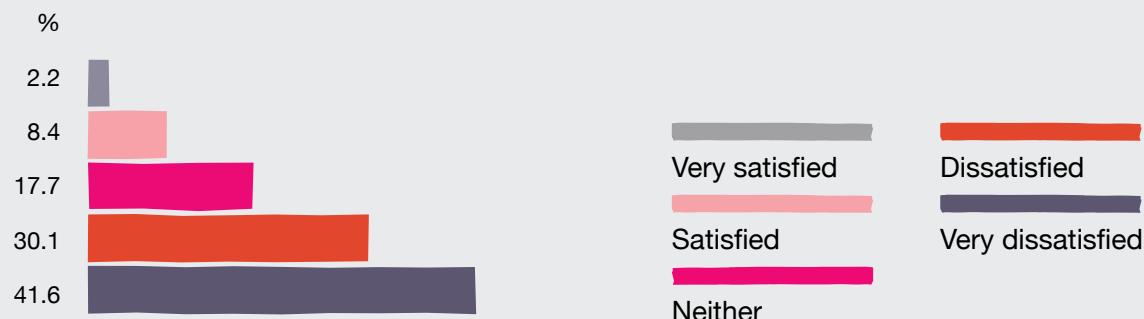
3.1.3: Support Needs as a Carer/Supporter:

Participants were asked a series of questions relating to their own support needs. The findings relating to these questions are outlined below.

Participants were asked to indicate the extent to which they were satisfied that HSE MHSs have considered their support needs. Approximately seven in ten (71.7%) reported that they were dissatisfied or very dissatisfied, while approximately one in ten were satisfied or very satisfied (10.6%). Less than one in six (17.7%) were neither satisfied nor dissatisfied (see figure 3.8). On average, participants were dissatisfied that HSE MHSs considered their support needs ($M=1.99$; $SD=1.06$).⁶⁵

Figure 3.8: Satisfaction with the extent to which HSE MHSs considered the support needs of FFCSSs.

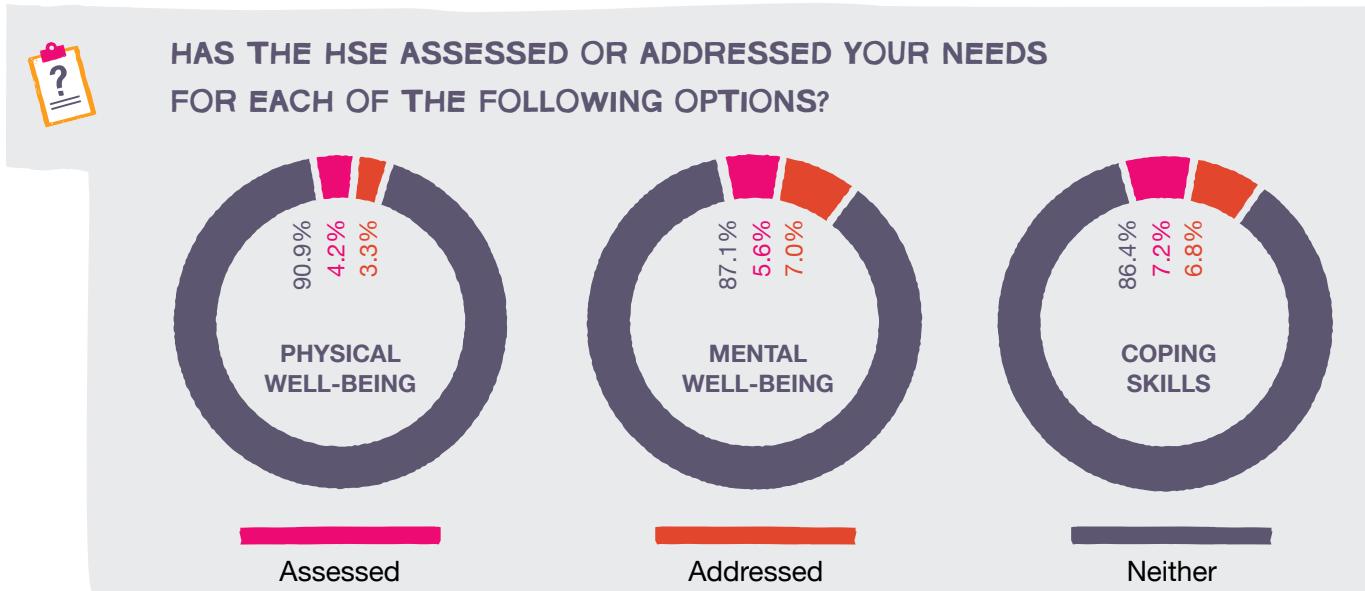
OVERALL, ARE YOU SATISFIED THAT HSE MENTAL HEALTH SERVICES HAVE CONSIDERED YOUR SUPPORT NEEDS?



⁶⁵ This M and SD are based on a five-point rating scale ranging from one (very dissatisfied) to five (very satisfied).

Participants were also asked to indicate whether three specific aspects of their own needs had been assessed and/or addressed by the HSE MHSs: their physical well-being; their emotional well-being; and their coping skills (see figure 3.9). Nine in every 10 participants (90.9%) reported that their physical well-being had been neither assessed nor addressed, while 4.2% reported that their physical well-being had been assessed and 3.3% reported that it had been addressed. Some 87.1% reported that their mental well-being had neither been assessed nor addressed, while 5.6% reported that their mental well-being had been assessed and 7.0% reported that it had been addressed. Finally, 86.4% of participants reported that their coping skills had neither been assessed nor addressed, while 7.2% reported that their coping skills had been assessed and 6.8% reported that they had been addressed.

Figure 3.9: Assessing and addressing the needs of FFCSSs.



Participants were asked whether they had the contact details of a designated mental health professional (key worker) in the HSE MHSs to provide them with support.⁶⁶ Approximately one in four (26.0%) indicated that they had the contact details of a key worker in the HSE MHSs, while almost three in four (74.0%)⁶⁷ reported that they did not.

In order to gather a picture of the types of supports that FFCSSs are availing of, participants were presented with a list of supports (including those external to HSE MHSs) and asked to indicate which of these supports (if any) they had personally accessed in relation to their support role over the past two years. Over half (51.2%) had accessed supports of some kind. Some 48.8% indicated that they had not accessed supports of any kind.

Of those who had not accessed supports (n=360), 58.6% were not accessing supports because they were not aware of available services, 23.1% reported that no supports were available and 24.2% did not access supports, despite their availability.⁶⁸

⁶⁶ Some 10.3% reported that they were not involved either 'by my choice' (4.4%) or 'by the choice of the person they support' (5.9%). These and missing responses were excluded from the figures reported here, leaving a sample of n=699.

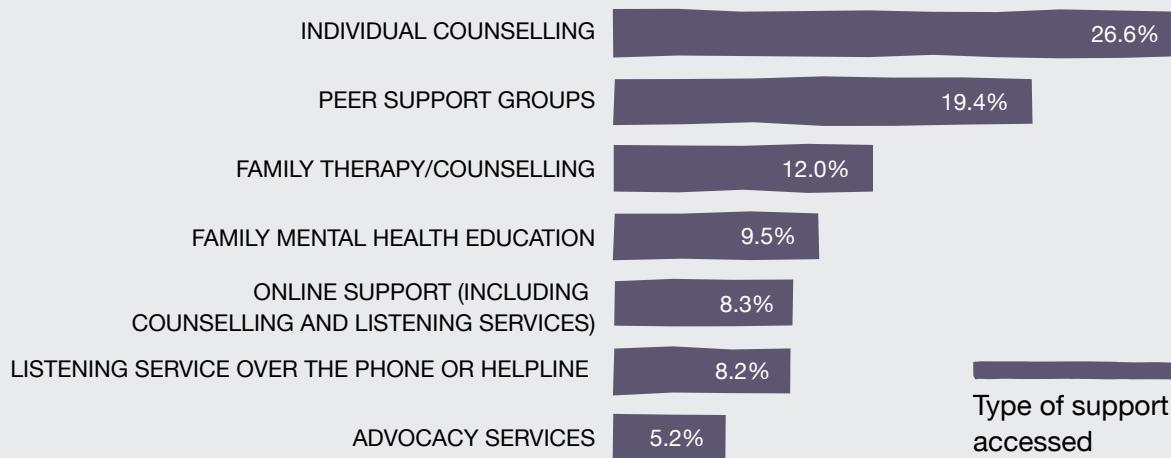
⁶⁷ Included in this figure are a small number of participants who reported not having contact details for a key worker but who also reported that they were 'in the process of getting contact details' (n=20).

⁶⁸ Note that these percentages do not sum to 100% as this was a tick all that apply question.



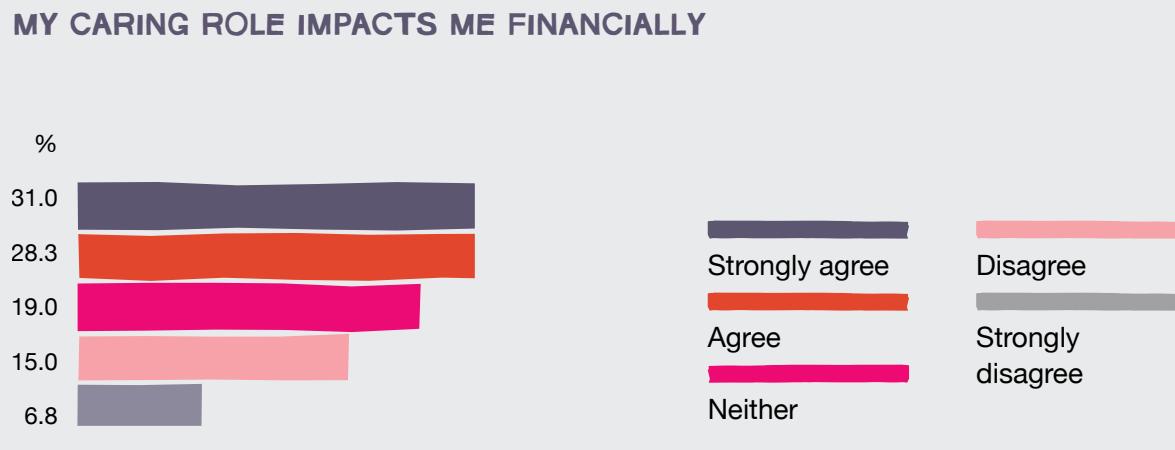
In descending order of frequency, the supports accessed by participants are outlined in figure 3.10. Individual counselling was the most common support accessed by participants, with approximately one in four (26.6%) accessing this type of support in the last two years. Advocacy services was the least common support accessed by participants, with one in 20 (5.2%) accessing this type of support.

Figure 3.10: Supports accessed by FFCSSs.



Participants were asked to indicate the extent to which they agreed that their caring role impacts them financially. Six in every 10 agreed (59.3%), while approximately one in five disagreed (21.8%; see figure 3.11).

Figure 3.11: Financial impact of caring role.





3.1.3.1 Qualitative Feedback: Relating to Support Needs

Additional qualitative feedback relating to the support needs of FFCSSs is outlined in this section.

BENEFICIAL SERVICES:

Participants were asked whether there were any services that were unavailable to them that they believe would have been beneficial to them. Responses were analysed using a conventional content analysis (see section 2.5 for more detail). The most common types of services and supports raised by participants in response to this question are outlined below.

Additional Support for FFCSSs:

A common view conveyed by participants was that supports for FFCSSs are lacking and more are needed. Many expressed a desire for '*more family supports*', while others highlighted the need for different kinds of supports including phone or online supports, the support of a key worker and/or social worker and supports geared towards developing their coping strategies and self-care skills.

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

"Any support for family would have been beneficial instead family left to care for individual on their own"

"A key worker that had regular concern about how I cope with supporting [them] and offering advice about how to manage depression in the home environment"

Some raised what they perceived as a complete lack of support for FFCSSs. The need for additional support for FFCSSs was further highlighted by those participants who emphasised the strain their caring role puts on them, be it financial, physical or indeed mental.

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

"There was no support for me to cope with what I was feeling but more importantly no education for me to help me help her"

Information, Advice and Education Services:

Another common view conveyed by participants was the need for mental health information, advice and educational services. Many participants indicated that they often felt '*lost*', '*overwhelmed*' and even '*fearful*' that they might '*do more harm than good*' in their role as a carer/supporter, and that more information, advice and education would help them better cope with, understand and help the person they support.

"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"



Related Qualitative Feedback:

Participants wrote of a need for general information and advice about how to care for and support a person experiencing mental health difficulties.

“Information on mental health, signs, symptoms and methods for supporting”

Others believed that detailed information about specific mental health difficulties and how best to support an individual experiencing these difficulties would be very beneficial.

“Coping support and advice on how best to support a person with a personality disorder”

Often describing crisis situations that they had found very difficult, some participants expressed that more information and advice for FFCSSs about what to do in case of a crisis was needed.

“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.”

“Information and support regarding prognosis[,] crisis intervention and medication”

Many felt that a contactable service geared towards answering questions from FFCSSs and giving informed advice could be an important and valuable resource.

“I needed someone to see me without her. To explain what was happening and what her diagnosis meant ...I have NO IDEA how to deal with this on a daily basis and as soon as the ECT [electroconvulsive therapy] worked she was discharged within DAYS - without any meeting or conversation with family. We have been destroyed by this, and continue to experience huge stress because of it”

“A simple phone number with someone AT THE OTHER END. It would have made such a difference”

Talking Therapy Services:

When asked if there was a service that they would have benefitted from but was unavailable to them, one of the most common types of services reported was talking therapy services. However, only some participants sought talking therapies for themselves, e.g. personal counselling, family or couples' therapy.

“Couple counselling/ Family therapy through HSE”

“Counselling and support for parents regarding how to manage his anxiety”

Many participants wrote of the need for more talking therapy for service users. Some believed that more therapy would be beneficial and a number of participants



highlighted specific types of talking therapy such as cognitive behavioural therapy (CBT) or dialectical behavioural therapy (DBT).

"The patient needs cognitive behavioural therapy and to see a doctor more frequently than once a month"

"Dialectical Behaviour Therapy for our son. Proper Family Therapy"

Out of Hours/Crisis Services:

As noted earlier, crisis MHSs were described by many participants as needed (see section 3.1.1 for more detail and sample quotes). Others believed that non-crisis services should also be available after working hours and at weekends.

