



Analysis of Mental Health Reform's 2015 online feedback

Mental Health Reform conducted an online feedback form as part of the annual public consultation process. The feedback form was live from March to June of 2015 and received a total of 281 responses. This informal questionnaire was offered as an opportunity for those who were unable to take part in Mental Health Reform's annual public consultation meetings to share their views on mental health services in Ireland. The form did not ask for demographic information of individuals; therefore comments do not relate to any specific Community Healthcare Organisation area. Participants were asked to provide closed ended or open ended responses to a number of questions.

The first two questions were closed ended and asked people to choose from two responses under the headings of:

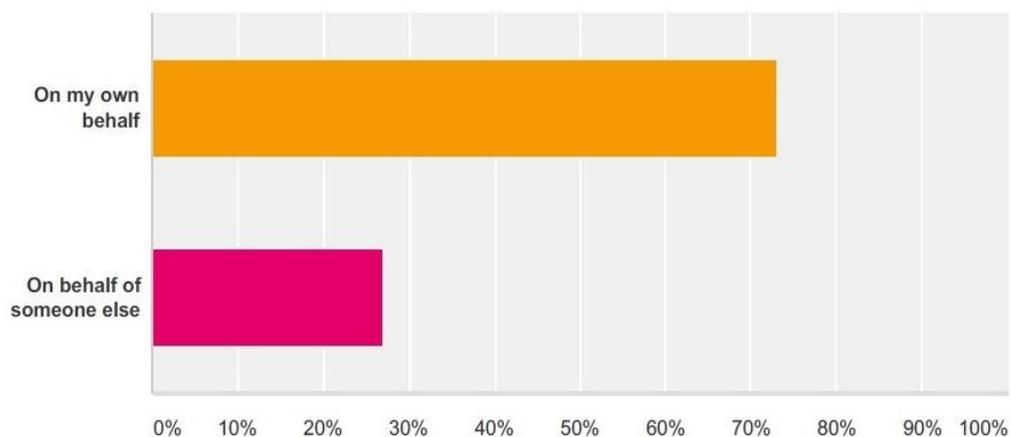
- Are you answering on your behalf or on behalf of someone else?
- Is this experience of mental health services current or in the past?

The questions that followed were open ended and asked respondents to provide comments on the following:

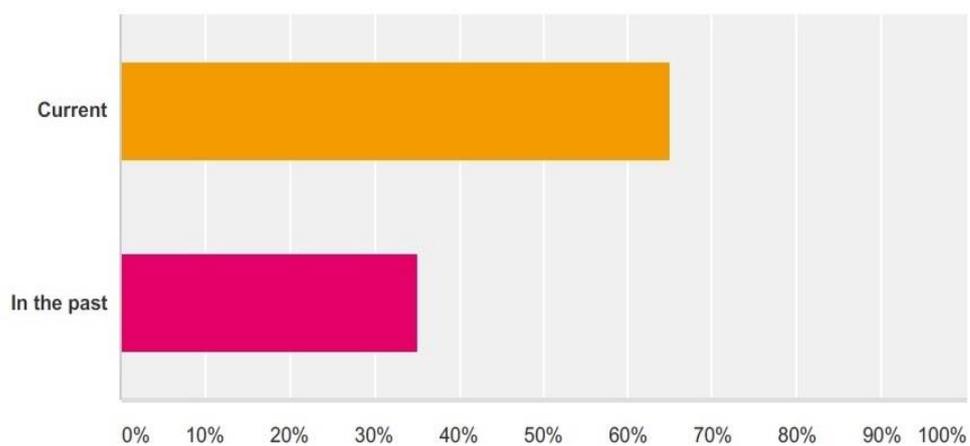
- What have you found to be positive about the mental health services?
- What have you found to be unhelpful about or missing from the mental health services?
- Outside of the mental health services, what barriers are there currently to an individual's recovery from a mental health difficulty?
- What suggestions do you have for things that can help in an individual's recovery?

