



# Mental Health Services The Way Forward

*The perspectives of young people and parents*

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# Contents

Foreword	2
Research Team	3
Acknowledgements	3
Background	4
Objectives of the study	4
Report format	5
Section 1: Literature Review	6
Section 2: Methodology	8
Choice of research design	8
Focus group procedure	9
Sampling and recruitment procedure	10
Validity of the sampling procedure	10
Describing the participants	11
Ethical issues	11
Data analysis	12
Section 3: Results	13
Defining mental health problems	14
Barriers to accessing services and support	17
Accessing services: consent and confidentiality	20
The quality of care: contributing factors to favourable and unfavourable experiences	22
Summary of key findings	29
Section 4: Discussion and Recommendations	30
Reflections on the study	31
Recommendations	33
Conclusion	34
References	35

## Foreword

Youth mental health is the major health issue for young people worldwide. Recent research carried out with adolescents aged between 12 and 15 in Dublin secondary schools has revealed that 15.6 per cent of those studied met diagnostic criteria for psychiatric illness (Lynch et al, 2006). A number of reports emphasise the need to develop and improve mental health services for young people (the Department of Health's *Planning for the Future* (1984), *Development Plan for Child and Adolescent Psychiatric Services in Ireland* (2003), and *A Vision for Change* (2006); *A Better Future Now*, 2005, Irish College of Psychiatrists; Dooley & Fitzgerald's *My World Survey*, 2012). This study is a unique insight into young people's perceptions of mental health services in Ireland.

Incorporating young service users' views into the planning and delivery of services is essential. There is an ethical stance that to consult implies that action will be taken and to consult without intention to act on recommendations is ethically unsound (Neill, 2005) and we hope that this report will increase awareness of the issues of concern that service users have raised and that services will strive to improve the experience for future service users.

The research team were very privileged to have the opportunity to meet with services users and some of their parents and to hear about their experiences of adolescent mental health services in Ireland. All participants hoped that the feedback they gave would help improve services for future service users and we learnt a lot from them.

The transition-year students who participated in the focus groups gave us a valuable insight into issues regarding stigma and awareness of mental health issues in school. There were many recommendations from both students and parents to reduce the stigma of mental illness and also suggestions that would reduce some of the barriers to accessing services for young people.

We hope that this report will highlight the voice of service users and that their feedback will be responded to by mental health policymakers and service providers.



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## Background

It is accepted both in Ireland and internationally that mental health services need to become youth focused and efforts need to be made to improve accessibility and to reduce barriers for young people with mental health problems. Similarly, it is now accepted that involving service users is beneficial to the development of health services (Dewan & Read, 2001; Hart et al., 2005). Furthermore, the need to consider the opinion of parents/carers has been increasingly recognised (Keogh, 1997) as has the role that parents play in deciding whether or not to seek to access mental health services for their children (Sayal, 2006).

Despite the widespread consultation that has taken place in compiling recommendations for service development for young people in Ireland, the opinion of young service users has not been sought. *A Vision for Change* (2006) recommends the involvement of service users at all stages of service development. The strategic actions recommended in *The Views of Adult Users of the Public Sector Mental Health Service* (Dunne, 2006) highlights the necessity of a similar collaboration with young people and this is one of the main aims of this study.

The widespread awareness of the value of involving young people in shaping the services of the future has not been translated into the active engagement with young service users that is fundamental to this process. Therefore we currently lack an essential perspective: the views of young people on how to develop the type of services that they would want to attend. A comprehensive understanding of the

experience of care for young people with mental health difficulties is essential to improve accessibility to and engagement with responsive mental health services. This report provides this essential data by detailing the experiences and views of a group of young people as to how services need to adapt to meet the needs of the population they serve.

### Objectives of the study

The overarching aim of this study is to explore, from both a service user and parental perspective, the experience of accessing mental health care for young people, and to identify what young people need from services. We hope to explore the barriers to accessing services and enablers to successful engagement with the mental health services. We hope to summarise factors associated with adverse experiences of care and develop recommendations to be incorporated in the model of mental health service provision to young people.

The aim of meeting with young people in transition year, who have not been service users, is to explore their awareness and understanding of mental health problems and their treatment. The focus will be particularly on the issues that would prevent them accessing care, should the need arise. The views of young people who have not attended services will be compared with those who have.

The fundamental goal is to use this information to inform the development of a responsive, recovery-oriented model of mental-health care delivery and help tailor it to young people's needs.

### Report format

The report is divided into a number of sections. Section 1 provides an overview of the key literature relevant to the current research. Section 2 details the methodology used, presenting key information on the procedures used. Section 3 presents the results, focusing on the key themes that emerged from the analysis of the data collected. Section 4 concludes the report with a discussion of the findings and recommendations for services.



## Section 1: Literature Review

Studies have shown that 75 per cent of mental illness begins before 25 years of age (Kendall & Kessler, 2002), yet only 29 per cent of those affected contact a professional service of any type (Sawyer et al., 2000). Given the poor prognosis for adolescents and adults with untreated psychiatric symptoms these low rates of access and treatment are very concerning (Hickie et al., 2001; Weissman et al., 1999).

Ireland's recent *My World Survey* (Dooley & Fitzgerald, 2012) confirmed that there was a peak in mental health difficulties in the late teens and early twenties in Ireland. The authors found that this peak in mental health difficulties was 'coupled with a decrease in protective factors such as self-esteem, optimism and positive coping strategies'.

The Australian Institute of Health and Welfare (AIHW) report on the health status of youth in Australia (Moon, Meyer & Grau, 1999) highlighted that mental health problems are the major burden of disease for this age group. Twenty per cent of those between 12 and 16 have mental health problems, rising to 27 per cent of those between 18 and 24 (Moon et al., 1999), results that are similar to studies of American youth (Irwin et al., 2002). The reluctance of young people to seek help for mental health problems is increasingly acknowledged as a challenge to effective early intervention approaches. Engaging in appropriate help is widely recognised as a generic protective factor and early treatment and intervention are vital during adolescence and young adulthood (12–24 years) because of the high prevalence of mental health problems at this stage

of life. A school-based Norwegian survey of 11,154 Norwegian teenagers aged 15–16 years reported that even at the highest symptom levels for anxiety and depression only a third had sought professional help (Zachrisson, 2006). The term mental illness is still frightening to most people; mental health is actually the opposite, meaning something positive. Mental ill health is a more accurate term, as it indicates that mental ill health occurs across a spectrum of severity and persistence, suggesting that the change may be transient and that recovery is likely (Association of Child and Adolescent Mental Health Special Interest Group in Youth Mental Health in Ireland, 2011)

Awareness of a mental health problem by self or others is a starting point. The actual symptoms of mental health problems and mental disorders play a smaller role than might be expected in prompting help-seeking (Rickwood, 1994). A wide range of factors are involved, including appraisal of a problem as something to seek help for, willingness to seek help and social norms that encourage such behaviour, access to appropriate services and choosing a choice of help. We were interested to



know what factors affected adolescents in Ireland, so we worked with focus groups of adolescents in transition years to hear what their opinions were about the issues regarding mental health as well as recognising mental illness in peers.

The literature for all types of health and mental problems demonstrates that if young people want to talk to anyone it is generally someone they know and trust (Booth et al., 2004). They are more likely to seek help from their friends and family for personal and emotional problems than from other sources (Rickwood, 2005; Boldero & Fallon, 1995). Of concern is the observation that the intention of adolescents and young people to seek help decreased as their level of suicide increased; at this stage they became more likely to indicate that they would not seek help from anyone (Wilson et al., 2005; Deane et al., 2001). The mental health problems commonly experienced by young people (depression, anxiety and substance abuse) similarly act to negate help-seeking by increasing social withdrawal and young people's preference to keep their distress to themselves (Gould et al., 2004; Rickwood, 2005; Dooley & Fitzgerald, 2012).

In the recent *My World Survey*, a national study of youth mental health in Ireland, 14,306 young people aged between 12 and 25 participated and 77 per cent of them reported that they would obtain information or support from the internet for their mental health (Dooley & Fitzgerald, 2012, p. 60). There are many resources available now online, providing support and information for young people with mental health problems. Computer-mediated

communication is an integral part of life for young people and many prefer to use the internet to look for information and to seek support than to meet professionals. ReachOut.com is run by the Inspire Ireland Foundation, which is a charitable organisation with a mission to help young people lead happier lives, and it provides information and support for young people as well as moderated forums around mental health-related discussion topics. The use of e-health applications has become a popular resource for young people with anxiety and depression (Christensen et al., 2011).

Mental health literacy is a term used to describe the ability to recognise mental health problems, knowledge and beliefs about risks, causes and effective treatments, and knowledge of how to seek mental health information and services (Jorm et al., 1997). Lack of recognition of mental health problems among young people and their parents is a major barrier for help seeking (Zachrisson et al., 2006). Young people are more likely to seek help when they recognise that they have a mental health problem and have the knowledge, skills and intelligence to seek help. Furthermore, many people with mental disorders delay getting help (Kohn et al., 2004), but they are more likely to get professional help when it is suggested by someone in their social network (Dew et al., 1991).

