

Family Carers Ireland's Submission to the Oireachtas Committee on the Future of Mental Health Care

Family Carers Ireland (FCI) welcomes the opportunity to submit our views to the Oireachtas Committee on the Future of Mental Health Care, and to set out what we believe should be the focus of our healthcare system in relation to the provision of mental health services and supports, specifically in relation to the needs of mental health carers. This submission is based on our experience of supporting Ireland's 355,000 family carers,¹ who collectively save the State some €10 billion each year in avoided health and social care costs². Many of these carers care for a loved one with a mental health difficulty. FCI also host a Working Group for Family Carers of People with Mental Health Difficulties, who provide a collective voice for mental health carers, raise awareness of the specific challenges they face and inform policy development in relation to the planning, design and delivery of mental health services. FCI and the Working Group enjoy a close working relationship with the HSE Mental Health Engagement Unit and Advancing Recovery Ireland.

About Mental Health Carers

One in five people in Ireland have experienced a mental health difficulty (Healthy Ireland Survey 2016) however, nearly two-thirds of people with a known mental disorder never seek help due to fear of stigma and discrimination. (WHO, 2012). The family's responsibility in providing care for people with a mental health difficulty has increased substantially due to the welcome shift towards community care and the deinstitutionalisation of psychiatric patients articulated in the government's mental health policy document Vision for Change, and it's now estimated that up to 90 percent of people with a mental illness live with relatives who provide them with practical and emotional support. However, caring for a loved one with a mental health difficulty can bring significant personal, financial and emotional challenges, and in extreme cases can place families and carers at risk.

A 2009 study carried out by the Royal College of Psychiatrists found that 66 percent of carers reported feeling mentally and emotionally drained as a result of caring and more than half reported a significant mental health problem themselves, the most frequent being anxiety disorder. International evidence found that carers are three times more likely to report ill-health than the non-carer population (Singleton et al, 2002)³, while Cummins (2007)⁴ found that carers who looked after frail, disabled or mentally ill relatives suffered extraordinary rates of depression and had the lowest level of well-being of any group in society. Additional risk factors that impact on the poor mental health of carers are; greater levels of financial pressure, lower levels of support and worse family functioning (Edwards and Higgins, 2009)⁵. Indeed, carers are consistently found to have significantly poorer mental health and higher rates of depression than the general population.

Summary of key points

- Ireland's mental health services are facing **significant challenges** on a number of fronts. A crisis in the recruitment of clinicians and frontline staff is leaving mental health services under-resourced and ineffective, and contributing to significant waiting lists; the lack of out of hours mental health services means patients and families are essentially abandoned and forced to endure endless waits in A&E if a crisis arises out of hours; the closure of beds in mental health units due to staff shortages and the

¹ National Carers Strategy (2012) defines a Family Carer as 'someone providing an ongoing significant level of care to a person in need of that care in the home due to illness or disability or frailty'.

² Based on Census 2011 and €12 per hour replacement care cost rate.

³ Singleton, Maung, N., Cowie, A., Sparks, J., Bumpstead, R. and Meltzer, H. (2002) *Mental Health of Carers*, London: The Stationery Office.

⁴ Cummins, R (2007) Unpublished report on wellbeing amongst Australian carers, Source: http://nnaami.org/media_topics/warning_signs_for_carers_wellbeing.html

⁵ Edwards, B. and D.J. Higgins (2009) Is caring a health hazard? The mental health and vitality of carers of a person with a disability in Australia, *Medical Journal of Australia*, 190 (7): S61 – S65.

widespread culling of vital community based services which see patients denied respite and families denied support have all contributed to this crisis leaving patients and families at risk of regression, or worse.