"24 hour assistant needed ... should include weekends"

"The mental health clinic should be open at the weekend"

In a related point, some participants expressed a desire for more home care and respite services. This would allow carers (particularly those caring for a person 24/7) to have regular breaks which would be beneficial for many, given the regularly mentioned strains (financial, physical, and/or mental) experienced by many participants as a result of their caring role.

"A small amount of home care would be helpful"

"Respite care also because you totally burn out looking after them"

"Cover during Holiday time such as Christmas"

Services for Service Users:

Though the question referred to supports for the FFCS, many participants responded with what they perceived as shortcomings in the services provided to the person they support. These participants stressed the need for, and benefits of, specialist services equipped to meet the needs of people with particular mental health difficulties. For example, some participants highlighted a lack of accessible addiction services; others expressed a need for more MHSs to support people with autism, while some highlighted what they perceived as a lack of, and need for, services aimed at supporting those with experiences of trauma.

"Autism understanding and support"

"Support following post-traumatic stress"

"Addiction services, free or subsidised rehabilitation services"

Other examples included eating disorder specific services (e.g. dietitian services), obsessive compulsive disorder (OCD) specialist services and others. Participants also expressed their desire for more and/or improved child and adolescent MHSs, while some described difficulties accessing these services.



Related Qualitative Feedback:

“Adolescent in patient treatment”

“Child psychiatrist with CAMHS”

“CAMHS great but short on beds for inpatient care which my child needed 3 times”

Similarly, some participants expressed a belief that the person they support would have benefitted from the services of specific types of mental health professionals but were unable to access these services, e.g. a psychologist or an occupational therapist. Other wrote that a key worker for the person they support would have been beneficial.

“Psychologist services and CBT [cognitive behavioural therapy] services”

“Occupational Therapy for vulnerable young person”

“Yes, access to a key worker who knows all of his information ... When there is a concern or a crisis that is when a single key worker to contact would be very helpful”

Mediator/Communication Service:
Related to a desire for increased involvement in the treatment and care of the individual they support, many participants expressed a desire for a mediation service or simply better communication between themselves and members of the mental health team of the person they support. These participants expressed that, in many cases, enhanced communication would be very beneficial,

for themselves, the service user and the service provider, resulting in increased partnership and improved care and support of the service user.

“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”

As noted in section 3.1.2, some participants described how patient confidentiality was a barrier to their involvement in the treatment and care of the person they support. Others described how difficult it can be when there is little or no communication between the mental health team and the carers/supporters.

“I was left completely on my own. Even when I was trying to contact nurses or therapist to express the worries about my partner, I was completely ignored. I felt so lonely in all the situation and so many times in crisis myself”

Peer Support Services:

Many participants expressed a desire for more peer support services to be available for FFCSSs, including group therapy. Others expressed that simply talking to someone who has experienced difficulties similar to their own would be very beneficial and may serve to reduce feelings of isolation, while simultaneously increasing their social support network.



“Formalised peer support at initial stages”

“Support of a peer group going through the same as me”

“Came across space program, which offers group sessions for parents of teenagers who self-harm and [are] suicidal. We found this really helpful meeting other parents going through the same difficulties as us and having a safe space to share our hurt and experiences. Wish it went on for longer, miss that support since it finished”

Community-Based/Local Services:
There was a belief expressed by some participants that community-based and/or local MHSs were lacking. Many of these participants complained that the person they support was required to travel, sometimes long distances, to access necessary services. They expressed a desire for more and/or improved community-based and local MHSs, with some seeking more home visits by members of the mental health team.

“Family support groups in [names Irish county] nearest are Dublin or Louth”

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

“More support locally”

“A fully functioning Community based person centred MH [mental health] Service with domiciliary visits”

No additional services required:

With regard to other support services that may have benefitted them, a number of participants responded simply with ‘no’, ‘none’, or some variation thereof. Others stated that they did not require additional services but the person they support did.

“I am ok”

“I’m fine. My brother isn’t”

Other Services:

Other potentially beneficial services were reported by participants. Although less commonly raised, this does not mean that these services would be any less beneficial. For example, some participants wrote about the need for social inclusion supports for service users, e.g. housing and/or employment supports, while others perceived the need for and benefits of follow-up MHSs for both themselves and the person they support.

“Job search and placement for my son. A low grade sheltered housing”

“Sufficient follow up care on discharge from hospital and sufficient hand over of medication needs to subsequent carers”



Related Qualitative Feedback:

Positive experiences of supports for FFCSs:

As previously noted, participants were also asked about their positive experiences of HSE MHSs. Highlighting the importance of addressing the support needs of FFCSs, positive experiences shared by participants often related to the family specific supports they received. Some of these participants described how they felt that they and their family were supported by members of the mental health team and that the team was interested in their well-being, alongside the well-being of the person they support.

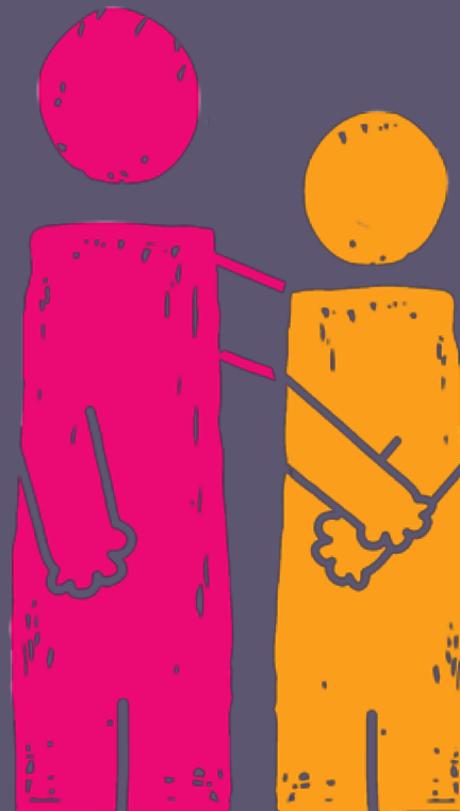
“A family therapist who focused on supporting me enabling me to support my child”

Others described how family counselling and/or individual counselling for family members was a very positive experience that helped them to cope in a difficult situation.

“Found the family therapy arranged some time following hospital time extremely helpful”

Some participants described the practical supports they received, e.g. education on how to support the service user. These practical supports were deemed important and beneficial and contributed positively to the experience of these FFCSs.

“Done a Family Connections Course⁶⁹ which I found very good”



69 A 12-week course providing education, skills training, and support for people who are in a relationship with someone who has Bi-polar disorder.

3.1.4: Views and Experiences of Inpatient Care:

Given that the inpatient-related questions focused on information and advice provided to FFCSSs, and the involvement and support needs of FFCSSs, these findings are reported in this subsection.

Almost half of all participants (48.3%; n=378) reported that the person they support had experience of inpatient care in the last two years. Of these, approximately six in ten (58.4%) reported that this was voluntary experience, while approximately one in five (21.4%) reported that it was involuntary experience or that the person they support had both voluntary and involuntary experience of inpatient care (20.3%).

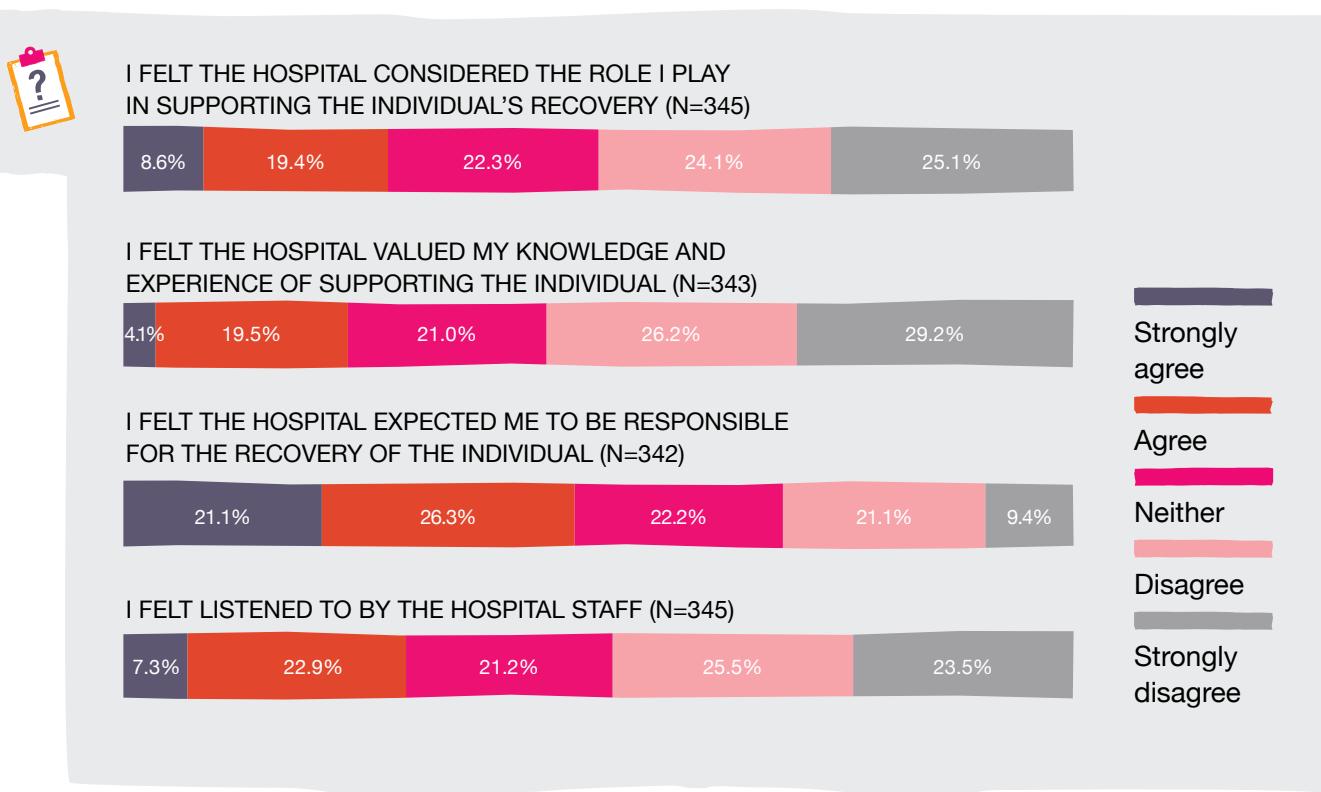
Participants who reported that the person they support had experience of inpatient care were presented with a series of statements and asked to indicate the extent to which they agreed with these statements (see figure 3.12).⁷⁰

47.4%

felt that the hospital expected THEM to be responsible for the recovery of the person they support.



Figure 3.12: FFCSSs' experiences of inpatient MHSs.



⁷⁰ In each case, participants had the option to respond 'I was not involved'. The proportion of participants who took this option ranged from 7.4% to 8.3% across the four questions. These and missing responses were excluded from the figures reported here.



In each case, more participants gave negative responses than positive responses. For example, almost half (49.0%) disagreed that they 'felt listened to by hospital staff', while under a third agreed (30.2%). Similarly, 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.

Participants supporting a person with experience of inpatient care in the last two years were also presented with a series of questions relating to the discharge of the person they support from inpatient care. Approximately six in every ten (57.8%) reported that MHSs did not involve them in the discharge planning for the person they support, while over one in ten (12.7%) reported that they were not involved, either by their choice (5.0%) or by the choice of the person they support (7.7%). Approximately three in every ten (29.4%; n=111) reported that they were involved in the discharge planning for the person they support.

Of those who reported that they were involved in the discharge planning for the person they support, four in 10 participants (39.1%) reported that 'all' (16.4%) or 'most' (22.7%) of their views and concerns were taken into account in the discharge planning process. Six in every ten participants (61.0%) reported that 'some' (45.5%) or 'none' (15.5%) of their views and concerns were taken into account.

Again, of those who reported that they were involved in the discharge planning for the person they support, over one-third (35.5%)⁷¹ reported that, before discharge, their support needs had been identified by the mental health team, while approximately two-thirds (64.5%) reported that, before discharge, their support needs had not been identified by the mental health team.

When asked if they had been given a minimum of two days' notice of the discharge of the person they support, a majority of participants who had been involved in the discharge planning (approximately six in every 10 or 61.8%) reported that they were given two days' notice. Three in every 10 participants (30.0%) reported that they were not given two days' notice and 8.2% reported that they sometimes received two days' notice.

With regard to follow-up after discharge, of the participants who reported that they were involved in discharge planning, seven in every ten (70.9%) reported that the person they support was notified of a date for a follow-up appointment before discharge. Less than one in five (18.2%) reported that this was not the case and 7.3% reported that the person they support was 'sometimes' notified of a date for a follow-up appointment before discharge (don't know/can't remember: 3.6%).

3.2: Views on the Care Received by the Person Being Supported

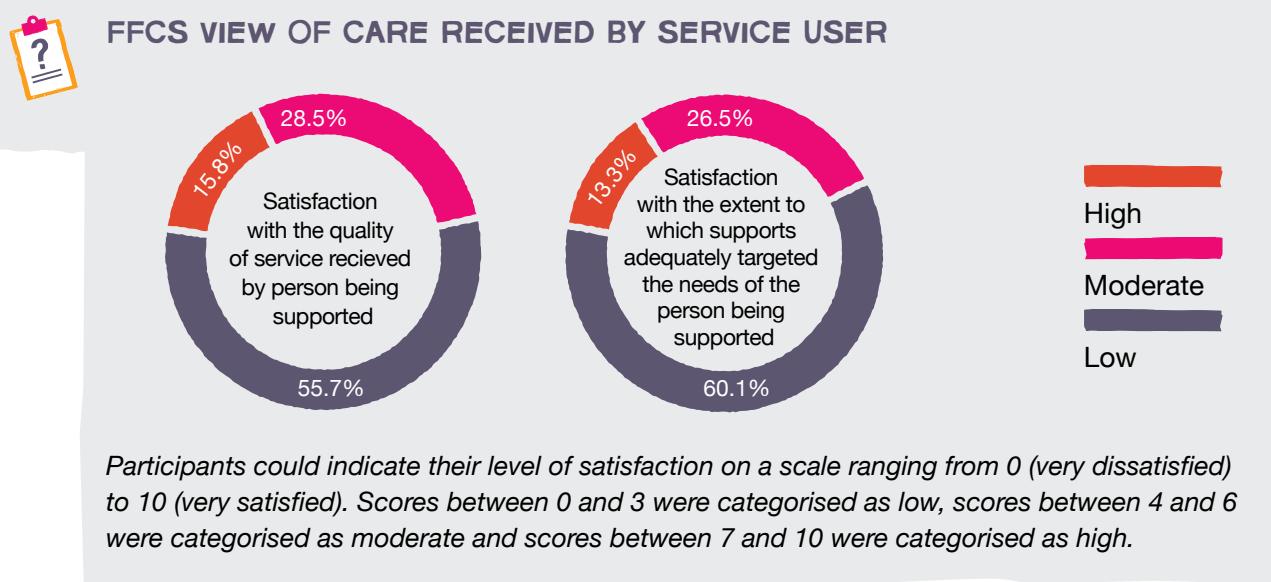
This section outlines findings relating to FFCSSs' views of the care provided to the individual they support. It is organised into two subsections: FFCSSs' views on care provided to service users and experiences of the transition from child and adolescent mental health services (CAMHSs).