## Section 2: Methodology

### Choice of research design

The primary aim of the study was to gather direct feedback from young people and their parents and as a result a qualitative approach was adopted. The methodology and analysis were influenced by the Mental Health Commission survey, *The Views of Adult Users of the Public Sector Mental Health Services* (Dunne, 2006), and a UK study of patients' perspectives on mental health in primary care (Lester et al., 2005), which had used a similar approach.

The advantage of qualitative research is the depth of the information it provides, studying phenomena 'in terms of the meanings people bring to them' (Denkin & Lincoln, 1994, p. 2) and using 'a holistic perspective which preserves the complexities of human behaviour' (Black, 1994, p. 425). The problems are not simply identified: the specifics of the difficulties are explored, allowing the respondent to detail very particular aspects of a service that need to be addressed.

Central to the present research is the active participation of young people in the process. The need to specifically involve young people in the consultation process is highlighted in the conclusions of the 2004 World Health Organisation conference entitled 'The Mental Health of Children and Adolescents', which stated 'Actions need to be planned in consultation with end users, and take place with the consent and participation of those at whom they are directed. This includes children and adolescents, who need to be consulted and involved in ways appropriate to their age and development.'

Eliciting views from young people about their experience of child and adolescent mental health services is central to the thinking of *Every Child Matters* (Department for Education (UK), 2004) and to the modernisation of the UK Child and Adolescent Mental Health Services (CAMHS) (Aynsley-Green et al., 2000). Children as young as 10 have been previously shown to have enough understanding of mental health to participate in focus groups (Roose & John, 2003). Adolescents have found focus groups to be an appropriate and acceptable way to give their views on mental health services (Nabors et al., 2004).

Young people have demonstrated a willingness to engage in collaborative projects to explore their opinions and have provided insights into their thoughts on the daily routine of inpatient care, the therapies available and how challenging behaviour is managed (Teggart & Linden, 2006).

There has been considerable progress in the move to consult with young service users. The National Bureau of Scotland has published a synopsis of the themes identified by young people with respect to mental health services (*Mental Health Services: What Children and Young People Want*, 2004). They can be summarised as follows: services should be age appropriate with flexible provision of appointments and provision of evening and drop-in services. The transition between CAMHS and adult services needs to be addressed. Staff in mental health services need to be skilled in working with young people and young people need the opportunity to establish relationships with staff over time. Mental health professionals need to value

young people's ability to consent, their right to confidentiality and their need for privacy.

The practice of involving young service users to shape the direction of service developments has been very successfully incorporated into service planning in a number of centres. For example, the London Borough of Chelsea and Kensington has successfully worked in partnership with young people to inform service planning and has demonstrated clearly the links between its consultation process and the model of service it provides (Teggart & Linden, 2006). Furthermore, the need for mental health services for young people to be easily accessible and responsive has been included in service models elsewhere, such as The Zone in Plymouth, UK, and the Orygen Youth Project in Melbourne, Australia. We hoped to explore different ways in which we could promote more choice for young people using the concept of choice meaning 'the power to make decisions' (Rankin, 2005).

Participation models discussed by Street & Herts (2005) help service providers think about how to implement changes based on young people's views and to think about how young people can be involved in decision-making throughout the service. The ladder of participation comprises eight stages or levels of participation, ranging from non-participation including tokenism, through to young people being consulted and informed, to the highest level when young people initiate decisions and share them with professionals.

### Focus group procedure

The guidelines for focus groups described in the Mental Health Commission Report (Dunne, 2006) were followed. The groups were of approximately 90 minutes duration with a fifteen-minute break for refreshment. Groups were held in non-clinical settings convenient for participants. There was a moderator and co-moderator present at all groups and both were mindful at all times of the potential for participants (particularly in the service-user groups) to become stressed or anxious.

All participants were reminded at the outset of the group of the intention to tape the session to ensure accuracy. The groups began with everyone introducing themselves, starting with the moderator and co-moderator. The participants were advised that they could introduce themselves on a first name only basis if preferred.

A literature review was carried out to develop a 'Topic Guide', which informed the agenda for discussions at the focus groups. The moderator used the 'Topic Guide' to help ensure that the discussion remains focused.

The moderator and co-moderator alerted the participants when the time for session close was approaching. If participants wished to run over time, this was facilitated.

It was hoped that parents would take part, but the number who did was limited. Given the nature of the interaction with this group, it might be best to consider the data collection with parents as interviews rather than focus groups. However these

interviews, particularly where more than one parent took part, were guided by the focus group procedure.

### Sampling and recruitment procedure

Groups were established for users of youth mental health services and young people who have not been service users, and interviews conducted with parents. The sampling procedure adopted is a non-probability, purposive procedure, whereby the researcher targets potential participants who are in a position to provide an insight into the topic at hand. Barbor (2001) refers to this approach as the identification of outliers who might not traditionally have been included in research. The involvement of both young people with experience of services, as well as their parents, and those who have not been exposed to these services, contributes to the representation of diverse groups. The aim is to ensure that a range of perspectives emerges from the discussions.

The National Service Users Executive was contacted to seek their input and advice on inviting service users to participate. National organisations and groups working with young people including Shine, Barnardos, Headstrong, Spun Out, Aware, Mental Health Ireland, GROW, Aspire, Rainbows Ireland, Parentline, ISPCC, OCD Ireland, Foroige, Bodywhys, Teen Counselling, Irish Advocacy Network, the Ombudsman for Children and the Mental Health Commission were also informed about the study.

To encourage participation we asked organisations to either advertise on their websites for us or to mention it to service users attending their services. A mobile phone number was provided and a

dedicated email was established for the study.

Schools were purposively selected from the database of schools and were reflective of differing levels of deprivation and of urbanisation. In 2009 we wrote to 80 school principals nationally inviting students from their transition year to participate in the study, but no school came forward. In 2010 transition-year students attending a national mental health placement in St Patrick's University Hospital were also approached and asked if they would like to participate in a focus group during their placement. These students represented students from secondary schools nationally. They came from urban and rural settings and a wide range of schools, including single sex, mixed, private and public, so we felt their views were representative of transition-year students in Ireland.

All respondents were given a letter of invitation, an information sheet detailing the format of the groups and a sheet detailing the topics that would be discussed. For those participants under the age of 18 the young person's consent was required in addition to parental consent.

### Validity of the sampling procedure

Service users had many different experiences of mental health services. Some had been being in an adolescent ward, while others aged under 18 had been admitted to adult wards. We had young people who had been in secure care as well as in locked adult wards. The service users came from both urban and rural parts of Ireland and, although their number was small, we feel that their experiences were representative of the adolescent



mental health services in Ireland. We agreed not to name specific institutions as the aim of the study was to hear about service users' experiences and we wanted them to feel free to express their views without being afraid that it would affect their relationship with their mental health service.

The inclusion of parents (albeit a small group) provided an additional insight into the context of the young people's experiences. The aim here was not to assume that the parents' views would validate the information from the young people, or indeed vice versa. However the parents have had an experience that parallels that of their children, thus providing them with an important perspective on their family's involvement with the mental health services.

The young people who contributed to the non-service user groups were not invited to take part in the research for their experiences of mental health, but as a voice of the wider population. Their views on mental health and mental health services were, in part, sought to provide an insight into the public face of these issues. In addition, we were conscious that as potential users of these services their attitudes and perceptions would broaden the scope of the findings.

Within this context, we feel that the principle of theoretical generalizability should be reflected in the breadth of the findings. Sim (1998) describes this principle as the extent to which the findings of qualitative research, and particularly focus groups, present sufficient generality to extend to individuals beyond the immediate participants, but who are similar to the participants. Given the groups involved in the research and the mechanisms by which they

were contacted, we are confident in the theoretical generalizability of the findings.

### Describing the participants

Eight focus groups and two interviews took place. There were six focus groups with young service users, two focus groups with transition-year students, and two interviews with parents who had experience of their teenager using the mental health services. Overall 24 young service users, 18 transition-year students and 3 parents took part. The 24 young people with experience of mental health services were aged between 15 and 24. In total 18 female and 6 male service users took part. There were 2 female and one male parent whose young people had experience of the adolescent mental health services. The service users had experience of child and adolescent and adult mental health services. Their combined experience included mental health services in the HSE, voluntary and independent health sectors. They came from urban and rural backgrounds; some were still in school, while others were unemployed or attending a third-level course.

The transition-year students were aged 16 and 17 years of age and there were 10 female and 8 male participants. They were representative of transition-year students nationally.