This report is a thematic analysis of the responses submitted by participants. Comments were grouped under themes and are broadly presented in order of the frequency of mentions. Themes that were most frequently discussed have been stated as such within the section and are represented first under each question heading. Quotes were selected on the basis that they best illustrated the overarching theme.

Are you answering on your behalf or on behalf of someone else?



Is this experience of mental health services current or in the past?



What have you found to be positive about the mental health services?

Staff

“The people working in this sector are its biggest asset” is how one person described staff in the mental health services. Many of those who gave feedback discussed the kindness shown to them by nursing staff. People also described nurses as “compassionate”, “friendly”, “helpful”, “considerate”, “supportive”, “understanding”, “reassuring”, “attentive” and “professional”.

People also felt that many of their psychiatrists were equally supportive in their approach. Respondents described doctors as; “nice”, “understanding”, “caring”, “easy to speak to”, “reassuring”, “compassionate”, “intelligent”, “knowledgeable” and “helpful”. One individual wrote: “My health professional and his team never gave up on me.”

The central theme that emerged amongst those who reported a positive experience with staff was that they felt satisfied by their interaction when they felt that they were being heard. A participant wrote: “There are some amazing people working in the service who take the time to listen.”

Respondents also noted that although staff appeared to be under-resourced, they worked well despite time constraints.

GPs

People similarly praised GPs for the support they offered individuals experiencing a mental health difficulty. Respondents stated that they found GPs to be “knowledgeable”, “understanding” and that they provided “a helpful approach”. One person wrote: “My GP has been my most positive experience. She is open, honest and very easy to communicate with. No judging and willing to tell the truth even if it's not what I want to hear.”

The level of accessibility to a GP compared to that of other mental health services was also considered to be a positive point. However, one respondent felt that although their general practitioner was extremely supportive, the GP was “really very limited in what he can provide”.

Psychology and Counselling Services

A number of those who took part in the online feedback commended the support provided to them by psychologists and counsellors. People felt that they connected well with these professionals and that this form of “holistic” treatment was “delivered in a positive way and an effective manner”.

One individual wrote: “Any counsellors I have been to have been very kind and understanding of my situation, and I always felt better after counselling sessions.”

Another participant noted that it was helpful that they were referred to an occupational therapist when counselling was proving to not be beneficial to them.

Voluntary Sector Supports

Many of the respondents discussed the support they have received from voluntary organisations. Some of these people described turning to charities such as Pieta House when they were unable to get timely access to public services. One individual wrote: "I went to pieta house when I became ill, initially because I couldn't get an application to see a psychologist or a psychiatrist for a number of weeks."

Voluntary organisations were praised for being community based. A respondent noted that SOSAD provided a highly accessible service. Another person wrote: "The Samaritans free phone number has been lifesaving."

Additional Answers

A large proportion of respondents stated that they could feel a cultural shift taking place in Ireland regarding attitudes towards mental health, many attributing this to mental health awareness and anti-stigma campaigns. Courses such as Stresspac and WRAP were also considered to be beneficial to service users, where available. Community centres were also cited as positive.

People described how they felt that improvements were taking place in mental health services regarding the move towards a recovery approach. One person wrote: "There's a gradual move towards multi-disciplinary teams, holistic treatment and community integration rather than institutions and over-medication."

What have you found to be unhelpful about or missing from the mental health services?

Staff Shortages

The majority of people who took part in the online feedback stated that they feel that the mental health services are suffering from a shortage of staff. One individual stated that they believe that this shortfall has led to a reduction in the quality of care: "Staff are under severe stress and pressure leading to poor service."

A respondent described seeing "a skeleton service that does not cater for the individual unless you fight for that attention, and a hospital service that can merely offer 'safety and containment', as one healthcare provider put it to me. In fairness, this is very much due to overworked staff and a lack of resources".

Many people wrote about a shortage of psychologists and counsellors. One individual wrote: "I find that there aren't enough psychologists available to me in the area I live in. When there happens to be a psychologist on the team, they only stay for a few months, and it can take up to a year for them to be replaced."