- Despite endless Government reports advocating initiatives to support community-based care, and strong economic and moral arguments to do so, **practice and policy remain at odds**, with access to mental health services in the community and at primary care level remaining inequitable, geographically diverse, under-resourced and unreliable.
- **FCI calls for an integrated network of mental health services and supports to be available at primary care level for service-users and their families. We believe that those who need home-based mental health supports should be included within the provisions of the statutory home care scheme currently being formulated by the Department of Health, including access to appropriate respite. The vision set out in the National Carers' Strategy 'to respect carers as expert partners in care and to support them to maintain their own health and wellbeing' is integral to this⁶.**
- Government must uphold the recommendations in *A Vision for Change* on the involvement of service users and family carers in every aspect of mental health service development and delivery. In 2013, the REFOCUS group made up of family supporters/carers and service users produced a report, which documented the needs of carers of people with mental health difficulties⁷. It recommends that the **critical role of carers be recognised within the mental health system** to ensure the well-being of not only the service user, but also the carer(s) and that mental health services should be aware of the psychological impact on carers when a family member develops a mental health difficulty. The National Carer's Strategy sets out a number of actions to ensure that carers are recognised and respected as key care partners and are included in decisions relating to the person that they are caring for. These actions should be considered in progressing the involvement of family members and carers in mental health service delivery.
- Issues of **confidentiality and information-sharing** between mental health professionals and families/carers can be difficult, with differences of opinion about the type of information that can be shared. However if carers are excluded from important discussions and decisions involving the patient, this can have serious practical, financial and personal consequences. While an important issue is the agreement of the patient to disclosure information to their families or carer, many are unaware of this and so miss the opportunity to have their loved ones involved. Carers also face problems with being listened to by health care professionals. For example they can be the first to notice worrying changes in the patient's behaviour, or negative reactions to medication, yet clinicians can be reluctant to listen. In some cases the patient may not realise that they are unwell and may not want professionals to be contacted so it is only their family or carer who recognises their need for treatment. Even when the patient refuses to give consent for their family's involvement, carers must be given sufficient information to enable them to provide effective care safely, without risk of harm to themselves or their loved ones. The provision of general information about mental illness, emotional and practical support for carers does not breach confidentiality.
- Caring for a loved one with a mental health difficulty can bring significant levels of stress for the carer and can affect their overall quality of life. Research on the impact of caregiving shows that half of carers suffer significant psychological distress and experience higher rates of mental ill-health than the general population⁸. In 2017 the HSE, along with other stakeholders including FCI completed work on a Carer Needs Assessment tool to be offered to carers alongside the interRAI Single Assessment Tool for Older People. FCI recommend the adoption of this tool with mental health services to **assess and address the needs of mental health carers** and thus support them in their caring role.
- While much has been done to raise awareness and address the stigma associated with mental health, efforts have focused on the person with the mental health difficulty, but fail to recognise the stigma,

⁶ National Carers' Strategy 'Recognised, Supported, Empowered' (2012): Department of Health.

⁷ REFOCUS CPsychI (2013) Who cares? Listening to the needs and experiences of carers of people with mental illness, p. 5.

⁸ College of Psychiatry 2009 report 'Carers of Ireland, Who cares?'

isolation and distress experienced by their carer. This is made worse by the fact that essential services available to other carers such as homecare or respite are not available to carers of people with mental health difficulties. Given the lack of supports available to family members and carers, FCI recommends that a **range of dedicated supports be developed to help family members** and carers, including:

- counselling and family therapy to help family members to handle their own stress and anxiety
 - access to dedicated respite services
 - provision of factual information about what services are available, how they work and how to access help in a crisis
 - introduction of a complaints mechanism for family members
 - listening to and respecting the views of family members
 - the appointment of a key worker or liaison for family members
 - adoption of a Carer Charter (discussed below)
 - development of our of hour supports
- Provide a national roll-out of **Home-Based Crisis Intervention Teams**, which provide immediate assessment, intervention and multidisciplinary treatment for individuals experiencing a mental health crisis in their own homes, making it available to families in all nine CHOs. Families who have availed of these teams in the areas where they are currently established have reported very positive experiences.
 - There is robust evidence supporting the effectiveness of family work in improving the quality of life for both the people living with mental health difficulties and their families. Indeed mental health carers who have had the opportunity to avail of **Behavioural Family Therapies** (BFT) or psycho-education programmes have reported very positive outcomes for both themselves and their loved one. FCI recommend investing in these types of family-based recovery programmes as a means of embedding family-based recovery within the implementation and delivery of services. Components should include information sharing, knowing how to spot signs of relapse, increasing problem-solving and coping skills, and looking at new ways for family members to communicate.
 - Voluntary admission to a psychiatric hospital occurs in the same way as admission to a general hospital, with patients required to be admitted through A&E. This is wholly inappropriate for patients who are likely to be in a distressed state, and it adds to the trauma of admission both for the patient and their carer as well as, from a practical point of view, adding to the pressures faced by A&E. *A Vision for Change* calls for **crisis intervention support** to be available in each local area, and for this support to be available 24/7. FCI urge Government to improve access to mental health crisis supports and establish regional psychiatric admission units.
 - FCI recommend the adoption of a **Carers Charter** by mental health service providers which clearly sets out their commitment to respecting and involving carers as expert partners in care and ensuring their role as a carer is acknowledged and their needs met. An example of FCI's Carer Charter for mental health carers is included in appendix 1.
 - Families and carers should have access to the treatment team when they know that their relative is in danger of relapse. A **crisis intervention plan**, which includes relevant telephone numbers of key contacts and services, should be in place.
 - FCI welcome the establishment of the **Mental Health Engagement Unit** within the HSE and the recruitment of nine Area Leads for Mental Health Engagement as members of the mental health services area management teams. We also welcome the recruitment of 114 assistant psychologists for primary care teams announced in June 2017 which will facilitate earlier access to mental health support for children and adolescents. These initiatives will help enhance the capacity of primary care to provide mental health support and in so doing enable early intervention and reduce the number of referrals to specialist mental health services.
 - There was some confusion regarding recent **Budget allocations** towards mental health, with a clarification following Budget 2018 that the announced €35m included €20m committed to in 2017. With recent figures showing that almost 1,963 extra staff are needed if the staffing targets set out in *A Vision for Change* are to be achieved and with some 2,400 children and adolescents currently on waiting lists for mental health services, FCI call on Government to fulfil their commitment to implement

