

The Advocacy Needs of Mental Health Service Users Living in the Community:

A Pilot Study



By Shari McDaid, PhD
and Anna Ní Bheara

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Mental Health Reform
Promoting Improved Mental Health Services

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We acknowledge with thanks permission from the relevant authors to use the Patient Self-Advocacy Scale¹ and the Self-Esteem/Self-Efficacy sub-scale within the Empowerment Scale.²

1 Brashers, D.E., Haas, S.M. & Neidig, J.L. (2009) 'The Patient Self-Advocacy Scale: Measuring patient involvement in health care decision-making interactions', *Health Communication* 11:2:97-121.

2 Rogers, E.S., Chamberlin, J., Langer Ellison, M., & Crean, T. (1997) 'A Consumer-Constructed Scale to Measure Empowerment among Adult Users of Mental Health Services', *Psychiatric Services* 48:8:1042-1047.

Introduction

Independent, one-to-one advocacy is about having someone available to help a person make decisions or access their rights and entitlements. These could be decisions about health care or other services, or access to social welfare, housing or other social entitlements or services. Independent one-to-one advocates can also help an individual to make a complaint or seek redress, thereby holding public services to account. An independent advocate is not the same as a health worker, social worker or doctor, who may also advocate for people's rights and entitlements. Independent advocates are people whose primary role is to support an individual around decision making or having their voice heard.

In the region covered by this research, three independent advocacy services are available to mental health service users living in the community.

The Citizens Information Board is the national statutory body that supports the provision of information, advice and advocacy on a broad range of public and social services. It provides the Citizens Information website www.citizensinformation.ie, and supports the voluntary network of Citizens Information Services (CICs) and the Citizens Information Phone Service 0761 07 4000. It also funds and supports the Money Advice and Budgeting Service (MABS) 0761 07 2000 and the National Advocacy Service for People with Disabilities.

The network of Citizens Information Services provides a generalist advocacy service that is open to people with mental health difficulties. Examples of the types of advocacy provided include intermediary support (including with landlords and local authorities), advancing payment claims and representation at appeals, supporting people to access health and related services and assisting people to use complaints procedures. Information and advocacy support are provided on site at the CICs, primarily through written correspondence or phone calls, either on behalf of the individual or directly by the CIC. Advocacy supports can also be provided on occasion through CICs for example by attending a service with an individual.

The National Advocacy Service for People with Disabilities (NAS) has a particular remit for people with disabilities (including people with a mental health disability) who are isolated from their community and services, have communication differences, are inappropriately accommodated, live in residential services, attend day services and have limited informal or natural supports. As a service providing advocacy support to very vulnerable people, NAS is not intended as a first port of call for information or advocacy. Approximately 19% of NAS service users have a mental health difficulty and the majority of these reside in residential care.

The Irish Advocacy Network (IAN) provides peer advocacy, information and support to people with mental health difficulties. While funded by the HSE, IAN operates as an independent advocacy service on an all-Island basis. IAN aims to provide information, support and choice for those who have experienced difficulties with their mental health and wellbeing.

Current funding arrangements create an environment in which IAN prioritises providing its services to inpatients though it is available to mental health service users in the community as well.

In addition to these advocacy services, certain public services are part of the system of support and redress for mental health service users. The office of the Ombudsman has a role in helping individuals to get fair administration of public services. The office of the Ombudsman also has a remit to examine complaints about unfair administration of public services. However, the Ombudsman's office does not act on behalf of the complainant, nor does it provide an advocacy or support service for individuals. Rather it provides an impartial service of examination of individual complaints. The office of the Ombudsman for Children has a somewhat wider remit not only to examine complaints with respect to children but also to "promote the rights and welfare of children and young people under 18 years old living in Ireland." Its work includes "supporting people, including children and young people, to find out about children's rights and how those rights can be respected, protected and realised."³

Finally, the upcoming development of the role of Peer Support Worker within the HSE's mental health services has the potential to play a complementary, though different, role to those of advocacy services. According to the HSE, Peer Support Workers are "people who have lived experience of mental distress and recovery. They use this experience to help others who are currently experiencing distress Peer Support Workers draw upon their own lived experience of mental distress and recovery to offer emotional and practical support to those currently experiencing mental illness. This involves helping and empowering people to have more choice and control in the type of support they receive."⁴ While Peer Support Workers will provide one-to-one support to mental health service users, they will not be able to be independent in terms of their position within the services since they will be members of their local HSE mental health team.

3 Information taken from <https://www.oco.ie/about-us/what-we-do/> on 4/2/2017.

4 Information taken from http://hse.ie/eng/services/list/4/Mental_Health_Services/advancingrecoveryireland/peersupport/ on 4/2/2017.

Rationale for the Study

In *A Vision for Change*, the Expert Group on mental health policy recommended that “advocacy should be available as a right to all service users in all mental health services, i.e. including hospitals, day centres, training centres, clinics, or elsewhere in all parts of the country.”⁵

The Community Advocacy Needs (CAN) survey was developed to investigate the level and nature of mental health service users' need for independent, one-to-one advocacy support.