### Ethical Issues

Ethical approval was received from the National Ethics Committee of the Royal College of Physicians in Ireland and the Ethics Committee of St Patrick's University Hospital, Dublin.

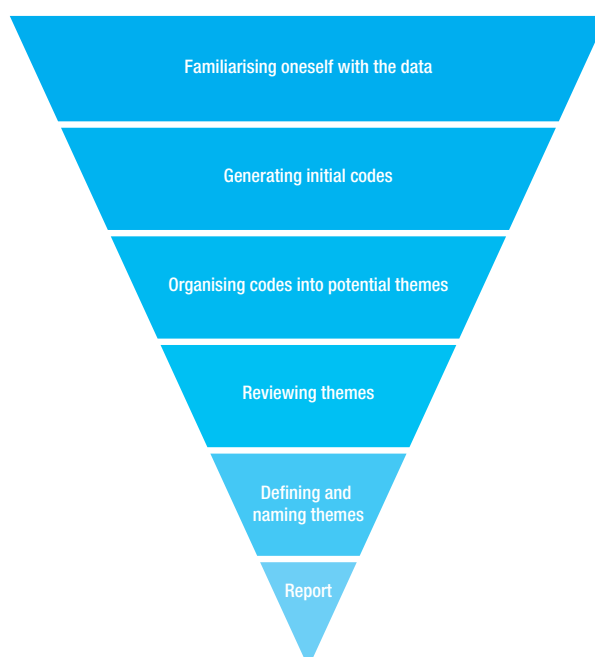
Incorporating children's and young people's views into the planning and delivery of services is essential. However Curtis et al. (2004) note that there has been no report of change taking place after the views of children and young people are elicited. They state that while methods for collecting the views of young people have been developed, the ability of services to respond to their recommendations lags behind and the pace of change is slow. It is important that the feedback from this study is reported and also acted upon (Worrall-Davies, 2008).

In addition to these broader issues there were a number of practical issues that needed to be addressed. Participants under the age of 18 required parental consent, which was secured in each instance. In addition, participants were not offered any incentive to take part and the only compensation offered was the reimbursement of travel expenses. A key issue was the protection of confidentiality and the requirements of data protection legislation. The research team were mindful of these issues at all stages of the research.

### Data Analysis

Each focus group discussion was audiotaped and subsequently transcribed. The transcripts were analysed to identify themes and sub-themes guided by the process outlined by Braun and Clarke (2006), which is described in Figure 1. Repeated reading of the data allows the reader to generate initial codes, which represent meaningful pieces of information relevant to the topic. These codes are reviewed and links between them inform the development of potential themes. These themes are then reviewed

and revised to ensure that they represent the most meaningful issues within the data. The penultimate stage involves the naming of the themes, as the intention is that the names capture the essence of the theme.



*Figure 1: Stages of thematic analysis applied*

The researcher carrying out the analysis (CD) was mindful throughout this process of information emerging that did not fit with the themes identified up to that point. The analysis of the data was conducted using NVivo (Version 7, QRS). We supported the validity to the themes identified by establishing concordance between groups and findings are reported as they were identified across the groups. In addition, once the analysis was complete the coding and themes were reviewed by another member of the research team.

## Section 3: Results

This study provides rich qualitative data about the experiences and views of young adult services users, young adult non-service users, and parents of service users. Findings are discussed under the following themes, identified from inductive analysis of the data:

- Defining mental health problems
- Barriers to accessing services and support
- Accessing services: consent and confidentiality
- Quality of care: contributing factors to favourable and unfavourable experiences

An overview of these themes, and key sub-themes identified within them, are presented in Figure 2 below. This chapter presents these themes supported by indicative quotes. To highlight the variation in the data all quotes are followed by the number of the focus group or interview that generated the comment (in brackets).

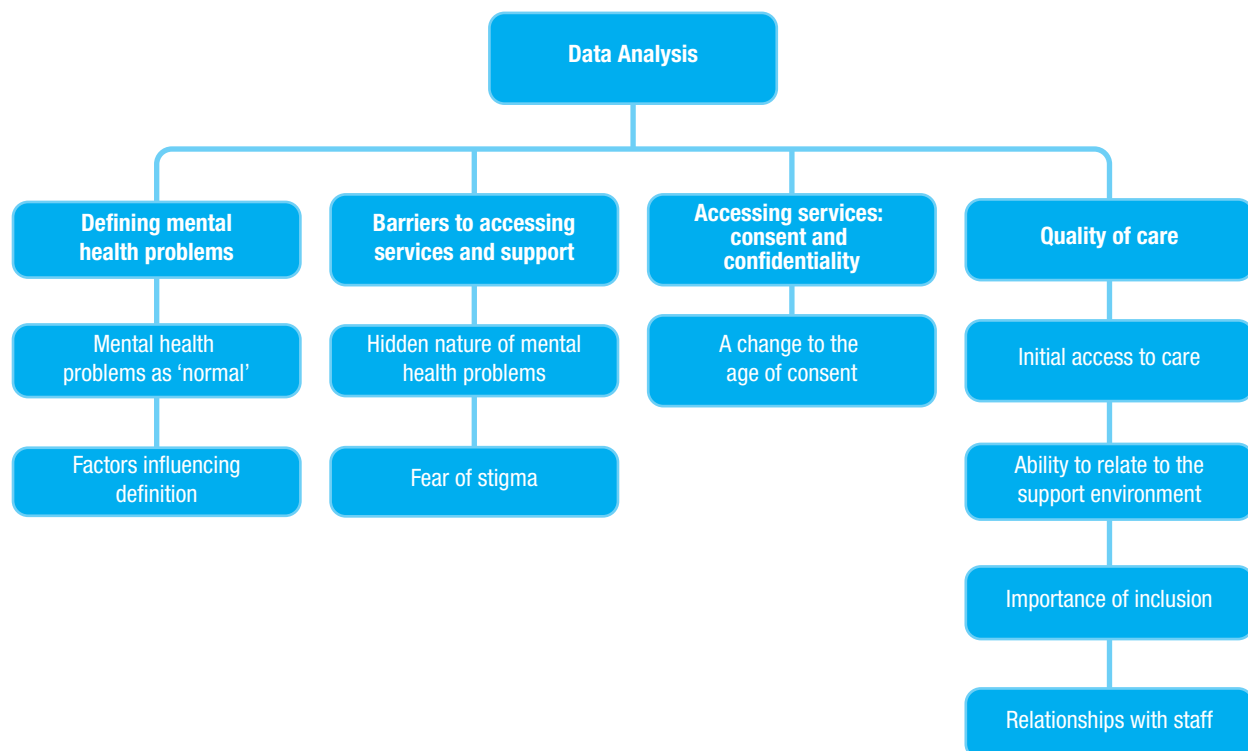


Figure 2: Overview of key themes identified during analysis

## Defining Mental Health Problems

A range of terms were used to define mental health problems. Firstly, mental health was described as an everyday constant experienced by all: *'whether it's good or bad everyone has it'* and as *'a term that encompasses absolutely everyone's state of mind rather than these typical illnesses'* (1). Terms used to describe mental health problems included: *'anorexia, bulimia, body dysmorphia, ranging now from bipolar now to schizophrenia'* (3); *'depression', 'ADHD', 'stress', 'psychotic' and 'self-harm', 'mild eating disorder, mild depression, anxiety'* (5); *'bipolar, depression, social phobia, OCD'* (2); and *'your state of mind ... your mood and stuff that comes into your head'* (6). Interestingly, there were no apparent differentiations between the views of service users and non-service users on what defines a mental health problem. Mental illness, on the other hand, was discussed by a minority of participants, not as being a deviation from good mental health, but rather as a separate experience. For example, one participant who identified with a mental illness commented that *'everyone has a mental health, even having a mental illness I still have a mental health, and mental health problems, and that keeps me as sane as everyone else, as every other human'* (5). No apparent reference was made elsewhere (with other participant groups) on there being a differentiation between mental health problems and mental illness.

### The need to make mental health problems 'normal'

By defining mental health as a universal, everyday experience, mental health problems were positioned

within a similar context. Participants' understanding of mental health problems were underpinned by an attempt to present as *normal*, the experiences as *'life problem[s] going through the world today'* (5). Notably, the causes of mental health problems were identified as everyday external pressures or a *'sort of trigger'* (2) that existed outside of the individual (rather than internal, physiological contributing factors). These included exam pressures, peer pressures, relationship breakups, family pressures, marriage breakup among parents, drug and alcohol use: *'too much drinking, too much coke, being emaciated, fashion pressures, high disposable income for discretionary items, relationship issues ... they're the kind of issues you see effected in mainstream society for mental health problems'* (5). In one instance, the experiences were directly related to drug use and family background, with the suggestion of a mental illness being put aside (7). As is apparent from the following statements, it was believed that mental health problems arose from an inability to cope with these pressures, without reference being made to the effectiveness of an individual's internal coping mechanisms: *'I think one of the things that triggered my illness was stress from the Junior Cert. That's how it's mostly triggered with other people'* (3); and *'I used to have constant tension on my stomach, constant anxiety ... probably crying a bit as well, depressed ... it wasn't a chemical imbalance, I was reacting to the situation, and I was reacting very bad, and I couldn't deal with the emotions I was feeling.'* (1)

Comments from service-user participants on their own mental health problems and related



experiences reflect how an understanding and, with this, a sense of identity is reached, based around the problems experienced. For some, this had meant coming to terms with what is required: *'you have to make friends with the idea of hospital and treatment facilities ... it's part of my life and probably myself'* (5). For others the idea of recovery was important, reflected in participants' comments on their progress since their initial admission: *'I'm not the person I was four years ago, I've come along way.'* (1) Notably, a number of participants referred to their subsequent involvement in mental health campaigns.