3.2.1: Views on Care Provided to Service Users:

Participants were presented with a number of survey questions relating to the care received by the person they support (see figure 3.13 for examples). The findings relating to these questions are outlined below.

71 This is a composite of all 'yes' (16.4%) and 'yes, sometimes' (19.1%) responses.

Figure 3.13: Highlights relating to FFCSs' view of the care received by the person they support.



When asked to indicate their level of satisfaction with the quality of service received by the person they support⁷², more than half (55.7%) of participants reported low levels of satisfaction. More than one in four (28.5%) reported moderate levels of satisfaction and one in six (15.8%) reported high levels of satisfaction. On average, participant satisfaction with the quality of service received by the person they support was low ($M=3.36$; $SD=2.83$).⁷³

Participants were also asked how satisfied they were that HSE MHSs had provided the individual with supports that adequately targeted their needs.⁷⁴ Six in 10 (60.1%) reported low levels of satisfaction, approximately one in four (26.5%) reported moderate levels of satisfaction and approximately one in seven (13.3%;

see figure 3.13) reported high levels of satisfaction. On average, participants were dissatisfied with the extent to which HSE MHSs provided the person they support with supports that adequately targeted their needs ($M=3.08$; $SD=2.74$).⁷⁵

Participants were also asked if the person they support had received adequate help during a crisis. Some 61.7%⁷⁶ reported that they had contacted community mental health services during a crisis, while 38.3% reported that they had not contacted community mental health services during a crisis. Of those who had made contact, half (50.8%) indicated that the person they support did not receive the help they needed as a result. Over a third (37.0%) indicated that they had received some help/advice and over one in 10 (12.3%) indicated that the person they support got the help they needed as a result.

72 Scored on a scale ranging from zero (very dissatisfied) to ten (very satisfied). Scores between 0 and 3 were categorised as low, scores between 4 and 6 were categorised as moderate and scores between 7 and 10 were categorised as high.

73 This M and SD are based on an 11-point rating scale ranging from zero (very dissatisfied) to ten (very satisfied).

74 Scored on an 11-point rating scale ranging from zero (very dissatisfied) to ten (very satisfied). Scores between 0 and 3 were categorised as low, scores between 4 and 6 were categorised as moderate and scores between 7 and 10 were categorised as high.

75 This M and SD are based on an 11-point rating scale ranging from zero (very dissatisfied) to ten (very satisfied).

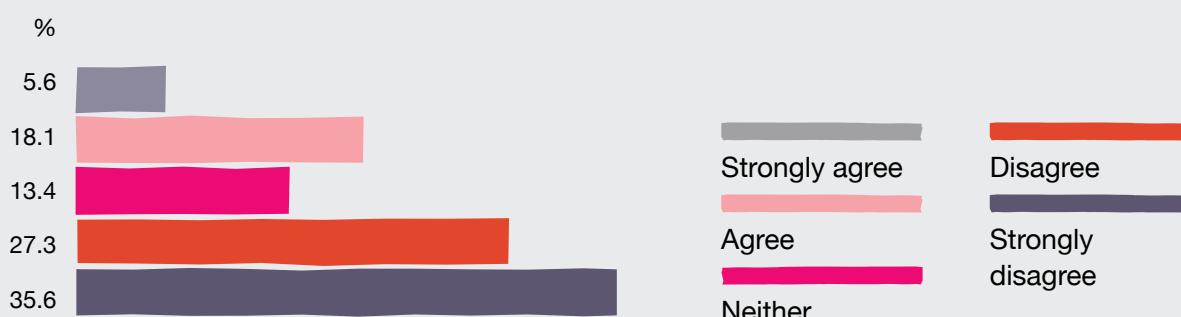
76 This equates to 465 participants.



Approximately four in every ten participants (43.5%) reported that the person they support had presented at an Emergency Department (ED) with a mental health difficulty in the last two years. These participants were asked if the person they support had received support that adequately addressed their needs when they did so. Less than one in four (23.7%) agreed, while a majority of almost two in three (62.9%) disagreed (see figure 3.14). On average, participants disagreed that the person they support received support that adequately addressed their needs when they sought help for their mental health difficulty in an ED ($M=3.69$; $SD=1.28$).⁷⁷

Figure 3.14: Perceptions of ED care for mental health difficulties.

IN THE LAST 2 YEARS, WHEN THE PERSON YOU SUPPORT SOUGHT HELP FOR THEIR MENTAL HEALTH DIFFICULTY IN AN EMERGENCY DEPARTMENT, THEY RECEIVED SUPPORT THAT ADEQUATELY ADDRESSED THEIR NEEDS



Of those who had made contact with CMHSs during a crisis, over **HALF**

50.8%

indicated that the person they support did not receive the help they needed as a result..

⁷⁷ This M and SD are based on a five-point rating scale ranging from one (strongly agree) to five (strongly disagree).



The quantitative findings were predominantly negative with regard to FFCSSs' perceptions of the care received by the person being supported. However, participants were specifically asked, through an open ended question, about what kind of positive experiences they had of the HSE MHSs. As a result, many participants shared positive experiences relating to the care and treatment of the person they support. It should be noted that it is not clear whether these experiences were the exception or the norm for these participants. It should also be noted that participants were not specifically asked about their negative experiences. Although this may have resulted in positively skewed qualitative feedback, in response to both open-ended questions, many participants took the opportunity to share negative experiences they had had or to raise what they perceived as important issues relating to the provision of MHSs in Ireland. Where possible, this feedback is reported alongside the positive feedback in an effort to provide a balanced view.

Therapies and Facilities:

Despite being asked about their own positive experiences, these participants described how particular therapies and/or facilities had had a positive impact on the person they support. Participants wrote about how specific types of therapies had been beneficial for the person they support, while some also wrote of the benefits of therapy for FFCSSs. These therapies included (but were not limited to) different types of talking therapy (e.g. CBT, DBT and schema therapy), medication, support groups, as well as alternative therapies, like music therapy, art therapy and exercise.

"Psychotherapy was fantastic, made a real difference"

"My daughter received DBT. We received helpful family therapy"

"Art therapy & gym/exercise in the DOP [Department of Psychiatry]"

Others alluded to how therapies that benefitted the person they support had knock-on benefits for them as well.

"Art therapy, yoga etc were arranged [for the person being supported]. These allowed me time to have a cuppa with my friends and a bit of a moan. Being a carer 24-7 is not good for my health but a day unit etc gives me a break - more please"

As regards HSE MHS facilities, these participants shared their view that the facilities were, in their experience, of a good standard. Day hospitals and community care facilities in particular were described positively by these participants.

"Having seen the inpatient facilities available in two different hospitals, I was in some way relieved to see the upgraded facility in [names Irish county] at least provided a degree of comfort and dignity for the patients, which cannot be said for [names hospital]"

Crisis Care:

As noted in sections 3.1.1 and 3.1.3.1, when asked whether there were any



Related Qualitative Feedback:

services that were not available to them that they would have benefitted from, crisis MHSs were described by many participants as needed. These participants wrote of their desire for, better crisis care, specialist 24/7 crisis services, better support and advice for FFCSSs on what to do in case of a crisis, and a service or professional that could be contacted at any time in case of, or leading up to, a crisis (see section 3.1.1 and 3.1.3.1 for sample quotes).

Although many participants conveyed the need for more and/or better crisis services that would be available whenever needed, when asked about their positive experiences of HSE MHSs, some participants wrote positively of their experiences of crisis care. Reflecting the minority who agreed that the person they support had received support that adequately addressed their needs when they sought mental health specific care from an ED (see figure 3.14), some participants wrote positively about the accident and emergency services and/or the staff of these services.

"A&E service in [names Irish county] children's hospital excellent"

"A&E staff and high dependency unit staff & consultant very supportive of my son"

Others described how the person they support received specialist crisis care and support when needed, either through a key worker or a specialist mental health professional.

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

"Current psychiatrist has stayed in contact over weekends and late in evening on a couple of crisis occasions, despite very obvious chronically busy workload"

Continuity of Care:

Many participants expressed frustration at what they perceived as excessive staff rotation and the potentially detrimental effect this can/did have on the treatment and care of the person they support.

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

"Regular changing of doctor was distressing for patient"

Many wrote of a lack of continuity of care received by the person they support. These participants highlighted what they perceived as a lack of cooperation or communication within and between MHSs which could/did result in the person they support having to be re-assessed, leading to delays in their treatment and care, as well as frustration and stress for both service users and their FFCSSs.

"More communication between all organisations"

"All services involved with an individual need to be talking with the person and each other, in a multi d [multi-disciplinary] approach with person present"



"We had a new junior adult doc on all her A&E visits some lovely some awful and a new full assessment to be done on each visit....madness"

In a related point, when asked about their positive experiences of HSE MHSs, some participants wrote positively about the follow-up and outreach care received by the person they support post discharge from acute inpatient MHSs.

"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"

"Community nursing staff that came to the house after leaving hospital were excellent and supportive. GP was good in the crisis situation"

In direct contrast, others wrote about what they perceived as a lack of follow-up care provided to them and/or the person they support post discharge from inpatient MHSs.

"Follow up following discharge ... No sign of public health nurse"

"On discharge the family were not invited to a family MDT [multidisciplinary team] meeting which was mentioned but never happened, this was much needed at the time. We also received no support when this person was discharged"

Recovery:

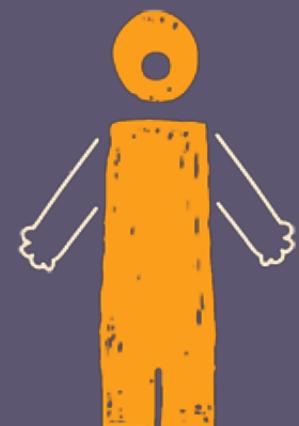
These participants wrote of how HSE MHSs had supported and facilitated the recovery of the person they support, with some indicating that this had enabled the person they support to return to work or education.

"My sibling has benefited for good care and recovery programs and is currently preparing to go back to work"

"Supported siblings recovery"

Some of these participants also wrote of how HSE MHSs had helped the person they support to live relatively independently and to cope with or better manage their difficulties day-to-day.

"At first I was very concerned - what would his care be like in the public sector? But he is very well cared for in the big scheme of things. He is treated with dignity and respected, supported to live as independently as possible, and has access to quite a few resources, especially in a crisis"





3.2.2: Experiences of the Transition from CAMHSs to Adult MHSs:

Approximately one in four participants (26.2%; n=204) reported that the person they support had accessed CAMHSs. Of these, approximately two-thirds (68.3%; n=138) reported that the person they support had been discharged from CAMHSs. Participants who reported that the person they support had been discharged from CAMHSs were presented with a list of issues relating to the transition of the person they support from CAMHSs to adult MHSs. The most common issue experienced was not having a follow-on key worker identified for the child/young person (60.9%), closely followed by a lack of support for participants as carers (58.0%). Eight percent reported that the person they support had not experienced any issues during their transition from CAMHSs to adult MHSs. Table 3.1 below summarises their responses.

Table 3.1: Issues experienced upon discharge from CAMHSs as reported by those who reported that the person they support had been discharged from CAMHSs.

Issues upon Discharge:	% who experienced these issues
No follow-on key worker identified for child/young adult:	60.9%
A lack of support from HSE MHSs for them as a carer:	58.0%
A gap in the support available:	42.8%
The person they support had to re-enter the system as an adult and required re-assessment:	34.1%
No referral or an issue with referral that meant they couldn't access follow-on MHS:	34.1%
Big change in environment between CAMHSs and adult MHSs:	22.5%
Person continues to use CAMHSs because adult MHSs were not suited to their needs:	3.6%
No Issues:	8.0%



3.3: Additional Qualitative Findings

The open-ended questions included in this survey gave participants the opportunity to express their views and answer in greater detail than did the closed ended questions on the survey. As noted, many participants responded to the open ended questions with feedback that was not specific to the questions asked. Instead, many chose to share negative experiences they had had or to raise what they perceived as important issues relating to the provision of MHSs in Ireland, the most prevalent of which are described below.

3.3.1: Involvement in Mental Health Service Planning

As noted in section 3.1.2, many participants used the open-ended questions to describe their involvement (or lack thereof) in the treatment and care planning of the person they support. See section 3.1.2 for more detail.

3.3.2: MHS System:

One of the issues reflected in the qualitative feedback was a poor perception of the mental health system. In response to both open-ended questions, participants often wrote of what they perceived as a poor system. Some wrote in very general terms, referring to a ‘flawed’, ‘broken’ or ‘faulty’ system.

“After several misdiagnosis and the resulting withdrawal of services at a critical crises point as “he was not engaging in process”... not a lot of good I can say. Some individuals in the system work as best they can but the system is so wrong”

“Individual committed staff in a dysfunctional uncaring system”

“Many of the staff nurses are trying their best in a bad system”

Others wrote more specifically about an ‘under resourced system’ with staff shortages, funding shortages and/or poor facilities, while others wrote negatively about what they perceived as a medication orientated system.

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

“The staff do their best but are severely underfunded and under resourced”

“Great staff in substandard facilities”

“The staff are engaging; however, emphasis is still very much on medication without adequate and sufficient talk therapy. Staff do what they can, but resources are extremely limited”

As evident above, when raising these issues, many of these participants also wrote positively about frontline staff working in the MHSs for their care, dedication and professionalism, despite the shortcomings in the system.

“Some dedicated and compassionate individuals like community mental health nurse have [helped/improved] my experiences with mental health services but they are limited in what they can do by working in a flawed, poorly run system”



Related Qualitative Feedback:

"I have had no negative experiences with individuals on the team. It's the broader system that can be frustrating and I think individual staff do their very best to work around a lot of system constraints"

3.3.3: Access Issues:

When asked about their positive experiences of HSE MHSs, some participants shared positive experiences, in which the person they support was able to access required services in a timely manner. These participants often described the swift response of MHSs when contacted and the speed with which the person they support had been assessed. Others wrote of the ease with which therapies had been accessed and/or the lack of significant delays accessing specialist MHSs.