Mental Health Reform (MHR) is aware that there may be a gap in independent advocacy services for people with a mental health difficulty living in the community.

MHR receives enquiries from individuals who are seeking information on how they can access better mental health services or how they can obtain redress for poor treatment received within mental health services. These individuals are often unaware of the advocacy services available.

MHR has also heard about difficulties that individuals experience in trying to make a complaint about mental health services.⁶ Reports of difficulties with the avenues for making complaints arose during MHR's consultative meetings with service users, family members/carers and staff during 2011 and 2012.

In MHR's consultations, people have described:

- Not knowing how to make a complaint
- Not knowing how to access an advocate for assistance in making a complaint
- Lack of clarity about the role of the Mental Health Commission and the Inspector in investigating a complaint
- Being afraid to make a complaint for fear of consequences to their future use of services
- Fear of returning to a service after having made a complaint
- Being discouraged by staff from making a complaint
- A lack of or dissatisfactory follow up when they have made a complaint
- Wanting accountability, follow up action, acknowledgement or apology

Apart from mental health services, there is a range of other social domains where people may need independent advocacy support. Most psychiatric hospitals in Ireland have now been closed and almost all mental health service users live in the community. They may live independently, or with family, or in a range of supported accommodation types including HSE supported hostels and group homes and voluntary sector supported housing.

One study of 300 people with experience of a mental health difficulty, published in 2010, found experiences of unfair treatment in every domain of social life, including by friends, neighbours, family, health service staff and the police, as well as in housing, education, work, public transport and

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

6 See Mental Health Reform (2012) *MHR Position Paper on Improving the Complaints System for the Mental Health Services* available at <https://www.mentalhealthreform.ie/mhr-position-paper-on-improving-the-complaints-system-for-the-mental-health-services/>

welfare.⁷ When asked to whom these individuals would turn to for assistance in instances of unfair treatment, participants showed a low level of awareness of support services.⁸

No research has ever been undertaken to specifically explore the advocacy needs of people with mental health difficulties living in the community. However, previous research has identified low levels of community participation among people living in HSE community residences.⁹ Research was therefore needed into this group's potential need for independent advocacy services and their preferences for advocacy supports.

Drawing upon some questions from previous surveys as well as developing new questions, the CAN survey focussed on the following questions about people who use secondary mental health services:

- The level and nature of their need for representative advocacy
- The level of their need for support for self-advocacy
- The level of awareness of their rights
- The level of their awareness of existing advocacy services
- The level of their awareness of existing complaints and redress mechanisms
- Who they would turn to for support

The aim of the CAN survey pilot was two-fold: firstly, to determine if the CAN survey instrument was user friendly and capable of capturing levels of need for advocacy services; and secondly, to describe the need for advocacy services in one mental health service area.

7 Mac Gabhann, L., Lakeman, R., McGowan, P., Parkinson, M., Redmond, M., Sibitz, I., Stevenson, C. and Walsh, J. (2010) *Hear My Voice: The experience of discrimination by people with mental health problems*, Dublin: Amnesty International Ireland.

8 Mac Gabhann, et al., op cit.

9 Tedstone Doherty, D., Walsh, D. and Moran R. (2007) *Happy Living Here...A Survey and Evaluation of Community Residential Mental Health Services in Ireland*, Dublin: Mental Health Commission.

Methodology

The survey instrument drew on existing, validated instruments that assess capacity for self-advocacy and self-esteem/self-efficacy, as well as developing original questions that assessed individuals' experiences of public and advocacy services, knowledge of how to seek redress, and preferred supports (see Appendix I). The survey incorporated the Patient Self-Advocacy Scale¹⁰ which is a measure of patients' confidence in being active participants in decisions about their healthcare, and the Self-Esteem/Self-Efficacy sub-scale of the Empowerment Scale.¹¹ The Self-Esteem/Self-Efficacy sub-scale measures individuals' overall self-confidence in being able to take action and their sense of self-worth. Questions on satisfaction with community involvement and own sense of control were taken from the *Happy Living Here* survey.¹² Feedback on the survey instrument was sought from people who use mental health services and family members through MHR's Grassroots Forum, and from an advisory group and staff of the Citizens Information Board. Ethical approval was received from the relevant hospital area Research Ethics Committee.

Recruitment of participants was through a convenience sample obtained in an urban area mental health outpatient clinic in order to reach individuals who are dispersed in the community and may be isolated from other community-based activities.

The area concerned is an area of deprivation with high levels of unemployment and poverty. The general adult mental health team in the study area serves a population of 79,062. The area is mostly urban with the central area of population zoned as high density, it also consists of upland farmland and hill top which is zoned high amenity with a very low population. Over five thousand adults attend the outpatients' department at a frequency determined by their care needs in consultation with their consultant psychiatrist. Three consultant psychiatrists (and three community mental health teams) cover the study area. The region also has a Day Hospital and Day Centre where some individuals may be seen for review; however the majority of service users attend the outpatients' department. The area also has an inpatient unit and if individuals are currently inpatients they would not attend the outpatients' department.