### Factors influencing definitions of mental health problems

The media and mental health campaigns were described as playing an important role in influencing wider societal perceptions of mental health problems and the way in which incidents of mental health problems are portrayed; however, concern was expressed that the majority of reports concentrated on mental health problems that are described by the group participants as extreme, misrepresentative or too specific, to the detriment of other mental health areas. Results suggest an inability to relate to these portrayed images because of the extent to which they deviate from the norm: *'you see the movies, they've dramatised it way too much so, if people are going to a mental hospital they're all in straitjackets and padded cells so that's what you're initial view of it is'* (2).

It was recommended that awareness campaigns and media images should focus on presenting mental health problems as *'natural'* (6), on *'how*

*normal it is to have a bad day and [how] everyone suffers from it at some stage ... like any other illness that you'd go to hospital for'* (2), and how *'it is natural to feel down and to feel anxious'* (6). Emphasis was placed on the need to move away from more specific terms such as *'schizophrenia'*, to focus more on everyday feelings and everyday pressures, despite these terms being used by some participants in defining mental health.

Favourable viewpoints were expressed on campaigns that aimed to remove stigma and present mental health problems as a normal human experience. For example, this participant favourably viewed ad campaigns that *'say look after your own mental health now ... there's pictures of people saying "I feel stressed sometimes, I feel down sometimes", then at the end then it says "do you think that these people look like they're all crazy?"'* (3). Interestingly, participants who identified more with experiences of mental illness commented negatively on the over-normalisation of mental health problems within wider society. Making a differentiation between mental health problems and mental illness, one participant commented that *'everyone nowadays says "Oh I've had depression, I have depression", but that's just kind of an emotional level of distress that every human being goes through ... I would have a mental illness ... I think what differentiates me is the fact that it's been so, obviously really symptomatic, resulted in hospital care and all this, and I had to live with it every day'* (5).

These participants felt there was a lack of clear differentiation between mental health problems and mental illness in wider society and a *'lack of clear*

*medium that accurately portrays mental illness',* causing further stigma and misguided perceptions as to what mental health problems and mental illness actually are: *'I think in all these mental health promotions, mental illness has been really left out of it because people are still not comfortable ...'* (5) A lack of direct reference to a differentiation between mental health problems and mental illness, in interviews, may support this point.

### The views of non-service-user participants

The views of non-service-user participants on how they would respond to incidents among friends (presented as vignettes), supports how they themselves define mental health problems, and what determines the nature of the response required. Responses to these vignettes were influenced by the perceived seriousness of the problem within an everyday context, i.e. the extent to which the incident deviates from normal behaviour. The response was also influenced by the ability of participants to relate to the problem, its perceived validity for the participant, and the time element or frequency involved, in other words the length of time the problem was being experienced by the friend.

Initial responses suggested attempts to normalise the incident by emphasising to the friend that *'it could be worse ... it's not like the biggest scenario'* (2), and *'reassure them that they're absolutely normal, well, like not normal but like ...'*, with a particular emphasis on distracting the friend by engaging them in activities. For example, *'distract [the friend] with things you know she likes, like*

*if she'd like to go somewhere, or the cinema or something'* (8), and *'they just have to keep working on it, and they have to try and motivate them to get up and try and distract them ... it's really a friend's help'*. Incidents that were perceived as being serious or as a deviation from what was perceived as being normal were given more direct responses, with less emphasis on a waiting period, or the need to distract with activities, and more emphasis on the need to avail of GP services, or speaking with parents. In incidents where participants could not make sense of the problem, words such as *'psycho', 'mad', 'crazy', 'a looper', 'mental', 'a retard' and 'freak'* (8) were drawn upon by participants.

In all responses significance was placed on the perceived validity of the problem, highlighting the importance of being believed for young non-service users; as a result, for some of these participants, a lack of sympathy and a questioning of the validity of the incident were apparent. The importance of trust, closeness, and confidentiality were apparent when supporting friends, with significance being placed on speaking with parents about the problems experienced, *'depends on how you think they'd react'* (8). This is despite (non-service users) participants' own fears of speaking with their friends and parents. Notably, all non-service-user participants recalled having more positive opinions of mental health problems as a result of visiting a support service environment (during study participation); afterwards they saw the environment as more normal than originally conceived, with these changes in opinion influencing how they defined mental health problems.

## Barriers to accessing services and support

This section presents results on participants' experiences when accessing services. Key themes dealt with in this section relate to the hidden nature of mental health problems, and fear of stigma.

### The hidden nature of mental health problems

The view of mental health problems as a hidden phenomenon was widespread among participants: *'there is that sort of secrecy about it'* (7).

Throughout interviews mental health problems were compared to physical disabilities. For participants, the latter differed because difficulties arising from physical disability are often more obvious; however, with mental health *'you don't look different, like anyone can have a mental illness'* (2). There is more awareness around physical disabilities in wider society, as explained by the following participant: *'when it's physical you hear about it differently, but you don't really hear about it when it's mental'* (6). These experiences are kept hidden because of the fear of being misunderstood or not being believed, along with a fear of stigma and a sense of failure.

These fears often meant that mental health problems remained hidden internally within the individual and then externally, at a family level. Participants who recalled experiencing mental health problems fed into this discourse, describing the strategies they employed in hiding and responding to their experiences, and the extent to which they shared their experiences with family and friends. In this way the hidden nature of mental health problems was perpetuated, a point supported by the following

comments: *'it's not talked about, and because it's not talked about people think it's not talked about because it's wrong, or there's something bad about it'* (2); and *'mental health is almost, see, "oh my God, mental", the word mental isn't really nice to tell people. You don't like saying "I have mental health problems".'* (6)

Participant comments reflected the isolation and inevitable loneliness that comes from experiencing mental health problems, augmented by keeping *'a front on ... pretending'* (6). There was also a tension between the external identity, *'the front'* (6), and the inner experiences the participant might be feeling, whereby *'[they're] putting out a front to make it look like they're being rational whereas behind the doors, they're cracking up'* (1). Related to this was a tendency to refrain from sharing experiences and instead, *'keeping it to yourself ... and you see where it goes and it just gets easier to deal with by yourself'* (6), for fear of being misunderstood: *'They [parents] don't always realise what's going on inside, like people find it hard to express what you're feeling'* (2) and *'People don't understand why you've dropped out of college or why you're out of work for whatever amount of time, so you need to come up with some kind of answer as opposed to "well, I'm in day care".'* (5)

The reported failure of schools to openly discuss mental health problems contributes to the hidden nature of mental health problems. This, in turn, underpins gaps in mental health awareness in schools, as reported by this participant: *'Our class gets on really well so you don't really notice anything ... there hasn't been any cases of anyone*

*really upset, so the teachers wouldn't say anything ... if they don't talk about it, it's not there, so it doesn't exist.'* (8)

Participants' comments on their perceptions of the potential for support in the school environment reflect the hidden nature of mental illness, as is evident in the following experiences: *'when I was in school, and the teachers didn't know what was going on, the principal hadn't got a clue'* (6) and *'once the teachers see that you're in school, that you look well, they don't really need to cover mental health'* (8).

### The fear of stigma

The hidden nature of mental health problems was also perpetuated among participants and their families for fear of being stigmatised when availing of services and support. For example, one participant felt there was a *'mentality that if you're going to see a psychiatrist ... they think you're loony, or "she's going into the loony bin", and forever branded that'* (3). These fears also impacted on the extent to which participants felt they could access information about supports. For example, non-servicer-user participants identified the benefit of awareness campaigns (such as posters), yet commented that *'if you were to actually go there [to the posters] and get the number, people would be, like, "what's she doing getting that number?"'* (8) Strategies were employed in ensuring that availing of services was not publically known. For example, one participant recalled availing of services *'in a city away from my home', however, 'I didn't want to be seen going in there either, it was too close to where I go to*

*college.'* (1) A second participant recalled how *'I lived just across the road from [hospital] and, but I had to be driven across ... my neighbour would walk me through and I was dragged behind and hidden down, like, a hedge, because they couldn't see me walk in, and that was kind of hard ...'* (5)

Undoubtedly, attempts to keep hidden mental health problems presented additional stress on the individual, as well as presenting barriers to availing of services. Speaking about accessing services, one participant felt *'there's so many people that you'd know going in and out of it if you wanted to use it, it would be difficult not to let anyone know'* (2). Another participant explained how she stopped attending appointments and felt there was a need for an outpatients service because of the distress of attending a psychiatric ward, *'that's the reason I didn't go back, just the fear about if somebody would see me, just the privacy, because you walk in the door and it's like "psychiatric ward" just hanging up there, so everyone will know'* (1).