"Early intervention is critical, an appointment within 2 weeks of referral from GP to camhs was significant to the illness been diagnosed and supported from an early stage and ensured it did not get to crisis level"

"Great GP referral and instant access to assigned psychiatrist"

A number of participants conveyed experiences where the person they support had been quickly admitted to acute services when needed, while others wrote of how members of the mental health team were easily contacted and accessible.

"Emergency appointment through GP referral"

"Fast admittance to psych ward"

However, despite being asked about their positive experiences, participants commonly and without prompt described difficulties accessing the services and supports required by themselves and the person they support. Some spoke in general terms about these barriers or difficulties.

"A mental health care coordinator who would provide a clear pathway to access services"

"Barriers put in front of you at every opportunity"

Others referred specifically to difficulties with hospital admissions, accessing specific mental health professionals or therapies and getting referrals.

"Help with admissions. We are finding it increasing difficult to get my mother admitted to psych ward when is unwell and a serious danger to herself and others ... The process can drag on for weeks, which is crazy, painful, and very mentally unhealthy for all the family"

"Very poor access to consultants"

"CBT counseling through the HSE not having to go private"

"It was difficult to get a referral to access the system but once in the system they try to do their very best"



Some wrote of the lack of locally available services and supports which increased the need to travel and reduced the accessibility of services and supports, particularly in rural areas.

"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 [names location] and it's rural"

However, the most common barrier to accessing MHSs raised by participants was excessive waiting times. Some of these participants wrote about the detrimental effect waiting times/lists can have, while others indicated that they were compelled to access required services and supports through private MHSs.

"The waiting lists for all services are too long"

"Care plan in place before discharge, not put in a list to wait. Things go wrong again whilst waiting and then it's back to square one"

"I am on a waiting list since October to get support for myself as to how best to deal with the person I am support[ing]. As of today I still don't have an appointment with this service. I ended up taking the person I support to private services"

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

3.3.4: MHS Staff:

When asked about their positive experiences of HSE MHSs, positive experiences with staff were by far the most common type shared. Participants often wrote positively about individual staff members that had been '*helpful*', '*positive*' or '*supportive*' both to the person they support and to them as well.

"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"

Other participants described how particular staff members built a '*connection*' or '*relationship*', both with the service user and their family and/or carer/supporter.

"The Child Psychologist was competent and approachable. He fostered a relationship of trust with my child. However, 8 sessions are not enough"

In contrast and despite being asked about their positive experiences, participants commonly and without prompt raised issues and/or difficulties they had experienced with MHS staff. Some expressed dissatisfaction with what they perceived as poor communication between staff (at various levels) and the FFCSSs of service users. Others wrote about what they perceived as a lack of time for both service users and their FFCSSs, and a lack of consideration of their support needs.



Related Qualitative Feedback:

"After many phone calls psychiatrist returned a call but had to cut it short as he had another meeting scheduled. Call lasted about 5 minutes"

Some participants also expressed a belief that HSE MHS staff needed to be better trained, while others described situations whereby they disagreed with staff and then felt ignored.

"Staff are not trained correctly"

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

However, it should be noted that these participants often attributed this lack of time to staff's 'workload' or the system in which they worked, while others wrote positively about some staff and negatively about others.

"Most of the nurses are capable, hard-working and committed. They are overworked, exhausted and undervalued. But most are excellent at their jobs and are the ones holding the system together"

"Some of the staff who are under dreadful pressure were excellent. Others including one nasty doctor downright rude and unhelpful"

"Some individuals have been nice but system is faulty, so overall treatment is poor"

3.3.5: Continuity of Care:

Many of these participants expressed frustration at what they perceived as excessive staff rotation and the potentially detrimental effect this can/did have on the person they supported. Many also highlighted what they perceived as a lack of 'cooperation' or 'communication' between MHSs (see section 3.2.1.1 for more detail and sample quotes).

3.3.6: Other Issues:

A variety of other issues were raised by participants in response to these open-ended questions but with less regularity than those outlined above. These included (but were not limited to) the following: the need for 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.

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

"Any kind of support at all. 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"



DISCUSSION





4. DISCUSSION

In this chapter, a discussion of the findings is presented in the context of mental health policy. The discussion is organised around the themes of information and advice, involvement in mental health service planning, support needs of FFCSSs and views on the care provided to the service user.

4.1: FFCS Experience

4.1.1: Information and Advice:

Findings relating to the information and advice provided to FFCSSs were stark. More than two in three participants reported being dissatisfied with the information and advice they received when the person they support first came into contact with the MHSs. Three-quarters of participants disagreed that HSE MHSs explained how to support the person in the long-term. Only one-third reported being given any information about what to do in the event of a crisis and, of these, less than half found the information useful. Just one in six participants reported that they had been given information by the HSE MHSs about available support groups for families and carers and nearly three in four reported that they had not been given this information.

It is important to note, however, that of those who were provided with information on support groups, the majority found it useful. Furthermore, more than eight in ten of those who had not received any information about available supports reported that they would have liked to. Finally, an overwhelming majority of more than eight in ten participants reported that no-one in HSE MHSs had let them know how to make a complaint about the services.

The lack of and desire for more and/or

better information and advice was also evident in the qualitative feedback. When asked whether there were any services that were unavailable to them that they believe they would have benefitted from, many participants highlighted the need for mental health information, advice and educational services. Many FFCSSs expressed a need for information of either a general or more individualised nature to enable them to better support the service user and enhance their own coping skills. In particular, participants reported a considerable need for more information and advice on what to do in the case of a crisis. Many felt that a contactable service geared towards answering questions from FFCSSs and giving informed advice could be an important and valuable resource.

The Expert Group on *A Vision for Change* recommended that “ongoing, timely and appropriate information [be provided by the MHSs] to both service users and carers”.⁷⁸ The Expert Group recognised that there may be times when FFCSSs’ information needs will conflict with the individual’s right to privacy. However, in order to address this, “a way forward should be agreed to ensure that the needs of the carer and family are also met”.⁷⁹



78 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office, p.31.

79 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office, p.30.

..participants reported a considerable need for more information and advice on what to do in the case of a crisis..

The requirement to provide information and advice to FFCSSs is also reflected in the MHC Quality Framework⁸⁰ and has been promoted by other organisations, such as Shine, the national organisation dedicated to campaigning for the rights and empowerment of all people affected by mental ill health.⁸¹

Despite a recognition in national policy that FFCSSs can play a valuable role in their relative/friend's care and recovery, such supporters continue to report challenges in communicating and engaging with the MHSs. While some FFCSSs may be getting information from the MHSs, the majority of this sample reported that they had not. The types of useful guidance that many of these FFCSSs are requesting include fundamental information on what to do in the event of a crisis, whereby FFCSSs often have to take sole responsibility for the care and safety of the person they support. There is an additional issue in terms of the quality of information provided; many participants who did receive information on what to do in a crisis did not find it helpful.

The EOLAS programme, funded by the HSE, is a mental health information and learning programme for service users with a diagnosis of schizophrenia, bipolar disorder or psychosis and their FFCSSs. While this initiative is positive, it is currently limited in providing support to FFCSSs in all parts of the country and to those who are supporting people with different types of mental health difficulties to those listed above. Based on the survey findings,

it appears that national policy on providing information to FFCSSs has not been fully implemented and requires further attention. Finally, it is imperative that all FFCSSs be advised of available support groups in their local communities. Where support groups do not exist, arrangements should be made to ensure access to family/carer/supporter peer groups as set out in the Best Practice Guidance for MHSs.⁸² Importantly, the findings show that there is a demand for information on support groups, and where it has been provided, the majority of survey participants found it useful.

4.1.2: Involvement in Mental Health Service Planning:

Findings relating to the involvement of FFCSSs in the care and treatment of the person they support were mixed, indicating considerable variation in the experiences on FFCSSs in this regard. When asked if their views had been incorporated into the individual's recovery/care plan, almost half reported that none of their views had been incorporated by the community mental health team.

In response to the survey open ended questions, one of the key issues raised by participants was their lack of involvement in the treatment and care of the person they support. Some participants described how their views were 'not taken on board', 'ignored' or 'not appreciated', while others described how they had had little or no contact with the person's mental health team. Highlighting the positive impact increased FFCSSs' involvement can have,

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

81 Shine. (2014). *Guidelines for realising a family friendly mental health service*. Dublin: Shine.

82 HSE Mental Health Services. (2017). *Best practice guidance for mental health services: Supporting you to meet regulatory requirements and towards continuous quality improvement*. Dublin: HSE MHS.



when asked specifically about their positive experiences of HSE MHSs, other participants described how the services had facilitated and even encouraged their involvement in the care and treatment of the person they support.

As far back as 1984, the policy document *Planning for the Future* identified that “families of patients...should be regarded as part of the psychiatric team”.⁸³

“As relatives are centrally involved in caring for the patient [sic.], they should be given a role in assessing progress and in planning care. Their knowledge and judgements should be taken into account by the psychiatric team”.⁸⁴

A Vision for Change reinforces this ethos of involvement by recommending that families and carers be involved at every level of MHS delivery.⁸⁵ The MHC’s Quality Framework also sets standards for the involvement of FFCSs in their relative/friend’s care and the HSE’s recent series of recovery documents provides specific guidance on involving FFCSs.

Findings from the survey also showed the extent to which FFCSs felt involved by the services where the person they support went into hospital for mental health care/treatment. Approximately half of all participants disagreed that they ‘felt listened to by hospital staff’, that they ‘felt the hospital valued [their] knowledge and experience of supporting the individual’ and that they ‘felt the hospital considered the role [they] play in supporting the individual’s recovery’. Just under half of participants

reported that they ‘felt the hospital expected [them] to be responsible for the recovery of the individual’.

FFCSs also reported on their experience of the discharge of the person they support from hospital, and their involvement in this process. A minority of less than one in three reported that they were involved in the discharge planning process; however, among those who were involved, a majority of more than eight in ten reported that their views and concerns were taken into account, at least to some extent. However, as part of the discharge planning process, only approximately one third of participants stated that their own support needs had been identified by the mental health team.

In an effort to identify if ‘confidentiality’ was a barrier to FFCSs’ involvement, participants were asked to report the extent to which this has or has not been the case. While over four in ten participants reported that confidentiality had ‘never’ been a barrier, nearly six in ten participants stated that it was either ‘sometimes’ or ‘always’ a barrier to involvement. This was echoed in the qualitative findings, where some participants expressed their view that confidentiality could be/was a barrier to their involvement in the treatment and care of the person they support.

Despite national policy and standards on FFCS involvement, the findings from this survey indicate that there is a severe lack of consistency across community mental health teams regarding this aspect of service delivery. The absence of a standardised approach to implementing national policy at local level has resulted in many FFCSs feeling isolated by the MHSs. The evidence indicates that many participants are not being involved at any level of MHS delivery. At a systems level, approximately three-quarters of survey participants disagreed that they were involved in service improvement.

83 Department of Health and Children. (1984). *Planning for the future*. Dublin: The Stationery Office, p.13

84 Department of Health and Children. (1984). *Planning for the future*. Dublin: The Stationery Office, p.13

85 *A Vision for Change* sets out that family members be involved in the care planning process with the agreement of the service user, as well as inclusion in the discharge planning process. See: Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office.

.there is a demand for information on support groups, and where it has been provided, the majority of survey participants found it useful..

However, the findings also show that where FFCSSs have been involved, for example, in hospital discharge planning, the vast majority perceive that their views are taken into account at least to some extent. This suggests that improvement in the experience of FFCSSs is possible with more consistent application of relevant guidance.

It appears from the research findings that there is a desire among many of the survey sample for increased involvement in the care and treatment of the person they support. Some participants expressed that enhanced involvement of FFCSSs would benefit not only the person being supported but the mental health team as FFCSSs could provide ‘insight’ or ‘background’ into the person they support and what may work for them.

The recommendations on FFCS involvement as set out in *A Vision for Change*⁸⁶ are not as strong as those in *Planning for the Future*.⁸⁷ However, there are numerous resources which provide practical guidance for MHSs to effectively involve FFCSSs. The HSE’s Best Practice Guidance for MHSs includes recommendations on families and carers being involved in the assessment, treatment and support, discharge planning and individual care planning of the person they support.⁸⁸ Similar guidance is reflected in the HSE’s *Family Recovery Guidance*

document, in addition to recommendations on involving FFCSSs in service development and change.⁸⁹

While the confidentiality and privacy of the person engaged in MHSs must be respected, involvement of FFCSSs in the recovery/care planning process should be encouraged in all circumstances, and enabled whenever the person consents. Of concern, the majority of participants stated that ‘confidentiality’ was at least sometimes a barrier to their involvement. In international jurisdictions the issue of confidentiality is approached as an ongoing process – one which is negotiated with the service user and FFCSSs on a continuous basis. Such an approach should be developed in the Irish context.

4.1.3: Support Needs of FFCSSs:

On average, participants were dissatisfied with how the HSE MHSs had considered their support needs, with approximately seven in ten reporting dissatisfaction. Similarly, approximately nine out of ten participants reported that their physical well-being, emotional well-being and coping skills had neither been assessed nor addressed by the HSE. Approximately one in four indicated that they had the contact details of a key worker in the HSE MHS, while almost three in four reported that they did not.

86 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office.
87 Department of Health and Children. (1984). *Planning for the future*. Dublin: The Stationery Office.
83 HSE Mental Health Services. (2017). *Best practice guidance for mental health services: Supporting you to meet regulatory requirements and towards continuous quality improvement*. Dublin: HSE MHS.

89 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.



When asked about the types of supports they had accessed, including those outside of specialist MHSs, almost half of survey participants reported that they had not accessed supports of any kind. Among those who had accessed supports, those most commonly availed of were individual counselling, peer support groups and family therapy/counselling. Less than one in ten had experience of family mental health education, online and/or listening supports and just one in 20 had accessed advocacy support services. Of those who were not accessing supports, almost six in 10 indicated that they were not aware of available supports, while approximately one in four reported that no supports were available to them.

When asked to identify any services that were not available to them, but would have been of benefit, participants reported a range of different family supports, including talk therapies to support their own mental health needs, access to a key worker, peer supports, family support groups, respite services, and liaison officers to promote communication between FFCSSs and the services. Many participants simply expressed that there was a dearth of available supports for FFCSSs and many more were needed. The need for additional supports for FFCSSs was further highlighted by those participants who emphasised the strain their caring role puts on them, be it financial, physical or mental.