Another person commented on the lack of therapists: "My CBT can be very spread out since I started. I might not have it for 3 or 4 weeks. The psychologist is stretched beyond her limits and has to see when she has a free appointment."

A respondent compared their experience in this country to another health service: "In Ireland I have felt let down by the system. I was treated in Australia last year for the same disorders. I was made to

feel comfortable around the clock with follow ups, and I had lots of one on one time with nurses and doctors who I felt really wanted to help.”

Medication

A considerable number of people who gave feedback were concerned with what they perceive to be an overemphasis on medication centred treatment. Respondents stated that they feel that medication was not a satisfactory long term solution and that additional treatment should be available to individuals using the mental health services.

Respondents felt that the prescribing of medications was often a hasty response by consultants. One person wrote: “Although the aim is to help people, the medication comes too quick into the conversation as if a chemical imbalance was everybody’s problem when it comes to mental health management.”

A prominent point in relation to medication was that many service users believed that they might benefit from talking therapies but that these were often not available. One individual stated: “There’s far too much drug therapy for issues such as depression and anxiety drugs which are only a temporary fix. Behaviour therapy at least gives you skills to manage your mental health.”

People also felt that they were not provided with enough information regarding the medications that were prescribed to them and what side effects might arise from receiving this treatment. Another frequent comment was that a more “holistic approach” should be taken when dealing with a mental health difficulty.

Continuity of Care

Another significant issue reported is the lack of continuity in the care provided by the mental health services and the problems that arise from this. A respondent wrote: “I saw a different doctor on each visit who had to read my notes each time and ask me the same questions, each with a different opinion and not very interested.”

This point was reiterated by another individual: “I rarely see my consultant, more often it's a member of her team, and as the team rotates every 6 months there's no opportunity to build up a relationship. I've often found myself meeting someone who has no clue of my history and so cannot understand the difficulties I'm facing at the time.”

Interactions with Staff

A large number of respondents felt that their psychiatrists dealt with them in an inconsiderate manner. Doctors were described by people as “cold”, “unfriendly”, “distant”, “unsympathetic” and “unsupportive” in their interactions.

One person wrote: “The psychiatrist did not make me feel very comfortable and there was always the underlying feeling that people in the mental health services were treating you like an unstable, second class citizen.” Another respondent stated: “I feel that doctors have limited insight, self-awareness and counselling skills, and cannot draw upon their own experience or intuition.”

The level of knowledge amongst staff of certain mental health conditions was also brought into question by one individual: "From having talked to people with OCD, BPD, schizophrenia, anxiety or addiction issues during my inpatient stays, a number of people feel like their particular illness is not prioritised or understood by the majority of medical personnel."

One person felt that staff acted defensively towards them when they decided to make a complaint regarding their treatment. A family member found it difficult to be heard by staff when highlighting the possible misdiagnosis of their relative.

Waiting Times

The time it takes to receive treatment was an issue that respondents found to be unhelpful. People reported waiting numerous months to have their mental health difficulty assessed by a consultant psychiatrist. A respondent stated that service users "should be able to lift the phone and immediately get help, not in 2 or 3 months".

Another person reported that they waited for three weeks to be admitted following a referral from a consultant due to the fact that there were no beds available at that particular time.

People also found the amount of time that it takes to gain access to counselling services and talking therapies to be unhelpful. One individual was concerned about the waiting times for adolescent counselling services in particular.

Community Supports

In the online feedback, people provided comments relating to "poor support outside of the hospital environment". Many of the respondents felt that they were no longer being supported once they left the hospital setting and that community care was greatly required. One individual wrote: "There is no community care [in my area]. I have quite literally got no one to contact if things get difficult again."

Another person felt that existing community services were being operated in a way that was not conducive to recovery: "Despite the introduction of multidisciplinary teams, inpatient units and supported housing are staffed exclusively by psychiatric nurses who, in the main, are reluctant to embrace holistic practice. Service users are overmedicated and live uneventful, depressing lives."