in full a *Vision for Change* as set out in the Confidence and Supply Arrangement and to invest €55M in mental health services by 2019 as committed to in Budget 2017. Priorities areas should be (i). recruitment of clinicians, (ii) addressing waiting lists in child and adult services (iii) establishing dedicated supports for families and carers (iv) investment in home and residential based respite services.

In Conclusion

FCl supports the approach taken by the Committee in recognising the need for a long-term, cross-party consensus on a mental health strategy. There can be little doubt that whatever strategy the Committee proposes, family carers will be the cornerstone of its implementation and success. To this end, we ask that the Committee continue to engage with the caring sector to ensure the needs of mental health carers are considered in your deliberations and reflected in your final recommendations. Finally, on behalf of Family Carers Ireland I wish the Committee every success in your work and look forward to improved mental health care services as a result of your efforts.

Appendix 1: Carers Charter: Expert Partners in Mental Health Care

Families and carers play a crucial role in supporting people who experience mental health difficulties. At *(name of organisation)* we acknowledge the important role carers play and respect them as expert partners in the care and treatment of their loved one. This charter provides a clear statement of how carers can expect to be treated by our staff when their loved one is receiving care from *(name of organisation)*.

A carer is a family member or friend who provides practical or emotional support to a person who is in need due to disability, frailty or illness, including mental health difficulties.

1. We will respect you as an expert partner and involve you in decisions relating to the care of your loved one.

This means we will:

- Treat you with respect, listen to your opinions and recognise your expertise.
- Take your worries and concerns seriously.
- Respect your right to be involved in decisions which affect you and your family's life.
- Recognise that you are integral to the care plan and ensure the service user is aware of their right to have their carer involved.
- With your loved one's consent we will share a copy of the care plan with you so you see who is involved in their care and what each partner's responsibilities are.

2. We recognise your need for information and will provide you with jargon-free information about your loved ones condition and care plan.

This means we will:

- Where possible, give you information about the illness and treatment of your loved one that is clear, accurate and in a format that is easy to understand.
- Respect carers and service users confidentiality and work to overcome barriers to sharing information, including making carers and service users aware of opportunities to give consent for the sharing of information.
- You will be given information about what to do and who to contact in times of crisis.

3. We will recognise your needs as a carer and support you to get help when you need it.

This means we will:

- Consider your needs without assuming that you are willing or able to continue to provide care.
- Signpost you to carer organisations who can help you get the support you need including emotional, financial and respite support.
- Create a 'carer friendly' environment across our services.

4. We will include carers views in the development of our services and train our staff to be aware of your needs

This means we will:

- Give you the opportunity to state your views on the quality of the services we provide and clearly outline our complaints procedure.
- Include carer's views in service development proposals and ensure that carers are represented and consulted at every level.

- Train our staff to be 'carer aware' and ensure they can identify carers at first contact so carers can access the help they need as early as possible in their caring journey.

What carers can do to help:

- Where possible encourage your loved one to attend their appointments and if you can, let us know in advance if you're loved one can't attend.
- Let us know if you or your loved one have any special needs such as alternative methods of communication.
- Ask questions, share your concerns and let us know important information about your loved ones condition.
- Tell us about your experience of our services whether good or bad.

Mrs. Mary Bloggs
Chief Executive Officer

Mr. Joe Bloggs
Director of Operation