It is now widely recognised that FFCSSs are inevitably impacted by the mental health and social outcomes of the person they support,^{90,91,92} including those children whose parent has a

- 90 Mental Health Reform. (2013). *Recovery: What you should expect from a good quality mental health service*. Dublin: Mental Health Reform.
- 91 REFOCUS College of Psychiatrists of Ireland. (2013). *Who cares? Listening to the needs and experiences of carers of people with mental illness*. Dublin: College of Psychiatrists of Ireland.
- 92 Kartalova-O'Doherty, K., Doherty, D., & Walsh, D. (2006). *Family Support Study: A study of experiences, needs and support requirements of families with enduring mental illness in Ireland*. Dublin: Health Research Board.

mental health difficulty.⁹³ Cross country comparison by the Organisation for Economic Co-operation and Development (OECD) found that the prevalence of mental health difficulties amongst 'carers' was 20% higher than amongst non-carers.⁹⁴ Furthermore, a Scottish study found that unpaid 'carers' had twice the prevalence of long term illness and disability as the rest of the population and almost nine in every ten participants in the study reported stress, anxiety and depression.⁹⁵

A Vision for Change sets out some practical measures for the MHSs to support FFCSSs, including the provision of timely and appropriate information and education, planned respite care and the appointment of a member of the multi-disciplinary team to act as a key worker/designated point of contact with FFCSSs.

The importance of providing supports for FFCSSs due to the adverse effect of caring for a person with mental health difficulties has been highlighted by a number of national organisations, including the REFOCUS advisory group⁹⁶ hosted by the College of Psychiatrists, Shine⁹⁷ and the MHC.⁹⁸ These organisations have all produced guidelines, which offer very practical measures on supporting FFCSSs.

93 Higgins, A., & McDaid, S. (Eds). (2014). *Mental health in Ireland: Policy, practice and law*. Dublin: Gill and MacMillan.

94 Organisation for Economic Co-operation and Development. (2011). *Help wanted? Providing and paying for long term care*. Retrieved from https://read.oecd-ilibrary.org/social-issues-migration-health/help-wanted_9789264097759-en#page1

95 Carers Scotland. (2011). *Sick, tired and caring: The impact of unpaid caring on health and long term conditions*. Scotland: Carers Scotland.

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

97 Shine. (2014). *Guidelines for realising a family friendly mental health service*. Dublin: Shine.

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

.unpaid 'carers' had twice the prevalence of long term illness and disability as the rest of the population.. Carers Scotland (2011)

Notwithstanding specific recommendations in national policy on supporting FFCSSs, the experiences of the survey sample suggest that there has been inadequate implementation of such supports. The majority of participants reported not having contact details for a key worker, despite this being national policy for over 13 years.⁹⁹ Based on the findings from this survey, it would appear that there is a dearth of available supports for FFCSSs to promote their own mental health and well-being, indicating a need to invest in the development of a range of supports for FFCSSs.

4.2: FFCSSs' Views of the Care Provided to the Individual They Support

4.2.1: Views on the Care Provided to the Service User:

This section outlines a discussion of findings relating to FFCSSs views on the care received by the person they support.

4.2.1.1: Quality and Individualised Care:
Overall, survey participants reported low satisfaction levels with the care provided by HSE MHSs to the person they support. More than half of FFCSSs reported low levels of satisfaction with the quality of service received, and only a minority of one in six reported high levels of satisfaction. On average, participants were dissatisfied with the extent to which the services provided the person with supports that adequately targeted their needs. Six in every ten participants reported low levels of satisfaction with the

targeting of supports towards individual needs, and less than one in six reported high levels of satisfaction in this regard.

Although not directly related to the findings on satisfaction with the care received by the person they support, participants provided extensive feedback through open ended questions on their positive experiences of HSE MHS, which are of some relevance. Participants highlighted the positive benefits of specific therapeutic programmes and supports for service users, recovery orientated service delivery, the high standards of some HSE mental health facilities and effective follow-up and outreach care provided by the MHSs.

In direct contrast, others complained about the perceived lack of follow-up care provided to them and/or the person they support. Additional concerns raised included the lack of continuity of care, limited availability of non-pharmacological therapeutic supports and the absence of specific mental health interventions to adequately target the needs of the service user.

The Expert Group on *A Vision for Change* incorporated quality and individualised care as key principles underpinning national mental health policy. *A Vision for Change* sets out that “services should be person-centred and adapted to each individual’s needs and potential”.¹⁰⁰ This should be achieved in part through individual care and recovery planning and facilitated in partnership with those who use the MHSs and their FFCSSs.¹⁰¹ The Expert

⁹⁹ Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office, p.5.

¹⁰¹ Standard 1.1 states that each service user has an individual care and treatment plan that describes the levels of support and treatment required in line with his/her needs and is coordinated by a designated member of the multidisciplinary team, i.e. a key worker.

⁹⁹ Mental Health Commission. (2005). *Quality in mental health - Your views: Report on stakeholder consultation on quality in mental health services*. Dublin: MHC.



Group also recommended the provision of quality MHSs and that the “treatment and care offered in [the services] should be of the highest standards”.¹⁰²

The MHC’s Quality Framework¹⁰³ provides a tool to support continuous improvement of the quality of all MHSs. The Framework sets out clear guidance on what constitutes a quality MHS,¹⁰⁴ how to achieve quality services¹⁰⁵ and how to monitor and sustain such services. The Mental Health Regulations provided for under the Mental Health Act, 2001, although limited, set out minimum standards for approved centres in order to promote quality and safety in the delivery of inpatient services.

Most recently, the HSE’s Best Practice Guidance for MHSs aims to contribute towards ensuring that people who use MHSs receive a high quality, recovery oriented, safe service that is responsive to their needs.¹⁰⁶ Specifically, theme two of

102 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office, p. 15.

103 The Quality Framework was informed by the Commission’s Quality in Mental Health – Your Views which documented the views and perspectives of all stakeholders on what constitutes quality in MHSs. See: Mental Health Commission. (2005). Quality in mental health - Your views: Report on stakeholder consultation on quality in mental health services. Dublin: MHC.; Mental Health Commission. (2007). Quality framework: Mental health services in Ireland. Dublin: Mental Health Commission.

104 The Quality Framework has developed themes on what constitutes a quality service to include the following: 1. The provision of a holistic seamless service and the full continuum of care provided by a multidisciplinary team; 2. Respectful, empathetic relationships are required between people using the MHSs and those providing them; 3. An empowering approach to service delivery is beneficial to both people using the service and those providing it; 4. A quality physical environment that promotes good health and upholds the security and safety of service users; 5. Access to services 6. Family/chosen advocate involvement and support. See: Mental Health Commission. (2007).

105 The Commission’s Framework also provides guidance on what is needed to deliver quality services. It states that staff skills, expertise and morale are key influencers in the delivery of quality MHSs.

106 HSE Mental Health Services. (2017). *Best practice guidance for mental health services: Supporting you to meet regulatory requirements and towards continuous quality improvement*. Dublin: HSE MHS.

the guidelines promotes the delivery of “the best possible service, to achieve the best possible outcome for the service user in a meaningful and individualised way”.¹⁰⁷

Based on the findings outlined above, it would appear that many FFCSSs are of the view that the persons they support are not receiving a quality MHS, which appropriately meets the person’s individual needs. Their perspective is corroborated by the findings from the service user survey that complements this survey. This view is also reflected in a recent report of the MHC which identified that “much needs to be done to ensure the delivery of consistent, timely and high-quality services in all geographic regions and across the full range of clinical programmes and age groups”.¹⁰⁸ The Commission raised additional concerns about the “continuing inability of some services to put in place an individualised care plan and therapeutic programme, which are the cornerstone of a recovery focussed person centred service as per national policy”.¹⁰⁹

The shortcomings in services identified by FFCSSs are likely facilitated by the lack of statutory regulation and inspection of community mental health services. There is an urgent need to provide statutory regulation and inspection of community MHSs in order to ensure an adequate quality of MHS provision.

4.2.1.2: Crisis MHSs:

Access to crisis ‘out of hours’ MHSs was reported as a key issue by many participants. Of those who had contacted community mental health services during a crisis, over half indicated that the person

107 HSE Mental Health Services. (2017). *Best practice guidance for mental health services: Supporting you to meet regulatory requirements and towards continuous quality improvement*. Dublin: HSE MHS, p.9.

108 Mental Health Commission. (2018). *Mental Health Commission annual report including report of the inspector of Mental Health Services*. Dublin: MHC, p.5.

109 Mental Health Commission. (2018). *Mental Health Commission annual report including report of the inspector of Mental Health Services*. Dublin: MHC, p.4.

..lack of continuity of care, limited availability of non-pharmacological therapeutic supports and the absence of specific mental health interventions..

they support did not receive the help they needed as a result, while just over one in ten indicated that the person they support got the help they needed, suggesting that crisis supports should be improved. Similarly, of those who supported a person who presented to an Emergency Department with a mental health difficulty in the last two years, a large majority of almost two in three disagreed that the person received support that adequately addressed their mental health needs.

When asked whether there were any services that were not available to them that they would have benefitted from, more and/or better crisis supports were described by many participants as needed. Reflecting the above, these participants expressed a desire for better crisis care, 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.

On the other hand, when asked about their positive experiences of HSE MHS, a number of participants wrote positively of the crisis care services and their experiences of these services. However, when considered as a whole, findings suggest that these positive experiences of crisis services are in the minority.

A Vision for Change sets out clear recommendations on the need for 24/7 crisis mental health supports and, more recently, the suicide prevention framework *Connecting for Life*¹¹⁰ made a commitment to the provision of a coordinated, uniform and quality assured

24/7 service for individuals in need of mental health care. In addition, HSE Mental Health have included commitments to the development of 7 day responses and 24/7 crisis intervention arrangements in its Operational Plans since 2014.

The roll out of a seven day a week service across all general adult mental health teams in Ireland commenced in early 2018. Notwithstanding such progress, FFCSSs' experiences of crisis care reported in this survey show that there is an urgent need to continue to develop 'out of hours' services in every community to ensure people receive timely access to support when they are in crisis.

There remain significant parts of the country where there is no 7/7 or 24/7 response provided by community mental health teams. Often, the only option for individuals is to access Emergency Departments that are not an appropriate environment for people in mental distress. Mental Health Reform's report on service users' experiences of the MHSs indicates serious shortfalls in crisis services.

For many years, individuals have reported to Mental Health Reform that they have experienced long waiting times in Emergency Departments, a chaotic, distressing atmosphere, lack of training among Emergency Department staff in relation to mental health difficulties and a lack of follow on care upon discharge.

In a recent report,¹¹¹ there was considerable variation in recommended 'next care' or 'follow on care' by hospitals, where

¹¹⁰ National Office for Suicide Prevention. (2015). *Connecting for Life: report of the research advisory group for the national framework for suicide prevention strategy*. Dublin: HSE.

¹¹¹ Griffin, E., Dillon, C.B., McTernan, N., Arensman, E., Williamson, E., Perry, I.J., & Corcoran, P. (2018). *National self-harm registry Ireland annual report 2017*. Cork: National Suicide Research Foundation.



individuals attended with self-harm presentations, particularly in relation to the proportion of patients admitted to the presenting hospital, the proportion leaving before a recommendation had been made and the proportion receiving a mental health assessment. In particular, there were considerable differences, by hospital, in relation to the numbers of individuals admitted to hospital, the numbers leaving hospital before a recommendation had been made and the numbers receiving a mental health assessment. It is clear that the services envisaged in Connecting for Life, which are of vital importance to reducing suicide among people with a mental health difficulty, are not yet implemented consistently across the country.

4.2.1.3: Experiences of the Transition from CAMHSs to Adult MHS:

Participants who had experience of a person they support being discharged from CAMHSs were asked to respond to a series of statements about the transition from CAMHSs to adult MHSs, where applicable. More than six in ten participants reported that no follow on key worker had been identified for the child/young adult upon discharge. Almost six in ten stated that there was a lack of support from the HSE MHSs for them as a carer/supporter. More than four in ten reported that there was a gap in support after the child/young adult was discharged. Over one third indicated that ‘the person they support had to re-enter the system as an adult and required reassessment’ and that ‘no referral or an issue with re-referral meant they couldn’t access follow on MHS’. More than one in four indicated that there was a ‘big change in environment between CAMHSs and adult MHSs’. It should be noted that the proportion of the sample with the relevant experience to complete this section of the survey was small. Therefore, these findings should be interpreted with caution.

The CAMHSs Standard Operating Procedure (SOP) sets out clear guidelines for the MHSs to ensure the smooth transition of young people from CAMHSs to adult MHSs. This

includes incorporating a transition plan within the young person’s individual care plan if it is intended that their care will move to adult MHSs, joint working between CAMHSs and MHSs, in addition to involvement from the young person’s key worker to support the transition process. The CAMHSs SOP applies to children and young people accessing community and inpatient MHSs.

The transition from CAMHSs to adult MHSs can be a distressing experience for the young people and their families involved, as the adult system is significantly different to CAMHS, involving new care teams and care planning, new peers, and a new physical environment, regulated by new policies and procedures. Research shows that this transition occurs at a time (generally between 16-18 years) of heightened mental health vulnerability among the younger population, in the presence of diminished supports.¹¹² Echoing this, Patrick McGorry, founder of Headspace in Australia, has noted that “public specialist MHSs have followed a paediatric-adult split in service delivery... however, the pattern of peak onset and the burden of mental disorders in young people means that the maximum weakness and discontinuity in the system occurs just when it should be at its strongest”.¹¹³ Research shows the benefits of putting in place appropriate transitional arrangements and advocates the benefits of establishing youth specialist MHSs.^{114,115}

There is a consensus at national level, as set out in the CAMHSs SOP, on the requirement to ensure smooth transitions between

112 Cannon, M., Coughlan, H., Clarke, M., Harley, M., & Kelleher, I. (2013). *The mental health of young people in Ireland: a report of the Psychiatric Epidemiology Research across the Lifespan (PERL)*. Group Dublin: Royal College of Surgeons in Ireland.

113 McGorry. (2007). The specialist youth mental health model: strengthening the weakest link in the public mental health system. *Medical Journal of Australia*, 187(7), S53.

114 Sainsbury, M., & Goldman, R. (2011). *Mental health service transitions for young people: Children's and families' guide*. London: Social Care Institute for Excellence.