Strategies were also employed by parents in hiding their child's experience from siblings, family members and the wider community. It was noted in one discussion that the parent informed family members that the child was attending college, while the parent was shopping in Dublin (the parent was instead visiting the child while the child was availing of services) (10). A second participant recalled the isolation experienced as a parent, which was augmented by not having parent support available within the family and community as a result of not informing family or friends of the child's experiences (10). Participants also commented on the strategies



employed by parents and how this subsequently contributed to the sense of isolation experienced by the child – as reflected in the following comment: *‘parents have issues with they want to keep your illness secret, and I found it very hard because I couldn’t tell anyone outside the family because then people might get back and tell the family. I found that hard then, because I felt very isolated with people I met, in subsequent years, because it’s always a secret you couldn’t tell ...’* (5)

### The views of non-service-user participants

Non-service-user participants expressed uncertainty on what to do and where to go should they experience a mental health problem. Referring to an advert, one participant commented that it doesn’t *‘really tell you where to go, what to do, who to turn to’* (8). The prevalence of schools in discussions with non-service users suggest the role, and potential, of schools in influencing views of mental health problems among young adults; however, schools tell *‘you things, like, to do exercise – [but they don’t tell you] how to deal with it ... if you actually feel sad ... if you’re actually depressed how to help yourself’* (8). The feeling of not knowing what to do was also expressed here: *‘I don’t think many teenagers actually know if they want to seek help themselves or if their parents, I don’t think they know where to go or what to do. I don’t think they’d do it’* (2), and *‘they [students] don’t know the doors are open’* (8). These feelings were underpinned by not being able to recognise a mental health problem and, as a result, misunderstanding and misinterpreting possible indicators. Responding to a vignette comprising a young man’s reported

encounter with aliens, one participant explained that *‘you would kind of laugh cause you wouldn’t know anything about it ... people don’t have a grasp on some sort of idea of mental health ... symptoms and signs of different things and how to deal with them’* (8). Not knowing how to respond translates into being *‘afraid because they don’t know how to deal with their [friend’s mental health] problem’* (8).

Concerns about *‘not being believed’*, whereby *‘they’ll think that you’re making the situation more dramatic than it is, like if you were suffering from depression’* (2), influenced participants’ feelings about speaking with parents and friends, and seeking support from service providers. This supports earlier points made by service-user participants on the importance of being understood when communicating one’s problems. The fear of *‘people talking’* (2) was also prevalent in the views of non-service-user participants, impacting on whether or not they’d feel comfortable accessing support, because *‘you’re afraid, ‘cause you’re like “oh, they’ll talk about me and they’ll think things about me”’* (2). The ability to access support in the school environment was particularly noted, with one participant outlining that *‘if there’s a counsellor, if you’re seen walking into a counsellor’s office, and all your mates see you, they’re obviously gonna think straight away there’s something wrong with him or the family or something ...’* (2)

Results show the importance for these young adults of being included and accepted in their peer environment, meaning that fears over mental health problems and receiving support often translate into related concerns over not being accepted socially, being *'mocked'*, and being excluded from the school environment. Though these participants emphasised the importance of talking to friends who might be experiencing mental health problems (as a means of providing support), uncertainty was also reported on whether or not they themselves would speak with friends, fearing stigma and a lack of confidentiality: *'your friends are one thing, but people talk and then stories change, and suddenly, rumours out to here, it just turns out to be ...'* (2). Another participant explained: *'Some people won't talk to their close friends and they'll shut out their closest friends because they might know their parents and their family and they feel maybe they might judge them ... makes it harder to talk to someone who knows your parents and knows your family...'* (8)

Recommendations made by non-service users to the providers of mental health information emphasise that they must be able to relate to the message that is being communicated, while at the same time knowing that the problems experienced are *'normal'*. These recommendations included: the need for a drop-in service and one-to-one engagement with a support provider; running campaigns (in schools) that inform young adults that *'it's normal ... there's nothing strange about it'* and *'if you had a talk in the school, and you had, say, one of the people that are in the place down*

*there [at the service provider] to come in and talk, that are our age, to see that they're normal'* (2); and portraying a positive image of the support environment. In one group, importance was placed on recovery and the need for this to be promoted in school programmes: *'someone who'd recovered came into our school who was our age' because 'you can relate to that type of person ... [they] reassure you, like.'*

### Accessing services: consent and confidentiality

The need to lower the age of consent was agreed on by the majority of participants: more suitable ages mentioned included 14, 15, 16 and 17 years (1, 2, 3, 4, 8, 9). Two parent participants agreed with keeping the age of consent at 18 years because *'I suppose that a parent would want to be able to vet the service, they'd want to know who the child is talking to and, you know, is it a good, safe environment?'* (7) Emphasis was placed on the state of *'mind'* (4), whether or not the adolescent was *'fit to consent'* (6), and how *'mature'* (2, 8) the young adult was and the young adults *'age emotionally'* (9). Interestingly, the criteria for determining whether or not an individual was fit to consent were not identified.

Not being always able to speak to one's parents about mental health problems was also regarded (by participants with and without service user experience) as one reason why young adults should be able to seek access to support services (such as a GP, for example) without parental consent, especially during the initial stages: *'if you have a*

*problem with your ma and da, if there is trouble at home ... if they don't know you are having a problem, you should be able to get help' (4); and again, 'If you could go to a doctor first and then have them explain to your parents what's wrong instead of you going to your parents, you might keep going complaining to your parents the entire time about headaches and feeling sad all the time and all this ...' (2)*

Further, this participant felt that parents *'don't know what's going on in your head and they don't know what you want or what you need'* (8). Fears about telling one's parents were also recalled by this participant: *'I couldn't face my parents, couldn't say, "Oh look, I'm after really screwing up this semester, I'm after really screwing up this year." I was ashamed; I was, you know, "God, they're after coming up with so much money for this degree"' (1); however, her anxiety after admitting herself to hospital was augmented by '... all I could think of was "my parents are going to kill me, what am I after doing?" (1)*

The necessity of parental support and including parents at some point in the treatment plan was emphasised, as *'you'd know that you wanted to talk to somebody, you can identify a problem, but you may not realise the solution' (1), or 'sometimes you don't know where to go to' (6). However, this could not be to the detriment of excluding the young adult, a point alluded to by this participant: 'You've no rights if you're under eighteen in services anyway, like it's all done through your parents. They, they give consent for you, so it's almost as if you're not there.' (3) Participants with experience of both child and adult wards noted differences in the level*

of control they had in their treatment, as a result of being allowed give consent once aged 18 years. Having recalled that *'it was down to my parents to give consent'*, and then *'being held on the floor and given Largatyl'* (5), one participant noted how this changed once she could give consent when in an adult ward. It was felt that a *mediator* or *advocate* role was required by parents and child, to provide support and information to both, and also to assist in situations where the service user might be passing through foster care, for example. Notably, and extending on this point, it was explained in one instance, that the second parent would not give consent to the child seeking support, consequently preventing the child from availing of support.

The *hidden* nature of mental health problems and associated fears of being stigmatised were prevalent in participants' concerns on confidentiality, especially within a social rather than service provider context. Elaborating on this point, one participant recalled that concerns with confidentiality *'wouldn't be from health care professionals, it would just be from the general public ... you want to have friends and you want to include people in your life, and even if you're in hospital you might just want a visitor or you might want to see someone, but it's kind of, like, is it worth the gossip?' (5)*

In another instance the participant reported that she should have waited to access supports at 18 years (rather than at 17 years) as this, she felt, would have allowed greater confidentiality: *'I could have just waited a year, I would have just waited the year till I was 18 ... to be an adult, to have that confidentiality.'* (5)

Concerns over confidentiality among friends were also identified by participants who were not service users, with these concerns preventing them from speaking with a friend on difficult issues. One participant in this group noted concerns about the information that is provided to parents, agreeing that, *'it should be your choice what your parents, like, find out about what's going on inside your head, like, or what caused it or whatever. It should be your choice what your parents find out about that.'* (2). Similarly, knowing that confidentiality was in place and that *'the information won't fall into the wrong person's hands'* was a necessary requirement for these participants when seeking support (2).