A respondent stated that we should "treat people who benefit from being in the community in the community". Another individual found it unhelpful that they were unable to access community services outside of their working hours.

Acute Facilities

A number of people's comments related to issues concerning the acute setting. One person wrote: "The design and layout of hospitals is entirely unsuitable for fragile individuals, and can be quite threatening and alien for some patients."

A respondent described their traumatic experience in an acute unit: "After being there for about an hour, extremely loud sirens went off and a group of men came running into the ward. The girl in the bed beside had tried to hang herself. She was resuscitated and assisted off the ward. This all

happened late at night. Not one nurse came to see me and our beds were right in front of the nursing station. I was more frightened in there than I was at home alone.”

One participant expressed concerns with the audibility of private discussions with doctors due to the thinness of the office’s walls. Other points raised regarding acute units were aggressive patients, dilapidation, damaged furniture and the lack of gender segregation of service users.

Family Involvement

Another issue that emerged from the online feedback was that people felt that they didn’t have all the information that they required to understand a mental health condition. This was particularly the case for family members of someone experiencing difficulties. Respondents also reported feeling that it was difficult to access supports for themselves as family members.

One individual wrote: “There are no family support services for family members of a person with mental illness. No counselling offered, people have to fight for it when they have enough to deal with.” Another person also highlighted this issue, stating that there’s a “lack of options in terms of support for my family members who didn't know how to help me or what was happening to me”.

Greater involvement in the recovery process was suggested by one respondent: “When someone needs help but they are too ill to seek it themselves, it should be easier for a family member, next of kin, to involuntarily admit them to the mental health services.” A lack of communication between staff and family members was also discussed in the online feedback.

Out of Hours Services

A lack of “out of hours” services for people experiencing a mental health crisis was discussed by respondents. One participant questioned why they could not be seen by a staff member other than a consultant in a crisis: “[It’s unhelpful] that they can get away with refusing to see you, even if you're actively suicidal. That they can refuse to allow you to see other team members even if you've already been referred or promised you would be.”

Transparency and Accountability

Another issue that was raised was a lack of transparency and accountability in the mental health services. One respondent reported: “There’s unwillingness to acknowledge patients’ rights, a lack of supervision of staff, no valid independent complaints process, vagueness around qualifications and a mentality of not allowing any challenge or questions.”

Additional Answers

Some of the people who gave their feedback discussed other concerns that they feel are not being dealt with effectively. One person discussed a “lack of deaf awareness training” and believes that “deaf people have no access to the services”. Another participant wrote: “There is very poor treatment for anorexia, a very outdated approach, an element of family blaming and a complete ignorance of evidence based approach of dialectical behaviour therapy.”

Several people discussed administration issues such as the lateness of replies to letters, notification of appointments without sufficient preparation time and issues around whether a person experiencing a mental health difficulty is in a position to correspond with the service in this manner. One individual wrote: "I received a letter after the OT had finished asking if I required further assistance. At the time I was struggling to cope and I didn't reply. When I found the letter and reread it, it said if I didn't reply I would be taken off the list and would have to be re-referred by my GP."

A lack of appropriate addiction services was also described by a respondent: "I struggled with alcohol issues but didn't feel that I could talk to my GP, psychologist or psychiatrist about it because I felt that they wouldn't do anything about it and just refer me onto AA."

There were also people who found the number of support groups available insufficient and people who believe that there are too many groups leading to confusion on who to make contact with. Another issue in relation to groups raised was "the negative attitudes of reform groups, who portray such a negative view of all services, would deter people in crisis from seeking help".

Although there has been a lot of work done around the destigmatisation of mental health difficulties, some of those who shared their feedback believe that there is still more work to do in this area.

Outside of the mental health services, what barriers are there currently to individuals' recovery from a mental health difficulty?

Stigma

Respondents felt that the greatest barrier to an individual's recovery was the stigma associated with experiencing a mental health difficulty. One person wrote: "In spite of efforts, mental health has a stigma attached and doesn't attract sympathy, tolerance or understanding in the same way as physical illness."