115 McGorry. (2007). The specialist youth mental health model: strengthening the weakest link in the public mental health system. *Medical Journal of Australia*, 187(7), S53.

..long waiting times in Emergency Departments, a chaotic, distressing atmosphere, lack of training among Emergency Department staff..

CAMHSs and adult MHSs. The findings from this survey, while arising from a small sample, underscore the need for implementation of transition arrangements between CAMHSs and adult MHSs. The gap created by lack of compliance with agreed standards has the potential to have considerable detrimental impacts on both the service user and their FFCSSs. There is an urgent need for enhanced collaboration between the CAMHSs and adult MHSs to improve the transition process and thereby, the mental health outcomes of young people engaged in MHSs in Ireland.

4.3: Methodological Strengths and Limitations

Mental Health Reform's *My Voice Matters* consultation with FFCSSs is the first national, large-scale survey in recent years to provide in depth and up-to-date feedback on the direct experiences of FFCSSs supporting people accessing community and inpatient MHSs.

4.3.1: Survey Design:

Considerable efforts were made to design a robust and accessible survey instrument. As noted in section 2.2, the survey was designed in a phased manner, which was an important strength of this research. As far as possible, survey questions were initially sourced from similar empirical research, e.g. the Caring for Carers Survey.¹¹⁶ Importantly, questions were also designed based on Mental Health Reform's previous consultations examining FFCSSs' experiences of the MHSs carried out

¹¹⁶ European Federation of Families of People with Mental Illness and KU Leuven. (2015). *Experiences of family caregivers for persons with severe mental illness: An international exploration*. Retrieved from http://www.eufami.org/c4c/c4c_reports/c4c_global.pdf.

across Ireland between 2011 and 2015. This helped to ensure the survey questions were meaningful and relevant to issues that were important to the carers and supporters of MHS users.

When designing the survey, researchers were aware that low literacy levels and/or language barriers may inhibit participation. Therefore, multiple in depth consultations¹¹⁷ with FFCSSs were carried out to ensure that the survey was as accessible as possible. However, the language barrier may have remained an issue for those with low levels of English. This may partially explain the low levels of participation among ethnic minority groups where English is not the first language.

Experts in both survey design and in the field of mental health were also consulted during the design of the survey, which served to further strengthen the survey instrument. The inclusion of open-ended questions afforded participants the opportunity to express their views and share their experiences in much greater detail. This in turn provided greater insight into the lived experiences of these FFCSSs and should be considered an important strength of this research.

The above resulted in a robust and accessible survey instrument which could serve to provide a valuable baseline against which to compare the results of future national consultations of this kind. However, this is not to say that the survey could not be further strengthened by addressing certain limitations.

The survey did not include a question to distinguish between those supporting someone accessing HSE MHSs and those

¹¹⁷ Two focus groups and 10 cognitive interviews with FFCSSs were carried out and changes were made to the survey based on feedback from these processes.



supporting someone accessing private MHSs only. To be clear, participants were asked whether the person they support had access to private MHSs of various kinds. However, indicating access to private services did not mean that the person they support was not also accessing public MHSs of some kind. This meant that a comparison of private and public MHSs was not possible. It is also possible that some participants who were supporting a person who had not accessed HSE MHSs in the last two years may have answered questions relating specifically to HSE MHSs. However, as survey questions which made specific reference to HSE MHSs were easily identifiable, this risk was modest and the number of cases where someone without relevant experience of HSE MHSs answered questions relating specifically to HSE MHSs was likely small. Even so, including a question designed to identify those with experience of private services only would avoid this issue in future consultations and facilitate an interesting comparison of the views and experiences of private only and public only FFCSSs.

The survey covered a variety of issues that may have been perceived as sensitive by participants. Therefore, some participants may have been uncomfortable or unwilling to answer these questions. For example, when asked to share the main diagnosis of the person they support, some answered that they would ‘prefer not to say’. However, the use of online surveys and assurances regarding confidentiality and anonymity likely served to reduce non-response rates for certain questions.

A small number of survey questions had missing responses exceeding five percent of the sample, perhaps indicating issues with these questions. These items should be examined and, if deemed necessary, changed to avoid similar issues in future consultations. Finally, although not inherently a limitation, the inclusion of validated scales (e.g. validated patient reported outcome measures) and the use of multiple-item measures of satisfaction could further strengthen the survey instrument.

4.3.2: Data Collection and Recruitment:

Although every participant had the option of requesting a paper version of the survey, the vast majority of participants completed the survey online. Research has found that online surveys have a number of inherent advantages over paper surveys, which were particularly relevant to, and served to strengthen, the present research. These include the following: online surveys can reach more potential participants quickly; they can reduce bias and measurement error as a result of questions relating to stigmatised topics (like mental health); and they can enhance participation of stigmatised populations.^{118,119,120,121} Research has also found that the quality of the data gathered via online surveys is at least as good as traditional survey methods.^{122,123} Online data collection was therefore an appropriate and effective method of data collection in this context, which facilitated recruitment.

Although the use of online surveys helped to recruit participants in this potentially difficult to access group, additional steps were taken to increase awareness of and participation in this research. Through its advocacy work, Mental Health Reform has developed a network of organisations, academic institutions and individuals who work directly with MHS users and their FFCSSs. Using snowball

118 McCabe. (2004). Comparison of web and mail surveys in collecting illicit drug use data: A randomized experiment. *Journal of Drug Education*, 34(1), 61-73. doi:10.2190/4HEY-VWXL-DVR3-HAKV.

119 McCabe, S. E., Boyd, C. J., Couper, M. P., Crawford, S. D., & D'Arcy, H. (2002). Mode effects for collecting alcohol and other drug use data: Web and U.S. mail. *Journal of Studies on Alcohol*, 63, 755-762. doi:10.15288/jsa.2002.63.755.

120 Rhodes et al. (2003). Collecting behavioural data using the World-Wide Web: Considerations for researchers. *Journal of Epidemiology and Community Health*, 57, 68-73.

121 Trau, R. N., Härtel, C. E., & Härtel, G. F. (2013). Reaching and hearing the invisible: Organizational research on invisible stigmatized groups via web surveys. *British Journal of Management*, 24(4), 532-541.

122 Gosling, S. D., Vazire, S., Srivastava, S., & John, O. P. (2004). Should we trust web-based studies? A comparative analysis of six preconceptions about Internet questionnaires. *American Psychologist*, 59, 93-104. doi: 10.1037/0003-066X.59.2.93.

123 Whitehead, L. (2011). Methodological issues in Internet-mediated research: a randomized comparison of internet versus mailed questionnaires. *Journal of medical Internet research*, 13(4). doi: 10.2196/jmir.1593.

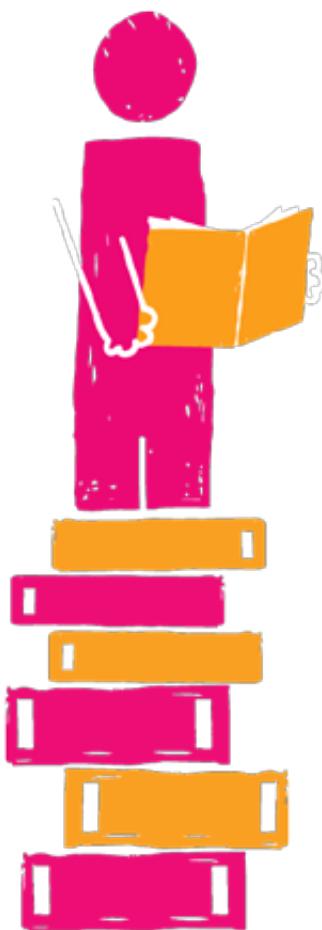
..based on the findings from this survey, it would appear that there is a dearth of available supports for FFCSSs to promote their own mental health and well-being, indicating a need to invest in the development of a range of supports for FFCSSs.

sampling methods, Mental Health Reform was able to draw on this extensive and well-established network to publicise this project and facilitate recruitment. Drawing on this extensive network also helped to combat a common criticism of snowball sampling, that the final recruited sample can be a reflection of/affected by the initial participants recruited or the starting community (see section 2.3 for more detail). National radio advertisements with a potential reach of 1.5 million people and an extensive social media campaign also helped to ensure that the survey was brought to the attention of as wide a group as possible. The above, in conjunction with the use of online surveys, resulted in a large and diverse sample of FFCSSs and should be considered a strength of this research.



Participants from all CHO areas, ages groups and backgrounds participated in this research (see section 2.3). However, there were issues with the sample. For example, three times as many females than male took part. Although there is a gender imbalance, according to the latest census data from 2016, more carers are female (60.5%) than male (39.5%), while gender ratios in previous research with carers was broadly similar, e.g. 82% female and 18% male.¹²⁴ It should also be noted that a high proportion of participants, more than 6 in 10, reported their highest level of educational attainment as 'third-level degree' or higher, indicating a very well educated sample. Indeed, this was not a representative sample of the target population. Rather, this was a self-selecting sample subject to non-response bias, wherein those who chose to take part may be different to those who didn't. Indeed, participants may have been those who were most motivated to contribute and/or those most engaged with services. The self-selecting nature of the sample meant that individuals with stronger views, either positive or negative, may have been more likely to participate in the survey. Therefore, the results are not generalizable to the whole population of FFCSSs of people using MHSs, notwithstanding the fact that this is a relatively large sample.

¹²⁴ O'Brien, F. (2009). *Family carers health survey*. Dublin: College of Psychiatrists of Ireland.



Finally, it was not possible to identify and exclude repeat respondents. Although there are methods to help reduce the likelihood of repeat respondents, e.g. ensuring that a single IP address can only access the survey once, these do not guarantee that repeat responses will not occur and often involve collecting potentially identifiable information. To ensure confidentiality and anonymity, and to ensure that the survey could be completed multiple times from the same computer, these methods were not deemed appropriate. Allowing for the survey to be completed multiple times from the same computer was particularly important in this target population as multiple members of the same family may have wanted to complete the survey, e.g. both parents of a service user. The potential exclusion of family members wishing to share their views and experiences by completing the survey was considered inappropriate.

..Mental Health Reform will continue to draw on the wealth of information gathered as part of this national consultation to inform our advocacy work going forward and by considering how best this consultation process can be carried out in the future..

As noted, Mental Health Reform's *My Voice Matters* consultation with FFCSSs is the first national, large-scale survey in recent years to provide in depth and up-to-date feedback on the direct experiences of FFCSSs supporting people accessing community and inpatient MHSs. In many ways, this could be considered a baseline study for an ongoing and regular consultation process with MHSs users and their FFCSSs. Every effort will be made to address the limitations of this research in the future to strengthen further any subsequent consultations. However, as evidenced by the methodological strengths outlined above, this research has provided a solid baseline against which to compare similar research in the future. This research has also provided significant insight into the views and experiences of a large group of those who care for and support MHS users in Ireland and invaluable first-hand feedback on the quality of MHS provision. Mental Health Reform will continue to draw on the wealth of information gathered as part of this national consultation to inform our advocacy work going forward and by considering how best this consultation process can be carried out in the future.

CONCLUSION AND RECOMMENDATIONS





5. CONCLUSION

Since 1984¹²⁵, national mental health policy has firmly embedded the role of FFCSs in the delivery of MHSs in Ireland. More recent policy¹²⁶ and guidance¹²⁷ has advanced this principle of FFCS involvement at all levels of the mental health system and provides specific, practical recommendations in which FFCSs can be effectively supported by the MHSs.¹²⁸

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 FFCSs 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 FFCSs are experiencing opportunities for participation in the care process for the person they support. For example, some participants wrote about how they had been facilitated and encouraged by the MHSs to be involved in the care and treatment of the person they support, while half of participants reported that their views were taken on board at least to some extent.

Notwithstanding efforts made by HSE MHSs to improve the experiences of FFCSs, the evidence also shows that many FFCSs 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 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 2019. The *My Voice Matters* FFCSs report represents one way of giving voice to FFCSs 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.

The findings detailed in this report can aid the Oversight Group to develop recommendations focussed on areas that FFCSs 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 FFCSs and more fully recognise their important role in enabling the recovery of many service users.

125 Department of Health and Children. (1984). *Planning for the future*. Dublin: The Stationery Office.

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

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

128 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.

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 to the attention of key stakeholders, including the HSE MHS, 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 FFCSSs of all those who use MHSs.



..We hope that the findings will lead to policy and service delivery that will enhance supports for FFCSSs and more fully recognise their important role in enabling the recovery of many service users..



RECOMMENDATIONS

1. HSE MHSs should provide FFCSSs 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 FFCSSs 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 FFCSSs 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 FFCSSs in individual care plans and in the discharge planning process. Where it is not possible to incorporate the views of FFCSSs, a full explanation should be provided by a member of the HSE MHSs.
4. HSE MHSs should formally assess and address the support needs of FFCSSs. In particular, the support needs of FFCSSs 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 FFCSSs 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 FFCS 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 FFCSSs to participate in service improvement initiatives.
8. The Government should ensure that independent advocacy is available for FFCSSs to support their engagement with MHSs.
9. To ensure a smooth transition for service users and their families from CAMHSs 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 FFCSSs' 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 FFCSSs 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 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.

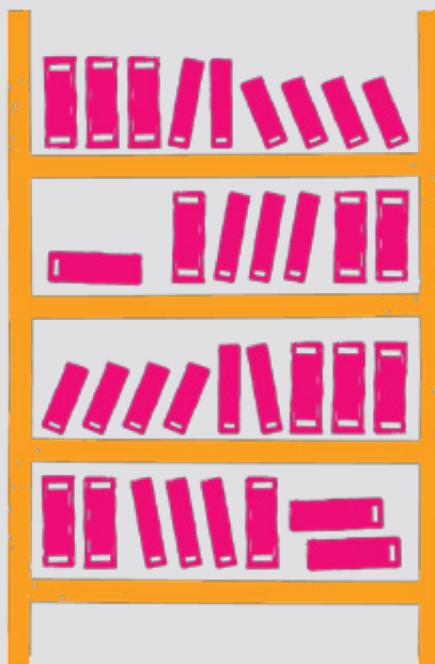
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RESPONSE OF THE GRASSROOTS FORUM

Mental Health Reform's Grassroots Forum (GRF) is made up of people with experience of the MHSs and FFCSSs.¹²⁹ 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.