### The quality of care: contributing factors to favourable and unfavourable experiences

This section presents the results that deal with the participants' experiences of care received. Following a description of their initial experiences, support-related factors that contribute to favourable and unfavourable experiences are presented. These factors include the ability to relate to the support environment, the importance of inclusion, and relationships with staff.

#### Initial access to care

The perceived quality of care received was influenced negatively by the length of waiting time and initial experiences of participants in the support service environment. Long waiting times prior to accessing support services were recalled by a

number of participants, often aggravated by a lack of service locally: *'It took me ages ... I came to primary care, and I saw a doctor, then I was waiting weeks, like waiting for a bed took ages, and then there was just nothing'* (6); *'mine was absolutely awful. I was on a trolley in [support service] and just didn't have a bed ... I was getting worse by the day and no one could take me, like I needed treatment and no one could take me'* (6); and *'I went to a doctor and it took seven weeks just to say "We'll get in contact with you"'* (6). As a result, private, fee-paying options were availed of by a number of service users. Two participants felt they had to 'bully' their way into receiving support and, as a result, *'we got in there straight away'* (3), and *'I got the appointment [for my child]'* (7); in two cases ease of admission was facilitated by family contacts (1). In a number of cases, participants recalled traversing an array of services in order to get adequate support. In one of these cases, an apparent feeling of isolation, lack of control, and hopelessness was apparent in the parent's recollection of attempts to find a suitable support service for her child. A second participant explained that *'I didn't get help when I asked for it and I ended up being brought here twice, the help is not out there.'*

Service-user participants recalled feeling *'scared'*, *'traumatised'*, *'disoriented'*, and *'anxious'* when they were first admitted to the service, added to by not knowing what was taking place, as recalled by these participants: *'I just wasn't sure what was going on, it was a bit scary'* (1); and *'[it was] very terrifying, you don't really know what's going on, and before I had*



*realised it, they had put me on medication, they'd put me on sleeping tablets, and they were just kind of giving them to me and said "take them there now" and I would have had no idea what I was taking or why I was taking them.'* (1, 4)

These feelings were augmented by a feeling of not having control, not being included in decision-making processes, and having concerns about being stigmatised within the family and wider society. Similar feelings were recalled by participants when making the transition from child to adult services, with fears and anxieties being added to by a lack of information for both parents and the child and uncertainty as to what to expect from adult services. Feelings of isolation during admission arose from being in an environment that the participant could not relate to, being isolated from family and friends and, in some cases, not giving consent to treatments received (as consent was provided instead by parents). A lack of local services specifically for adolescents, or decisions to avail of services elsewhere (away from the local environment because of fear of stigmatisation) added to the isolation. Further, a number of participants (5, 9, 10) recalled being away from home prior to being admitted into the support service, either on holiday or with relatives elsewhere; being away from home also adding to the anxiety experienced.

### **The ability to relate to the support environment**

The ability to relate to one's environment was important in providing a more favourable experience of services. Negative experiences suggest that

being able to relate to the ward environment contributes to a sense of normalcy for young service users, by knowing that there are others in similar age groups that share common experiences, a point outlined by the following participant: *'for people on a ward together, you think "I hope they're all teenagers", I think when everyone's young together they're going through the same things together, they're all trying to go home together going back to a normal life ...'* (6). A similar point was noted by this participant; *'the most therapeutic thing ... is actually, sitting down and talking to people and realising "oh you know what? You're just normal, you've just, you've had a couple of knocks and you're the exact same as me",'* while a third participant (who had spent time in an adolescent unit), identified peers as a form of support (9).

These points are also agreed upon by non-service user participants. There was wide consensus on the need for a specific adolescent/young adult's service that involves being among one's peers and provides a service that does not terminate at age 18 years, but instead provides a continuum of support from mid-teenage years to the mid-twenties, followed by post-discharge access to services and therapeutic support. Similarly, one participant's recollection of not having help *'three months prior to my Leaving Cert. ... it's very hard to study when you're inside there ...'*, highlighted the need for suitable access to education and learning during hospital placement.

Reports of a lack of suitable, age-specific activities in children and adult wards highlighted the importance of bringing peers together and keeping active for this particular group of service users,

with the belief that *'you need to be occupied to get better ... you can't expect someone to get better when they're just bored, no one, you'd go mad'* (6). Favourable experiences recalled included having access to activities such as *'pottery and creative writing'* (5). Stating the necessity of maintaining some sense of control, opportunities to engage with activities were regarded as important because *'one of the most distressing parts was that your freedom was gone'* (5). Referring to their positive perceptions of a support environment, non-service user participants identified access to *'really good stuff, like the pottery and stuff, like you wouldn't have that in any other hospital'* (8).

Experiences of isolation in children and adult wards were common across participant groups. The sense of isolation included feeling *'stranded, alone, sad ... you're in a whole world of your own'* (5), *'all by myself'* (6), and was magnified by a lack of supportive peer group (9), a lack of suitable activities for young adults, and being among non-peer groups. One participant explained how *'I was kept up the top bed of the ward all the time, and there was nothing for me, only they used to bang in DVDs and videos and shove them into my room all the time like.'* (3) Despite needing access to peer interaction, emphasis was placed on the need for *'personal space'* (1), and *'privacy and dignity'* (3). Referring to negative experiences on an adult ward, one participant (with experience of adult wards) recalled fears about safety and security: *'they had a door separating males from females, one door and not locked. So people were coming into the ward and no, no supervision of sex, separation*

*or anything like that ... I found it difficult being on wards, being in nightclothes around older men.'* (5)

Participants placed on adult wards and those placed in locked facilities recalled feeling traumatised, with one participant reporting how *'it makes you feel totally mad when you go into a ward that's locked'* (6).

Interestingly, participants used their admission experiences and ward placement (particularly those with experience of adult wards) to carve out a sense of identity and understanding around their own mental health experiences. This was done by comparing their own situation to that of other patients on the ward (usually describing the problems of other patients as being more extreme): *'For the first few days I wouldn't move from my bed, and I suppose that's stigma itself on my part, because, I was looking at these people, as scary, and "am I like that? Is that girl like me, am I that sick, to say that I'm in here?" ... it was scary for a 21-year-old being in a hospital, you're sitting there and you're completely with it, and then being surrounded by people with very serious types of illness.'* (1)

Another participant recalled that *'the person beside me must have been thinking she's a lunatic, she was in for dialysis ... they should have a ward'* (4). Notably, drawing on her own ward placement, this point is further supported by this participant's belief that: *'within mental health you've got so many different demographics that you know, internal stigmatisation ... So, the girls with eating disorders would kind of just ... you could see all*

*the differences, the judgements, and you were just crazy, they were not crazy, we were crazy', and the impact of this on the placement experience, 'so, different demographics, clashing really ...' (5).*

Results showed the importance participants attach not only to being among peers but also groups with similar experiences, with recommendations made for separate ward environments for young adults, such as *'something in between and I think that people should be specifically trained to kind of deal with younger people. We're not generic, no matter how much they want to put us in the same category.'* Recommendations point to the need for a more sensitive approach to the needs of young adults at the time of admission, taking into consideration their feelings of isolation and fear and, as apparent from the following statements, their understanding of mental health problems. Included in these recommendations were calls for a specific admissions area for young adults, *'instead of just putting you in at the deep end'; 'something between an adult ward and a psychiatric ward ... a "recuperation ward, recovery ward" ... with no stigma attached'* (2); and noted in one focus group, *'an inpatient service for young people aged 16 to 26 years'* (3).

### The importance of inclusion

Participants recalled mixed experiences on the extent to which they felt included in the support they received. Feelings of inclusion were determined by the relationship between the participant and staff, the extent to which participants felt informed about their treatment and medication plan, and

were important in contributing to favourable experiences and the willingness of the participant to comply with the treatment plan.

Where inclusion was experienced, the participant commented on the importance of knowing one's options and what's involved, and how this contributed to feelings of inclusion because *'they listened to me and talked through the treatment process, and what were my options, and what to take, go to, maybe take medication, go to occupational therapy, go to other services'* (1). In instances where participants did not feel included, reference was made to not being *'listened to'*, or *'the team didn't talk to me'* (4), and an apparent failure by support providers to communicate appropriately with participants. Alluding to this, one participant explained that: *'it's just the way that nurses would speak to you, it's not like you're on their level at all, they'd talk down to you a bit, you know, "I know best, and I'm", you know, and "You're not well", so you have no say in how, or what kind of treatment you're going to receive.'* (1)

Feeling that *'nobody was listening to me'*, this same participant explained that she *'refused to take all tablets'*. Similarly, other participants (1, 6, 9) reported not feeling included *'when they change your meds and don't tell you ...'* (1). This participant went on to say, *'you need to be consulted on that, you need someone to come up to you and say, is it ok, we have you on [medication type]'* (6). The need to have a say in everyday activities during hospital placement was also pointed out by service user participants. For example, alluding to a friendship with a fellow patient, this participant

recalled the challenges experienced and a feeling of lack of control over making decisions, saying, *'if you wanted to go anywhere together, you'd have to ask a nurse, and then the nurse had to see does she have to the time to go ... well I think it's unfair on both of us really, like I wanted to talk to her and I could just not go there'* (3).