The feedback suggests that people find it difficult to discuss their mental health difficulty. A respondent reported: "Admitting to a mental health issue for some can be seen as a weakness. It's not as acceptable as a physical health problem." Another participant felt that this was particularly prevalent amongst the male population: "Stigma definitely needs to be lifted and especially around men. They need to be encouraged to open up more."

"People avoid the conversation about mental health," wrote one person. Other respondents discussed the difficulty of having to "come out" to people about their mental health issues and described feeling "ostracised" by their community. It was also noted that stigma can lead to an individual not seeking help when they need it.

Access to Services

A particularly common response received was the lack of support offered to people once they left an acute unit. Many of the respondents felt that there were no "follow ups" and that there was a lack of continuity in care that should be ongoing, and in their communities. One person wrote: "When you're not in a service you are fighting by yourself."

People also felt concerned by the lack of access to 24 hour services in certain parts of the country for those experiencing a mental health crisis. Respondents also described a disparity between the services that were available to them in rural areas compared to that of the urban setting. One person described how there were no Child and Adolescent Mental Health Services available to them where they live: “The only option was Dublin and the physical, mental, and financial strain of having a child so far away is not taken into account.”

Another participant described the difficulty in accessing services for those in employment: “I think that all the programmes on offer only suit people who don't work. I can't afford to not work so I can't attend an outpatient programme during the day. They need to cater for people that work and have evening or weekend programmes.”

Financial Difficulties

A significant barrier to recovery reported by respondents was difficulties in financial circumstances. People discussed issues regarding access to employment, government charges, an inability to afford adequate healthcare and counselling, an inability to socialise, a lack of access to affordable housing and maintaining a job when experiencing a mental health difficulty.

A person described the effect that financial difficulties can have on an individual's health: “The severe level of poverty through not being able to work has had a huge effect on my life. With the cut back of the fuel allowance alone, people like me end up spending a lot more time at home. Cold, therefore tense, hungry and even more reluctant to get out of bed or look after my hygiene.”

Problems in accessing social welfare and how certain departmental procedures can prevent a person from participating in the workplace were described. One respondent wrote: “Benefits are administered in such a way as to frighten people out of trying to find work when they would much prefer to work.” People also described the middle ground of being “too sick to function but not sick enough for help to be given” and the narrow terms of eligibility for Disability Allowance.

One person wrote about the impact that this can have on personal relationships: “I have worked all my life and now I have to depend on my partner. I am entitled to nothing and it feels awful to be so dependent on someone to pay my medical bills especially as we are not even married.”

Uncertain employment contracts and work instability was said to have an impact on a person's mental health. A respondent described the strain that taking time out from work can have on a professional life: “When you need time away from work to recover it's a challenge on an employer's patience and their understanding runs thin.”

Information

A lack of information on mental health and the availability of services was also seen to be a factor in inhibiting recovery. People felt that supports and services should be advertised and that mental health education should not be limited to those who have experienced mental health difficulties. One person also felt that the messaging in anti-stigma campaigns was not in line with the attitudes of clinicians.

Respondents felt that there was a shortfall in information regarding statutory rights in the areas of employment and discrimination as well as entitlement to social welfare payments. Another person

mentioned that support groups were often communicating via social media and believes that those who don't have access to these platforms were at a disadvantage as a result.

Participants also felt that family members of those experiencing mental health difficulties often did not fully understand their relative's condition enough to properly support them and that they needed to be educated in this area. One person suggested creating a campaign similar to that of the drink driving advertising that could help create greater public awareness. Another respondent felt that the media gave a "negative portrayal of long-term mental illnesses".

CAMHS

The transition from CAMHS into adult mental health services was a concern for one individual: "From my experience of the service for adolescents who then pass into young adulthood, the service is very limited and can be very traumatic for patients who have to leave behind the counsellors and psychiatrists etc."

Another person wrote: "There are not enough services that are not formal CAMHS. We need more supports for young people like Jigsaw. Schools cause and add to stress. Schools do not do enough to help young people learn how to look after their own mental health and deal with stress".