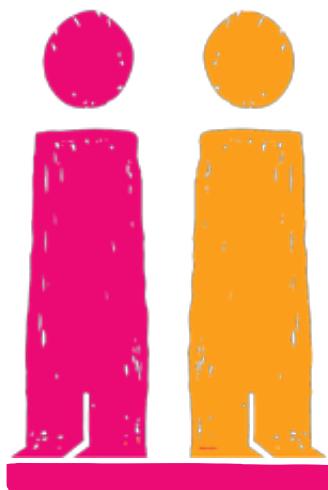
Furthermore, it appears that many FFCSSs are dissatisfied with their level of involvement in the mental health care planning and delivery of the person they support. They want more involvement and communication with the MHSs. In our view, it is important for mental health staff to seek input from FFCSSs 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.

¹²⁹ 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 FFCSSs 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 FFCSSs to promote their own mental health and well-being. In our view, MHSs have a responsibility to care for FFCSSs as well as service users and more supports should be made available to FFCSSs 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 FFCSSs; 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 FFCSSs and acknowledge how isolated individuals can feel when these are not provided. The HSE MHSs should ensure that FFCSSs are made aware of all available supports in their communities.

While the positive experiences reported by FFCSSs 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 FFCS 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 FFCSSs. This national consultation has been hugely important in giving voice to the views of FFCSSs who support people who use the MHSs in Ireland. There is, however, a need for an ongoing consultation process to ensure FFCSSs have a key role in improving the MHSs through collaborative service planning.



..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..

APPENDICES



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APPENDIX A: INFORMATION AND CONSENT SHEET



Mental Health Reform
Promoting Improved Mental Health Services

My Voice Matters National Consultation on Mental Health Services

Please read the following information below before deciding on whether to participate in the survey.

What is this research for?

My Voice Matters is a national consultation that will gather feedback through two surveys, one for people who use mental health services and one for their family members, friends and carers. The surveys will look at three main issues:

- What services are available
- Experience of services provided
- How services could be improved

This information will help Mental Health Reform identify gaps in the mental health services and, in turn, campaign for improvements in these areas.

The survey is focused on people who have used mental health services within the last two years so that MHR can gather up-to-date information on the services based on people's most recent experiences.

This survey will take approximately 15-20 minutes to complete.

Who is Mental Health Reform (MHR)?

Mental Health Reform is the national coalition driving reform of Ireland's mental health services and the social inclusion of people with mental health difficulties. Our vision is of an Ireland where people with mental health difficulties can recover their wellbeing and live a full life in the community. With 62 member organisations¹²⁴ and 15,000 individual supporters, MHR provides an independent, coordinated voice to Government, its agencies, the Oireachtas and the general public on mental health issues. This research is being funded by the HSE but the HSE will have no editorial control over the findings or final report.

Where does the information go?

- No names or contact information will be collected and therefore you cannot be identified
- All information collected is confidential and will be stored securely
- Your answers will be archived - again you cannot be identified through this process

¹²⁴ The number of member organisations stated here was accurate when data collection began in November 2017. At the time of publication of this report, Mental Health Reform's membership had grown to 73 member organisations.



- Your answers will be collated and analysed for inclusion in a Mental Health Reform report that will be published

Where can I get further information?

If you need any further information, would like clarification on any of the above, or would like to be kept informed about the survey, you can contact Oscar James, Research Assistant at 01-874-9468. You can also find out more about Mental Health Reform by going to our website at <https://www.mentalhealthreform.ie>.

If you would like support to fill in the survey, contact Oscar James at 01-874-9468.

Consent

Your participation is entirely voluntary. It is your decision whether you would like to take part or not.

1. I confirm I have read the information about this national consultation and have had the appropriate information and contact information to ask questions.
2. I understand my participation is voluntary and I have the right to withdraw at any time. I accept that once the survey is completed, I cannot withdraw due to the anonymous nature of the survey.
3. I have the right to confidentiality. All information obtained is strictly confidential and is stored securely at the offices of Mental Health Reform and on a secure cloud server.
4. I understand that once the study is over, the data will be archived in the Irish Social Science Data Archive (ISSDA), and used in future research.
5. I have the right to be kept informed about the progress of the project and to be provided with a copy of the final report.

If you have any questions about the survey, please do not hesitate to contact Mental Health Reform.

Please tick the box to indicate your consent to participate in the research. If you do not consent, please do not complete the survey

APPENDIX B: MEDIAN AND MODES FOR LIKERT SCALE SURVEY QUESTIONS

Table 1: Medians and modes for Likert scale survey questions.

Question	Response Options/ Scoring	Median	Mode
<i>'Are you satisfied with the information and advice you received from the HSE mental health services when the person you support first came into contact with the services?'</i>	Scale: 1 (very dissatisfied) to 5 (very satisfied)	2.0	1.0
<i>'The HSE mental health services explained to me how to support the person long-term'</i>	Scale: 1 (strongly disagree) to 5 (strongly agree)	2.0	1.0
<i>'How satisfied are you with the information given about mental health services on the HSE website?'</i>	Scale: 1 (very dissatisfied) to 5 (very satisfied)	2.0	3.0
<i>'In the last two years, I have had the opportunity to provide feedback to the mental health services to inform service improvement'</i>	Scale: 1 (strongly disagree) to 5 (strongly agree)	2.0	1.0
<i>'Overall, are you satisfied that HSE mental health services have considered your support needs?'</i>	Scale: 1 (very dissatisfied) to 5 (very satisfied)	2.0	1.0
<i>'Overall, how satisfied are you that the person you support has received a good quality service from HSE mental health services?'</i>	Scale: 0 (very dissatisfied) to 10 (very satisfied)	3.0	0.0
<i>'Overall, how satisfied are you that HSE mental health services has provided the individual with supports that adequately target their needs?'</i>	Scale: 0 (very dissatisfied) to 10 (very satisfied)	3.0	0.0
<i>'In the last two years when the person you support sought help for their mental health difficulty in an emergency department, they received support that adequately addressed their needs'</i>	Scale: 1 (strongly disagree) to 5 (strongly agree)	2.0	1.0
<i>Note: The median is the value in a set of responses where all responses are equally likely to fall above or below this value. The mode is the value that most often appears in a set of responses.</i>			



APPENDIX C: FFCS SURVEY



Mental Health Reform
Promoting Improved Mental Health Services

Family, Friends and Carers Survey

Information & Consent

My Voice Matters National Consultation on Mental Health Services

Please read the following information below before deciding whether to participate in the survey.

What is this research for?

My Voice Matters is a national consultation that will gather feedback through two surveys, one for people who use mental health services and one for their family members, friends and carers.

The surveys will look at three main issues:

- What services are available
- Experience of services provided
- How services could be improved

This information will help Mental Health Reform identify gaps in the mental health services and, in turn, campaign for improvements in these areas.

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Where does the information go?

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If you would like support to fill in the survey, contact Oscar James at 083 0520 491.

Consent

Your participation is entirely voluntary. It is your decision whether you would like to take part or not.

1. I confirm I have read the information about this national consultation and have had the appropriate information and contact information to ask questions.
2. I understand my participation is voluntary and I have the right to withdraw at any time. I accept that once the survey is completed, I cannot withdraw due to the anonymous nature of the survey.
3. I have the right to confidentiality. All information obtained is strictly confidential and is stored securely at the offices of Mental Health Reform and on a secure cloud server.
4. I understand that once the study is over, the data will be archived in the Irish Social Science Data Archive (ISSDA), and used in future research.
5. I have the right to be kept informed about the progress of the project and to be provided with a copy of the final report.



If you have any questions about the survey, please do not hesitate to contact Mental Health Reform.

- * 1. Please tick the box to indicate your consent to participate in the research. If you do not consent, please do not complete the survey.

I agree to take part in the above study.

Introduction

This survey aims to capture the views of individuals supporting people with mental health difficulties on public mental health services.

This survey asks about:

- 1) the person that you are supporting, and their experiences of the services
- 2) how your support needs were addressed

This survey can also be completed by people who have recent experience supporting people with mental health difficulties, but are no longer providing that support.

There are many different ways that people identify with their role in supporting people with mental health difficulties, and there is yet to be a single word to describe it. For the purposes of the survey, we use the words 'support' and 'care' to describe this role.

Screening question

This is just a question to see if this survey is relevant to you.

If the person you support has no contact with mental health specific services in the last 2 years, the questions aren't relevant to your experience, please do not continue with the survey.

- * 2. Has the person you support had contact with the following mental health services in the last two years?

Please tick all that apply.

- Psychiatrist
- Community Mental Health Services
- Inpatient Mental Health Services
- None of these

Section A. About the person you support

In this section, questions are about the person you support. Please answer the questions in relation to that person.

These questions are important to get an idea of the breadth of experiences that family, friends, and carers have when supporting people with mental health difficulties. For example, different ages, diagnoses, or levels of contact with the HSE mental health services may change the experiences of people in a supporting role.

3. Who is the person you support?

- | | |
|---|--------------------------------------|
| <input type="radio"/> Spouse/Partner | <input type="radio"/> Other relative |
| <input type="radio"/> Parent | <input type="radio"/> Friend |
| <input type="radio"/> Child (including adult child) | <input type="radio"/> Other |
| <input type="radio"/> Sibling | |

4. What is the age of the person you support?

5. Overall, how long have they been in contact with HSE mental health services?

- | | |
|--|---|
| <input type="radio"/> Less than 1 year | <input type="radio"/> More than 10 years |
| <input type="radio"/> 1 to 5 years | <input type="radio"/> They are no longer in contact with HSE mental health services |
| <input type="radio"/> 6 to 10 years | <input type="radio"/> Don't know / can't remember |

6. Do they have a...

Tick all that apply.

- Medical card
- GP access card
- Over 70s card
- Drugs Payment Scheme card
- None of the above

7. Are you living with the person you support?

- Yes
- Some of the time
- No



Primary care

This section relates to the person you support. Please answer the questions in relation to them.

* 12. The GP....

Please tick yes or no to each of the answer options.

	Yes	No	Don't know
Prescribed them medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referred them to a psychiatrist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referred them to A&E	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referred them to a psychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gave them information or referral to counselling/psychotherapy services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referred them to the HSE community mental health team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Informed or referred them to a local voluntary group or service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section C. Your support needs

This section is about you, and your support needs.

* 13. My caring role impacts me financially.

- | | |
|--------------------------------------|---|
| <input type="radio"/> Strongly agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly disagree |
| <input type="radio"/> Neutral | |

14. Please describe your role in relation to the person with mental health difficulties

- Carer
- Supporter
- Other (please specify)

15. Please indicate if you have used any of the following advocacy services.

Tick all that apply.

- Citizens Information Centre
- Irish Advocacy Network
- Money Advice & Budgeting Service (MABS)
- National Advocacy Service for People with Disabilities
- None of the above
- Other (please specify)

16. Have you accessed any of the following in relation to your support role in the last 2 years?

Tick all that apply.

- | | |
|---|--|
| <input type="checkbox"/> Peer support groups | <input type="checkbox"/> Listening service over the phone or helpline |
| <input type="checkbox"/> Individual counselling | <input type="checkbox"/> Online support (including counselling, listening service) |
| <input type="checkbox"/> Family therapy/counselling | <input type="checkbox"/> No support accessed, though it was available |
| <input type="checkbox"/> Advocacy service | <input type="checkbox"/> No support available |
| <input type="checkbox"/> Family mental health education | <input type="checkbox"/> I was not aware of available support |

17. Please indicate whether the HSE has assessed or addressed your needs for each of the following options.

When we say assessed we mean have the mental health service staff asked you what your needs as a supporter are in terms of your wellbeing and coping skills.

When we say addressed we mean that mental health services have provided supports to you based on their assessment of your needs as a supporter.

	Assessed	Addressed	Neither
Your physical wellbeing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your emotional wellbeing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your coping skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section D. Information and advice given to you by HSE mental health services



15. Please indicate if you have used any of the following advocacy services.

Tick all that apply.

- Citizens Information Centre
- Irish Advocacy Network
- Money Advice & Budgeting Service (MABS)
- National Advocacy Service for People with Disabilities
- None of the above
- Other (please specify)

16. Have you accessed any of the following in relation to your support role in the last 2 years?

Tick all that apply.

- | | |
|---|--|
| <input type="checkbox"/> Peer support groups | <input type="checkbox"/> Listening service over the phone or helpline |
| <input type="checkbox"/> Individual counselling | <input type="checkbox"/> Online support (including counselling, listening service) |
| <input type="checkbox"/> Family therapy/counselling | <input type="checkbox"/> No support accessed, though it was available |
| <input type="checkbox"/> Advocacy service | <input type="checkbox"/> No support available |
| <input type="checkbox"/> Family mental health education | <input type="checkbox"/> I was not aware of available support |

17. Please indicate whether the HSE has assessed or addressed your needs for each of the following options.

When we say assessed we mean have the mental health service staff asked you what your needs as a supporter are in terms of your wellbeing and coping skills.

When we say addressed we mean that mental health services have provided supports to you based on their assessment of your needs as a supporter.

	Assessed	Addressed	Neither
Your physical wellbeing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your emotional wellbeing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your coping skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section D. Information and advice given to you by HSE mental health services

* 18. Are you satisfied with the information and advice you received by the HSE Mental Health Services when the person you support first came into contact with the services?

- | | |
|--------------------------------------|--|
| <input type="radio"/> Very satisfied | <input type="radio"/> Dissatisfied |
| <input type="radio"/> Satisfied | <input type="radio"/> Very dissatisfied |
| <input type="radio"/> Neutral | <input type="radio"/> I wasn't supporting them when they first came into contact with the services |

19. How satisfied are you with the information given about mental health services on the HSE website?

- | | |
|--------------------------------------|---|
| <input type="radio"/> Very satisfied | <input type="radio"/> Dissatisfied |
| <input type="radio"/> Satisfied | <input type="radio"/> Very dissatisfied |
| <input type="radio"/> Neutral | <input type="radio"/> I have not accessed the HSE's website |

20. The HSE mental health services explained to me how to support the person in the long term.

- | | |
|--------------------------------------|--|
| <input type="radio"/> Strongly agree | <input type="radio"/> Strongly disagree |
| <input type="radio"/> Agree | <input type="radio"/> Not involved by my choice |
| <input type="radio"/> Neutral | <input type="radio"/> Not involved by choice of the person I support |
| <input type="radio"/> Disagree | |

21. Did anyone from the HSE mental health services let you know how to make a complaint about the mental health services?

- | |
|---|
| <input type="radio"/> Yes, on more than one occasion |
| <input type="radio"/> Yes, once |
| <input type="radio"/> I found the information displayed in their facilities (clinic, website, leaflets) |
| <input type="radio"/> No |

22. Do you have the contact details of a designated mental health professional (key worker) in the HSE mental health services to provide you with support?