A failure to communicate with the child alongside the parents was also cited as undermining opportunities for inclusion. Two participants reported that though their parents were included and informed on their child's treatment plan, this inclusion was undermined by a failure to actually inform and consult with the participant. One participant commented that: *'it's shocking for the actual person who is going through it when they're young, because parents are told everything and the child is told nothing ... when I was in hospital, I was asking "why am I here, is this a punishment, what's happening to me, why are you always giving me tablets?", the only answer I got back every time was "You're sick" ... they wouldn't even tell me what tablets I was taking.'* (3)

Parent participants reported feeling included in their child's support. Concern was expressed by some participants, however, over their parents being under-informed yet expected to provide consent to medication plans, for example: *'like any of my drug treatment would have been more discussed and decided with my parents than me ... parents would probably do what the doctor says, but they should get a certain degree of support. So if parents are making decisions on behalf of the child, they should be very well informed, and at the same time*

*the child is well enough, should be educated and informed'* (5).

Negative experiences relating to being included in medication plans were echoed throughout the experiences of the wider group. The failure to include participants through informing them adequately on what they should expect from treatment, and on their medication plan (and changes in this plan) contributes to the fear and isolation experienced by participants during their time in hospital, especially when they first entered the mental health service. Concerns about medication side effects are particularly noted, as apparent in the following statements: *'medication should be explained first and discussed before being shoved down their throat anyway, and alternative therapies first instead of medication, because there's a lot of side effects that can affect the way your way of life, and the way you live, you know, so I definitely think the person should consent with first ...'* (3); and *'they could let you know how you actually benefit, we're actually going to be putting you on this, you're actually going to be taking this tablet four times a day, and tell you'* (6). Developing this, participants felt there was an overemphasis on medication in support services to the detriment of informing service users of other alternative approaches.

Inclusion in treatment and medication plans enabled participants to feel in control of their lives during their time in the support service. During placement, being able to maintain a feeling of control enabled a sense of normalcy to exist in the life of the participant. This point is reflected in the

following comments on what was important while in a hospital setting: *'to know that you still have some control over your life ... it's not like you're putting the control of your life into someone else's hands, to know that you're still, you're still making some decisions'* (2). As with not being included, not being in control over what takes place during placement in support services contributed to the already existing anxiety and fear, as *'people are doing things you don't want them to'* (6). A point which is reiterated in the following recollection: *'I just remember being told I couldn't go home. And I remember starting to cry, and this nurse saying "Oh, do you want to give me something to help you?", and I said "no, hang on, no no no, I have to tell someone I'm here", and she said "I'm going to ...", she was giving me sleeping tablets to put me to sleep, and I remember having to fight her on it, saying "no, like, I have to ring my parents, I need to tell them where I am, I need to tell someone".'* (1)

Female participants particularly noted concerns on the impact of medication on their physical appearance, alluding to an inability to control their appearance, arising from the side effects of medication (3, 5). In this particular case, the participant recalls not being informed about the side effects: *'I was lovely and slim, and they didn't tell me anything about it, and I was starting to have one, and three dinners, and I gained almost two stone by the time I came out of hospital. And people said to me, "were you in hospital because you had an abortion?", because the sudden weight gain ... So if they had explained it to me I would have curbed my appetite and I would have tried it.*

*But I didn't know what was happening, I thought it was, I just needed the food because I was hungry, but I wasn't, it was the false hunger. See that's what I mean now, that's devastating like. So, definitely it should be explained.'* (3)

### Relationships with support staff

Positive relationships with staff contributed to participants' favourable experiences of the support provided and the extent to which they felt included. Similarly, negative relationships were influential in contributing to an overall negative experience. Unfavourable contributing factors included a lack of time and available opportunities to meet with staff, and a lack of sensitivity from staff to the patient's needs and requirements.

Referring to a lack of time to meet with staff, it was noted during one focus group that the participant had to *'corner'* their consultant, stating that *'if you just see him normally you will get two minutes whereas if you corner him you may get four minutes'*. Speaking about another healthcare professional, a second participant recalled how *'I felt he didn't understand, I couldn't talk to him ... he'd come in for two minutes and tell me all I had to do and that was it.'* Similar experiences were recalled across the participant groups, with evidence also pointing towards a lack of sensitivity, a perceived lack of understanding and a lack of patient-centred approach. For example, one participant noted that *'They [nursing staff] made my life a misery inside there, it was terrible. They used to come in to you all the time, and I was crying 'cause I was depressed, they used to be laughing*



*at me ... It's worse than prison.'* (3) A second participant felt that *'their styles and their manner of dealing with people ... they could have come across as very cold, and very, very clinical'* (1).

Arising from these negative relationships, the experience and expertise of staff is questioned, especially in their ability to work appropriately with young adults. This highlights the importance of professional expertise, for service users, in building a sense of trust and quality of care for participants. For example, while reiterating the importance of being able to relate to one's environment, one participant also stressed *'we need more young nurses, if they're around teenagers they can identify better with the teenagers ... so, "oh, it's a 20-year-old that's telling me, it's not a 40-year-old or 50-year-old that has no, no clue of where I'm coming from"'* (5).

The emphasis on experience is also reflected in this comment: *'the junior doctors can be quite detrimental, they come along, and they've so many set ideas with, with clinical ideas and lacking massively in experience'* (5). In addition to having control over medication options and changes in medication, the need to have a say in everyday actions during hospital placement is also recommended. Alluding to a friendship with a fellow patient, this participant recalls the challenges experienced and a feeling of lack of control over making decisions: *'If you wanted to go anywhere together, you'd have to ask a nurse, and then the nurse had to see does she have to the time to go ... well I think unfair on both of us really, like I wanted to talk to her and I could just not go there.'* (3)

Factors contributing to more favourable relationships included the support role going beyond their role to provide support, in the words of one participant, *'they just go that extra mile'*, with participant experiences referring to having access to their consultant, being listened to and understood, and being given sufficient time. One favourable example included a consultant faxing a prescription to the participant while on holiday. Another participant explained how *'the doctor dropped the medication over to me when I wasn't great, and he has done a lot for me ...'* Similarly, trust and confidence in the expertise and experience of support staff enables a more positive opinion: *'they know what to say to us, they knew what to say to the child as well ... it was a child-friendly environment ... he listened to what I had to say'* (7).

Access to a key worker was regarded as promoting inclusion – the benefits including daily contact with a support role, someone who may recognise that *'sometimes you don't know that you need help, until someone comes to you, you don't realise how overwhelmed, you don't realise how things are getting to you like, until someone actually asks you to think about it'* (6), and provides opportunities to relay concerns to support staff. Recommendations for an inclusive supportive environment included appropriate communication with the patient on their treatment plan, whereby it is explained that *'we think you're having some problems, we want to figure it out, we want to tell you, we'll tell you step by step', been explained, being in the loop, but not told you're sick'* (3), inclusion on medication plans, and a say in day to day activities.

### Summary of key findings

- Access to services can be very difficult and delays can greatly increase stress for young people and their families.
- Feelings of inclusion were determined by the relationship between the participant and staff, and were an important factor in contributing to favourable experiences and the willingness of the participant to comply with the treatment plan.
- Service user, parent, and non-service user perspectives highlight the extent to which stigma remains a key barrier to accessing support.
- Access to a key worker for young people who were inpatients was regarded as promoting inclusion.
- Young people highlighted that being among peers with similar experiences was helpful and they made recommendations for separate ward environments for young adults. Participants placed on adult wards and those placed in locked facilities recalled feeling traumatised.
- Non-service-user participants expressed uncertainty on what to do and where to go should they experience a mental health problem.
- Mental health problems are often kept hidden by the individual and also externally, at a family level, and this contributes to issues of stigma.



## Section 4: Discussion and Recommendations

Dunne (2006) in *The Views of Adult Users of the Public Sector Mental Health Service* recommended the involvement of young people in the development of services. Furthermore, the benefit of including the perspective of parents is also noted, given their role in accessing mental health services for their child (Keogh, 1997; Sayal, 2006). The concept of children and young people having views and choice about their health care is accepted internationally but there is also a need for their views to be taken seriously and services need to adapt to be more responsive to their patients' needs (Coad & Houston, 2007).

### Reflections on the study

Results from focus groups with young service users, non-service users, and parents of service users highlighted themes of defining mental health problems, barriers to accessing services and support, the importance of consent and confidentiality, and the quality of care. A number of key points can be made relating to these findings.