Additional Answers

A number of people felt that medication was overprescribed and that people often "don't need medication, just someone to listen". The inability to easily access affordable counselling or alternative therapies was also discussed.

Some people felt that when they went to their GP regarding a mental health difficulty, they had been dealt with in an inappropriate manner. Respondents attributed this to GPs "not fully understanding various mental health problems". One person wrote: "I was once told by a GP that 'I can't be too bad as my nails were clean'. I actually had suicidal thoughts at the time."

It was stated by some participants that Ireland's alcohol culture creates barriers for individuals working towards maintaining good mental health. Another person wrote: "Treatment for addiction problems must be ongoing to help prevent mental health or criminal issues."

A respondent was concerned about the lack of childcare available to them when they needed to access residential care. Difficulties in accessing affordable amenities to improve physical health were also highlighted. One respondent wrote about a lack of recovery plans and another individual discussed harmful content on social media.

What do you think needs to happen to improve how mental health or other public services support individuals' recovery?

Resources and Funding

A large proportion of those who took part in this online feedback felt that in order to improve mental health services, greater funding needs to be provided by Government. People felt that the

mental health services were under-resourced, particularly in the area of staffing, and suggested that more funding be allocated to recruit sufficient staff to allow more one-to-one care and to facilitate a “joined up” service.

People felt that resources were lacking locally, and that community nurses and additional multi-disciplinary staff needed to be recruited to allow for earlier intervention. Respondents also felt that services for children and adolescents were operating without sufficient numbers of staff. Counselling services were also seen to be significantly under-resourced and in need of improvement.

Out of Hours and Community Services

Another point made by respondents was that they felt that services needed to be accessible on a 24 hour basis. One person wrote: “All services should be there for everyone night and day.” “What happens if you are having a bad time or are suicidal and it is the weekend or outside 9-5 hours?” questioned another respondent. People also stated that crisis services should be available in the community for those in distress.

The Emergency Department was also considered to be an inappropriate environment for a person experiencing a mental health crisis. One person stated: “Seriously ill people shouldn’t have to go through normal A&E as 8 hours for someone distressed is not acceptable and most staff do not know how to handle them in this busy environment.”

It was also felt that a non-clinical setting would be more beneficial to service users when meeting with mental health staff. One individual said that they would like to have “somewhere to go to have a chat and a cup of tea that is not a medical place”.

A respondent suggested: “All areas should have support groups facilitated by a trained individual and this should be at least weekly. Again these should be supported and run by the HSE. There should also be support groups for families if needed.”

Acute setting

Respondents offered suggestions for improvements to the acute setting from the perspective of service users and family members. Some of those suggestions focused on a lack of appropriate visiting areas: “My kids would not come to see me when I was in hospital as it was scary for them with no separate place for them to see me when I was in the acute ward.”

An issue that concerned some of the people who gave feedback online was the fact that people with varying degrees of mental health difficulties are resident together in the acute setting. One person thinks that there should be “separate units with different types of mental health issues”.

People also felt that acute facilities were not always a positive environment and that treatment in a community mental health centre would be preferential to them. One individual stated that hospitals should only be used for “brief emergency stopovers”.

Service Disparity in Different Locations

Some people discussed a disparity between the services available in the capital and the rest of the country. Rural areas were described as being underserved by mental health services and it was felt that community mental health services should be within easy access to people throughout all

regions. A respondent wrote: "I've been told that the therapy I need for my diagnosis is not available to me in my area."

Medication

"Decrease the over reliance on medication as the main solution" was a suggestion offered by one respondent that could aid an individual's recovery. People felt that those experiencing a mental health difficulty primarily need support and that additional assistance in the areas of counselling, nutrition, fitness and other alternative therapies could be beneficial.

One individual discussed the positive impact that medication has had for them in their recovery: "The medication I am on now has literally changed my life and yet I was reluctant to go on it initially as my trust in the system had been exhausted."