- | | |
|---|--|
| <input type="radio"/> Yes | <input type="radio"/> Not involved by my choice |
| <input type="radio"/> No | <input type="radio"/> Not involved by choice of the person I support |
| <input type="radio"/> In the process of getting details | |

23. Did the HSE mental health services give you information about a support group in the community to support your needs?

- | | |
|---|--|
| <input type="radio"/> Yes, but only at my request -> go to Q24 | <input type="radio"/> No, but I wouldn't have wanted this information -> go to section E |
| <input type="radio"/> Yes, without prompt -> go to Q24 | <input type="radio"/> Not involved by my choice -> go to section E |
| <input type="radio"/> No, but I would have liked to receive this information -> go to section E | <input type="radio"/> Not involved by choice of the person I support -> go to section E |



24. Only if you received information, was this information useful?

- The information was useful
- The information wasn't very useful

Section E. Supporting in-patient care

When we say inpatient care, we mean staying in a mental health ward in a hospital, or in a psychiatric hospital.

25. Has the person you support been a voluntary or involuntary inpatient in the last 2 years?

- Yes, a voluntary patient -> go to Q26
- Yes, an involuntary patient -> go to Q26
- Yes, both voluntary and involuntary patient -> go to Q26
- No inpatient experience. -> go to section F

Section E. Supporting in-patient care

26. The last time the person was in hospital...

Please provide an answer for each.

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	I was not involved
I felt listened to by the hospital staff	<input type="radio"/>					
I felt the hospital expected me to be responsible for the recovery of the individual	<input type="radio"/>					
I felt the hospital valued my knowledge and experience of supporting the individual	<input type="radio"/>					
I felt the hospital considered the role that I play in supporting the individual's recovery	<input type="radio"/>					

Supporting in-patient care

These questions relate to the last time the individual was in hospital.

* 27. Did the mental health services involve you in the discharge planning for the person you support?

- Yes -> go to Q28
- No -> go to section F
- I was not involved by my choice -> go to section F
- I was not involved by choice of the person I support -> go to section F

Supporting in-patient care

These questions relate to the last time the individual was in hospital.

28. Were your views and concerns incorporated into the discharge plan for the person you support?

- All of my views and concerns were taken into account
- Most of my views and concerns were taken into account
- Some of my views and concerns were taken into account
- None of my views or concerns were taken into account

29. Before discharge were your support needs identified by the mental health team?

(support needs as a friend/family member/carer)

- Yes
- No
- Sometimes

30. Before discharge were you given information about how to access any of the following:

Please tick all that apply.

- Community mental health services
- Advocacy services
- Relevant voluntary organizations
- Relevant community groups
- Supported employment for the individual
- Crisis point of contact
- I was not given any information



31. Were you given a minimum of 2 days notice before the person you support was discharged from the mental health inpatient unit?

- Yes
- No
- Sometimes

32. Before the individual's discharge, was the person you support notified of the date for follow up appointment?

- Yes
- No
- Sometimes
- Don't know

Section F. Child and Adolescent Mental Health Services (CAMHS)

* 33. Has the person you support accessed Child and Adolescent Mental Health Services (CAMHS)?

- Yes -> go to Q34
- No -> go to section G

Discharge from CAMHS

34. Has the person you support been discharged from CAMHS?

- Yes -> go to Q35
- No -> go to section G

Transition from CAMHS to Adult Mental Health Services

35. Upon discharge from CAMHS, did you experience any of the following issues?

Please tick all that apply

- | | |
|--|--|
| <input type="checkbox"/> There was no follow-on key worker identified for the child/young adult | <input type="checkbox"/> There was a gap in the support available after discharge from CAMHS |
| <input type="checkbox"/> The person I support had to re-enter the system as an adult and required reassessment | <input type="checkbox"/> There was a big change in environment between CAMHS and Adult Mental Health Services that did not suit the person I support |
| <input type="checkbox"/> There was no referral, or there was an issue with the referral that meant they couldn't access follow-on mental health services | <input type="checkbox"/> I experienced a lack of support from HSE mental health services for me as a family carer |
| <input type="checkbox"/> The person I support continued using CAMHS because Adult Mental Health Services were not suited to their needs | <input type="checkbox"/> None of the above |

Section G. Crisis care

A crisis is when a person with a mental health difficulty needs urgent help because their mental or emotional state is getting worse very quickly.

36. Were you given information about what to do in the case of a crisis?

- Yes, and it was useful
- Yes, but it wasn't useful
- No, but I would have liked to receive this information
- No, but I wouldn't have liked to receive this information.

37. In the last 2 years, if you tried to contact community mental health services during a crisis did the person you support get the help they needed for their mental health difficulty?

- I have not contacted community mental health services during a crisis
- I tried to contact the community mental health services but the person I support didn't receive the help they needed/no answer
- I contacted them and received some help/advice
- I contacted them and the person I support got the help they needed

Section H. Emergency department



* 38. In the last 2 years, did the person you support need to go to an Emergency Department for their mental health difficulty?

- Yes -> go to Q39
- No -> go to Section I
- Don't know -> go to Section I

Emergency department

39. In the last 2 years, when the person you support sought help for their mental health difficulty in an Emergency Department, they received support that adequately addressed their needs.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

40. In the last two years when the person you support went to an Emergency Department for a mental health crisis, what is the longest they waited to be seen by a mental health professional?

- 0-2 hours
- 2-4 hours
- 4-6 hours
- 6-8 hours
- 8-10 hours
- 10-12 hours
- 12-14 hours
- 14-16 hours
- 16-18 hours
- 18-20 hours
- 20+ hours
- Never saw a mental health professional

Section I. Overall Feedback

* 41. Overall, are you satisfied that HSE mental health services have considered your support needs?

- Very satisfied
- Satisfied
- Neutral
- Dissatisfied
- Very Dissatisfied

42. Are your views incorporated into the individual's recovery/care plan?

- | | |
|--|---|
| <input type="radio"/> All of my views and suggestions were taken into account | <input type="radio"/> None of my views or suggestions were taken into account |
| <input type="radio"/> Most of my views and suggestions were taken into account | <input type="radio"/> Not involved by my choice |
| <input type="radio"/> Some of my views and suggestions were taken into account | <input type="radio"/> Not involved by choice of the person I support |

43. Has confidentiality between the mental health team and the person you support ever been a barrier to your views being taken into account by the mental health services?

- Never
- Once
- Sometimes
- Always

44. In the last 2 years, I have had an opportunity to provide feedback to the mental health services to inform service improvement.

NOTE: By feedback, we do not mean complaints.

- | | |
|--------------------------------------|---|
| <input type="radio"/> Strongly agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly disagree |
| <input type="radio"/> Neutral | |

45. Overall, how satisfied are you that the person you support has received a good quality service from HSE mental health services?

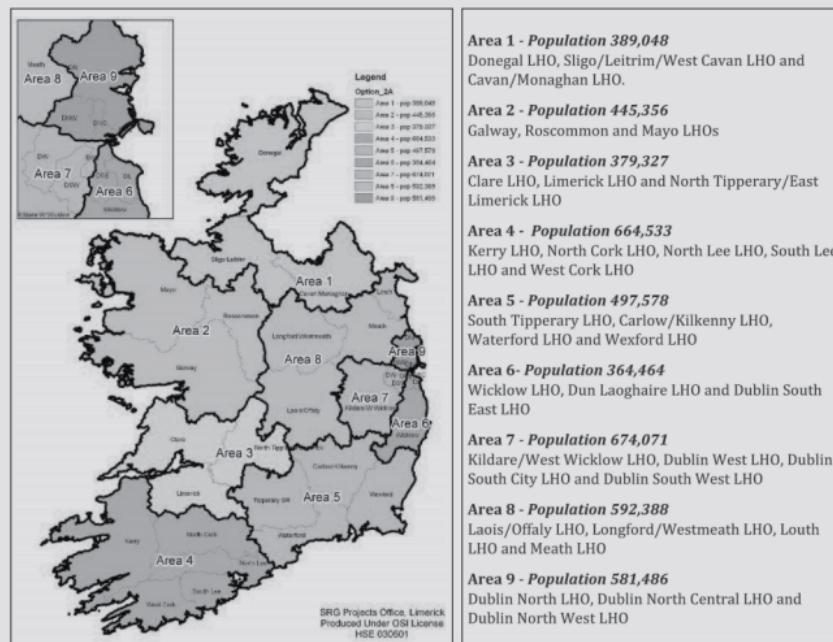
Please tick a number to indicate your answer, where 0 means very dissatisfied, and 10 means very satisfied.

- | | |
|-------------------------|--------------------------|
| <input type="radio"/> 0 | <input type="radio"/> 6 |
| <input type="radio"/> 1 | <input type="radio"/> 7 |
| <input type="radio"/> 2 | <input type="radio"/> 8 |
| <input type="radio"/> 3 | <input type="radio"/> 9 |
| <input type="radio"/> 4 | <input type="radio"/> 10 |
| <input type="radio"/> 5 | |



* 50. What is your Community Healthcare Organisation catchment area?

The nine Community Healthcare Organisations are outlined below:



- CHO Area 1 (Donegal, Sligo/Leitrim/West Cavan, Cavan/Monaghan)
- CHO Area 2 (Galway, Roscommon, Mayo)
- CHO Area 3 (Clare, Limerick, North Tipperary/East Limerick)
- CHO Area 4 (Kerry, North Cork, North Lee, South Lee, West Cork)
- CHO Area 5 (South Tipperary, Carlow/Kilkenny, Waterford, Wexford)
- CHO Area 6 (Wicklow, Dun Laoghaire, Dublin South East)
- CHO Area 7 (Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West)
- CHO Area 8 (Laois/Offaly, Longford/Westmeath, Louth/Meath)
- CHO Area 9 (Dublin North, Dublin North Central, Dublin North West)

51. Do you have any of the following long-lasting conditions or difficulties?

Tick all that apply.

- An intellectual disability
- A difficulty with learning
- Autism spectrum disorder
- Remembering or concentrating
- A speech and language difficulty
- A psychological or emotional condition
- Blindness or a serious vision impairment
- Deafness or a serious hearing impairment
- A difficulty with pain or breathing
- Other chronic illness or condition
- A difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying
- None of the above

52. How would you describe your current work status?

- Paid employment, full time or part time
- Student
- Looking after home or family
- Unable to work due to permanent sickness or disability
- Unemployed
- Retired from employment
- Other (please specify)

53. What is your main source of income?

- Income from work or self-employment
- Job seekers allowance/benefit
- Occupational or personal pension
- Back to education allowance
- State old age pension
- Disability allowance
- Income from investment or savings
- Informal family support
- Carer's allowance
- Invalidity pension
- Other (please specify)

54. What is your highest educational attainment level?

- No formal education/Primary school only
- Third level non degree
- Lower secondary
- Third level degree
- Upper secondary
- Post graduate qualification

55. What is your age in years?

56. Are you

- Male
- Female
- Other

57. Are you...

Tick all that apply.

- Straight/heterosexual
- Transgender
- Gay/Lesbian
- Intersex
- Bisexual
- Other



58. What is your ethnic or cultural background

- | | |
|--|--|
| <input type="radio"/> Irish | <input type="radio"/> Bangladeshi |
| <input type="radio"/> Irish Traveller | <input type="radio"/> Chinese |
| <input type="radio"/> English/Welsh/Scottish/Northern Irish/British | <input type="radio"/> Any other Asian background |
| <input type="radio"/> Any other White background | <input type="radio"/> White and Black Caribbean |
| <input type="radio"/> African | <input type="radio"/> White and Black African |
| <input type="radio"/> Caribbean | <input type="radio"/> White and Asian |
| <input type="radio"/> Any other Black, African, Caribbean background | <input type="radio"/> Any other mixed or multiple ethic background |
| <input type="radio"/> Indian | <input type="radio"/> Arab |
| <input type="radio"/> Pakistani | |
| <input type="radio"/> Other (please specify) | |

he end!

Thank you so much for taking part in Mental Health Reform's survey!

Our feedback is extremely important for us. With your feedback, we will write a document that highlights areas for improvement in the HSE mental health services.

If you would like to add your voice to Mental Health Reform's campaign to make mental health a national priority you can sign up to receive our newsletter and/or follow us on any of our social media platforms.

If you have any questions, please do not hesitate to contact us by:

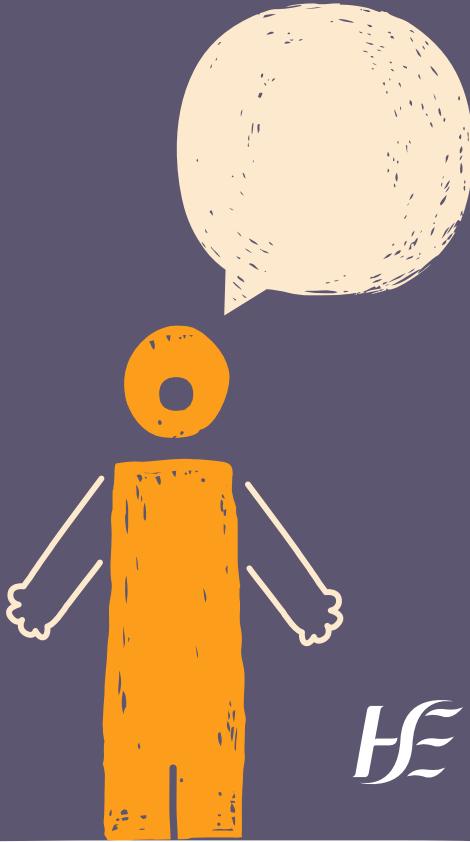
email: info@mentalhealthreform.ie

website: www.mentalhealthreform.ie

phone: 01 874 9468 or 0830520491

Please return completed hard copies with the pages stapled together further privacy to the following address:

**Scar James,
Mental Health Reform,
Oleraine House,
Oleraine St,
Dublin 7.**



Mental Health Reform
Promoting Improved Mental Health Services

Mental Health Reform
Coleraine House,
Coleraine Street, Dublin 7.

T: (01) 874 9468
E: info@mentalhealthreform.ie
www.mentalhealthreform.ie

[mentalhealthreform](#)
 @MHReform
 @mhreform

CHY: 19958
COMPANY NO: 506850
RCN: 20078737



Seirbhís Sláinte
Níos Fearr
á Forbairt

Building a
Better Health
Service