### Normalising mental health problems

A key theme emerging from this study was participant attempts to normalise mental health problems. A range of terms were used to define mental health problems although, overall, explanations sought to position mental health problems within a normalised context, caused by external pressures. Where mentioned, mental illness was regarded separately, as not necessarily being attributed to mental health or mental health problems.

Given the emphasis on the role that media and schools play in influencing attitudes about mental

health problems, undoubtedly media messages impact on how young adults define mental health problems and related experiences. On one hand, messages that focus on normalising mental health problems (such as depression) are welcomed; however, for those who associate more with a mental illness, such normalising is seen as undermining the existence of more minority experiences and instead legitimising everyday experiences as contributing to mental health problems. More consideration may therefore be required on presenting a spectrum of experiences, especially in tackling stigma as a barrier to accessing services.

Studies have highlighted that in some films and television programmes people with mental health problems are often represented in stereotypical roles and sometimes language such as 'crazy' or 'loony' is used to describe the characters portrayed (Wilson et al., 2000). Though the benefits of presenting mental health experiences as normal are reported in the results, awareness campaigns must take into consideration situations that cannot be placed in an everyday context. This is especially important, given the findings which suggest that the perceived normality and seriousness of a problem determines the nature of the response of young adults (as shown in their responses to the vignettes), with situations that were perceived as less serious being dismissed. Similarly, perceived validity and being understood are important for this same group, in their decisions on whether or not to seek support and share their experiences; therefore, in order to build a greater culture of

understanding, messages aimed at tackling stigma and informing on mental health problems should aim to incorporate the full spectrum of mental health and mental illness-related problems.

### **Barriers to accessing support and services**

The hidden nature of mental health problems, fears about being misunderstood, and concerns about confidentiality and stigma, present as barriers to accessing support and services. Interestingly, these barriers also serve to undermine the extent to which mental health problems can be normalised, through the strategies employed by service users and their families. Service user, parent, and non-service user perspectives highlight the extent to which stigma remains a key barrier to accessing support (at a school level and support service level). The hidden nature of mental health problems contributes to a sense of isolation, highly prevalent in the experiences of those with mental health problems and their families, especially in the absence of family support. Many young people experiencing mental health problems do not consult with their GP (Potts et al., 2001). This isolation is carried forward into the mental health service environment, augmented by an inability to relate to the environment, a lack of age-specific approach within healthcare delivery and access to peer groups, and the physical isolation of facilities such as locked wards. Furthermore, the failure to include service users in the decision-making process, by informing them of options and the nature of their treatment plans, undoubtedly adds to this experience of isolation.

Service-user and non-service-user participants referred to the extent to which mental health and

mental health problems were openly discussed in the classroom environment, with comments alluding to (and supporting the views of service-user participants) the way in which mental health problems remain a hidden and isolating experience in schools. The need for social acceptance and, related to this, fears about stigma and confidentiality, present barriers to young adults availing of support and sharing their concerns within schools. Therefore, the school environment plays a vital role in informing perceptions of mental health problems, building a culture of tolerance and understanding, while removing the hidden nature of negative mental health experiences. Studies have shown that interventions in schools can be very successful; for example, an anti-bullying project in schools can lead to implemented, successful change and reduce stigma (Tyler et al., 2006).

### **Reflections on consent**

Discussions on the need to lower the age of consent revealed the importance of including and informing service users of their treatment plans, regardless of whether or not they or their parents provide consent. In cases where parents provide consent, adequate information must be provided to parents and the service user, so that the process of consent is well-informed and all are aware of the possible side effects, especially with certain medications. However, given the anxiety and stress experienced by the service user at the time of admission, any method of including and informing service users must be sensitive to their needs at this particular stage. A range of ages below 18 years was given by service users as potentially

more suitable ages of consent, though emphasis was placed on other criteria such as emotional maturity and state of mind. The concept of young service users having a choice about their treatment is accepted internationally and this area should be developed more in mental health services (Stewart, 2001; Villalon & Leclair, 2004; Boshoff et al., 2007; Coad & Houston, 2007). These terms are rather subjective and further exploration may be required to determine what constitutes emotional maturity, for example. One central theme related to concerns about talking initially with parents, despite the recognition by service users and non-service-user participants of their importance in providing support. This result suggests the need for promoting among young adults possible mechanisms whereby they feel comfortable in approaching their parents – mechanisms that could be addressed in mental health campaigns, both in school and third-level education environments. The United Nations Convention on the Rights of the Child (1989) recommends for states to ‘assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age of maturity of the child’ (Article 12).

### **A quality of care**

Attempts to normalise mental health problems were carried forward into participant recommendations for improved health service delivery and information campaigns. Being able to relate to one’s environment, feeling included and in control

of one’s treatment plan, and having access to suitable, age-appropriate activities, including education, point to the need for an environment which removes the isolation experienced by those with mental health problems, while reassuring them that their experiences are common to others. Interestingly, however, despite the need for a peer environment, ward placements were used to make sense of one’s identity, by comparing oneself with other cases on the ward. Results reflect the importance of being able to relate to one’s surroundings, perhaps in an attempt to normalise one’s personal experiences, remain in control, and reach a greater understanding of what is taking place. Consideration is therefore required on the placement of young adults who present with mental health difficulties. It can also be argued that though young adults may present with a mental health problem, their own views of wider mental health problems and of what constitutes a mental health problem may be quite limited. Mental health service providers could play an important role in helping service users contextualise and understand their experiences through the environment they create. Therefore, consideration must be given to the need for opportunities not only for peer-to-peer interaction, but also for group activities aimed at bringing different mental health experiences together. Building up young people’s protective factors (including family support and supportive peer interactions) can help them express themselves and help them participate in making decisions and accessing supports to improve their mental health.



### A note on methodology

The central aim of this study was to explore, from both a service user and parental perspective, the experience of accessing mental health care for young people, and to establish what young people need from services. The use of a qualitative approach allowed for these issues to be explored in some depth. While it is important to recognise that the young people and parents who contributed to this study may represent those who are comfortable sharing their views and experiences, we are confident that this does not detract from the validity of the views gathered.

### Recommendations

These results address the current dearth in published mental health research in Ireland, pertaining to the opinions of young service users and their experiences, and provide an evidence-base for the development of a more patient-centred approach to the delivery of mental health support. Indicators for improvement directly from young service users are presented, which can be incorporated into promoting greater access to health care, improved health care delivery and mental health awareness campaigns. In particular, these include the need for a more sensitive approach to the requirements of young adults, incorporating a supportive care environment based on access to peer groups with common experiences, age specific activities, inclusion, and opportunities for service-user input and consultation with support staff. Furthermore, results provide an understanding into the way non-service users make sense of mental health problems, the barriers that exist for them in accessing services, and how they respond to mental

health problems among friends. The requirements of service users are supported by the views of non-service users on what is required to develop and maintain a suitable, supportive environment for young adults.

### Suggested strategic actions

- Including young people's and their parents' views in developing youth services is crucial, since they are stakeholders whose views need to be taken into account.
- Services need to act on knowledge of service users' experiences and also commit to continuing to involve young people and their parents and to hear their views. Giving patients a real choice and the opportunity to give feedback about the services they receive will improve the standard of care and assist in reducing their distress.
- If consultation with young people and their parents does not lead to change this undermines the process and they will view it as waste of their time. If they feel that they are not heard they may no longer wish to contribute and refuse to provide feedback in the future.
- Age-appropriate and accessible services and increasing patient-centred care is needed.
- Good communication with the young person greatly enhances their experience of care and allows for better trust and relationship with staff.
- Incorporating young people's views into the planning and delivery of services is essential to

a modern, effective mental health care service. There needs to be a commitment for feedback from service users and their parents to be disseminated widely so as to effect change amongst policy makers and service providers.

- It can be complex to involve parents in treatment decisions, balancing the need for individual care, family needs for intervention, young people's views and choices against their parents views and their need to be involved and informed in the young person's treatment.
- There is no national advocacy service available for young people with mental health problems in Ireland. This needs to be addressed as a matter of urgency as it would help young people express their views about their treatment and help them advocate for better quality services.

## Conclusion

The issue of stigma and accessing appropriate help seems to be an ongoing concern with service users and their parents. Young service users have recommended that they should have access to staff that understand their needs and ideally should be admitted to a ward with other young people in it. Transition-year students have asked for more help in schools to raise awareness of mental health problems and how to seek help, as currently mental health problems are often hidden and can lead to feelings of isolation in school. Stigma-reducing interventions should be made part of mental health promotion strategies in schools.

It is important that the feedback from this study is reported and also acted upon. It has been suggested that it is unethical to solicit the views of young people without young people having an explicit understanding of the extent of the capacity to meaningfully act on the views expressed. There needs to be a commitment and information needs to be disseminated widely so as to effect change amongst policy makers and service providers.

Young people and their parents want to have more say in the planning and development of youth mental health services in Ireland. The project team would like to advocate that including service users' views and working collaboratively with them is the way forward.

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