Recovery Plans

A more structured and individualised recovery model was discussed by some respondents. These people felt that the existing system was a "one size fits all approach" and that those in recovery needed guidance in many areas of life. A participant wrote: "A plan needs to be set out with stages of recovery and goals in relation to personal issues, employment and social interaction with constant interaction from GPs, psychologists & psychotherapists."

It was felt that care should be ongoing and that there needs to be more in the way of employment supports. One person described how the service should "encourage people in treatment to go back to work. Even if it is charity work. It helps to gain back dignity and to be part of the community and society". Another individual stated that there should be a greater emphasis on programmes such as WRAP.

Talking Therapies

Many people discussed a greater need for counselling services, cognitive behavioural therapy, dialectical behaviour therapy and other talking therapies. It was felt that there is too much of an emphasis on medication-based treatment and less focus on a form of care that people believe might be significantly beneficial to those experiencing a mental health difficulty.

Some of the respondents who feel that talking therapies could improve recovery stated that they believe that these were not available to people due to a lack of funding.

Staff Interaction

Many of the respondents who took part in this online feedback felt that staff within the mental health services didn't fully understand the experience of someone dealing with a mental health difficulty, often writing that medical professionals lacked empathy. A participant wrote: "There's a huge difference in studying mental health disorders for years and actually living these disorders 24/7. Some professionals display a real sense of lack of understanding."

It was also felt that people were not always fully consulted regarding their treatment and that "doctors need to stop seeing patients as a condition". One individual wrote: "Psychiatric staff need to be fully assessed on a monthly basis to test their interest and knowledge of someone's mental

health. Situations need to be drawn up and staff need to be competent in answering them and be truthful.”

Peer Led Services

People felt that those who have experienced a mental health difficulty were well placed to offer advice and guidance on how mental health services should operate. Respondents described involvement at all levels. One person stated that there should be “service user representation on management, not tokenism”.

Education

Respondents commended public awareness campaigns in the area of mental health such as #littlethings. Participants felt that there had been considerable destigmatisation in recent years, however further work needed to be done. People suggested that mental health education be introduced to workplaces to create supportive employment environments and introduced to schools to start personal mental health awareness from an early age.

Other suggestions included “pop up information kiosks at festivals, fairs, schools and GAA clubs”. Another person would like the HSE to “take out lots of pages week after week in newspapers and radio until everyone knows where they [the services] are, and how to go there because people still don’t know”.

Some people felt that staff should be educated in user experience. One individual wrote: “I may not have schizophrenia or voices in my head but I'm still suffering from a mental health issue, take me seriously. They don't realise the profound effect they have on patients.”

Family Involvement and Support

Participants in the online feedback discussed a lack of dialogue between mental health staff and families of service users. One person wrote, “There needs to be more communication with family members of the client who is availing of the service because it is the family who are often the carers and are doing so in the dark because the services will not communicate with them.”

It was felt that families were often left unsupported by the services. A respondent said: “When my husband had his breakdown I had a small baby and no one to turn to. I was the one who had to look after him when he came home, I had no idea how to handle him. Even now I don’t know what I should get him to do.” People also felt blamed for their family member’s condition by staff.

Additional Answers

Other improvements to how mental health or other public services support individuals' recovery suggested by people included consistency of clinical staff, observing best mental health practice in other nations, greater controls for GPs and adequate mental health training for public sector workers in Government departments. It was also suggested that a specialist Garda team be set up to specifically deal with individuals experiencing a mental health crisis.

Some stated that improvements needed to be made in accessibility for deaf people in Ireland. These issues concerned an inability for deaf people to communicate with staff due to the lack of the provision of an interpreter when using mental health services.

A respondent suggested that the Health Information and Quality Authority should take a supervisory position: “HIQA should have oversight of mental health services along with other health services because the quality of the buildings, the staffing and the support services available to service users is utterly inadequate and under-resourced.” Another person made the suggestion that a mental health ombudsman be put in place.

One individual called for a redress scheme to compensate people who have come to harm whilst under the supervision of mental health services in Ireland.