The general adult services in the area are largely community-oriented with an emphasis on delivering care in the community and have well developed community mental health and homecare teams (CMHTs). An Assertive Outreach Team also covers other general adult mental health teams within the CHO area. The larger area also has four high support hostels; three medium support hostels and seven low support houses. These accommodations are generally full, with approximately 90 individuals, and the majority of these attend their respective outpatient departments for review.

10 Brashers, D.E., Haas, S.M. & Neidig, J.L. (2009) 'The Patient Self-Advocacy Scale: Measuring patient involvement in health care decision-making interactions', *Health Communication* 11:2:97-121.

11 Rogers, E.S., Chamberlin, J., Langer Ellison, M., & Crean, T. (1997) 'A Consumer-Constructed Scale to Measure Empowerment among Adult Users of Mental Health Services', *Psychiatric Services* 48:8:1042-1047,

12 Tedstone Doherty, D., Walsh, D., & Moran R. (2007) Op. Cit.

In order to participate in the research, participants had to:

- be adult mental health service users and
- have not been hospitalised for their mental health difficulty within the last 3 months.

Participants who required assistance in completing the survey were facilitated by a Peer Research Assistant (PRA) who was supervised by the Principal Investigator (PI). The PRA was identified through MHR's Grassroots Forum and was selected based on being a trained Wellness Recovery Action Plan facilitator with suitable skills to facilitate data collection.

In advance of starting data collection, the PRA, PI and key liaison person for the CMHT met to discuss how the data collection process would operate within the outpatients' department. They considered how participants may be keen to discuss their experiences and that this would be facilitated by the PRA. This turned out to be shown in practice: the PRA reported later that people needed to talk, and usually this was seen in the course of completing the survey. They also considered supports to be put in place for the PRA which included regular debriefing with the PI, ensuring that the liaison person introduced the PRA to the CMHT, and availability of the key liaison person on an on-call basis. The PRA also reported that using journaling was a helpful way to process the experiences she had heard.

The use of a PRA situated within the outpatient clinic proved to be a very effective method of supporting individuals to complete the survey. In total, the PRA attended the outpatient clinic for 62 hours over a 20 days from November 2015 to February 2016. A total of 64 surveys were completed on site and 72 were handed out. Overall the PRA reported that assisting people with the CAN survey pilot at the outpatient clinic was a "very positive experience".

All participants were given an information sheet and completed a consent form. Anonymity was assured.

Data collection took place between November 2015 and January 2016. The sample was obtained from an urban area outpatient mental health clinic. A total of 76 mental health service users took part, 39% (30) were male and 59% (45) were female; one participant did not disclose this information. The PRA reported that there was some survey fatigue among people at the clinic as there had been a survey carried out there quite recently. However, while this was a challenge, it was not as significant a barrier as had been expected and only six individuals cited this reason for their lack of participation.

Findings

The results for each question are outlined below, presented in graphical format, subsequent to a brief commentary describing the findings.

Where a participant did not complete a question, this is reported in the results as 'missing data'. Where a mean score is reported, only those participants who answered the question were used to calculate the mean.

1. Profile of Participants

A total of 76 mental health service users took part, 39% (30) were male and 59% (45) were female (Figure 1.1); one participant did not disclose this information.

The 72 participants who disclosed their age were between 19-70 years old (M = 40.65, SD = 12.686).

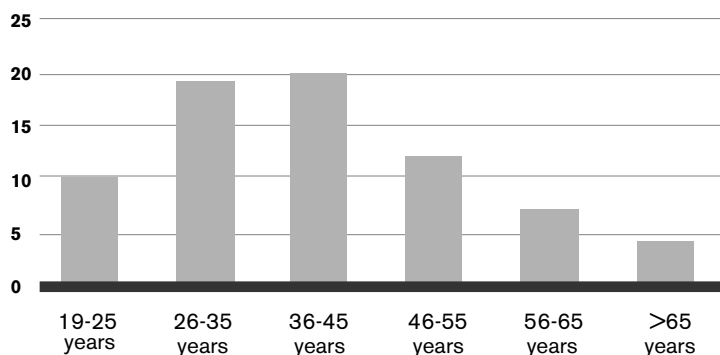


Figure 1.1 Number of participants per age group

1.1 Civic Status

Almost half of participants (49%) identified as being single, just over a quarter as married (26%), and 11% as having a partner (Figure 1.2). Only 5% selected that they were widowed, 4% as separated, and 4% as divorced. As the data was collected in a mental health clinic, the low number of participants who identified as 'widowed' or 'divorced' is of interest, as there is a documented link in the literature between mental health difficulties and relationship status. Studies have frequently documented a significantly higher degree of mental distress in people who are divorced, or widowed, or single, as opposed to those with a spouse or a partner.^{13, 14, 15} In particular, the relationship between

13 Byles, J., Vo, K., Thomas, L., Mackenzie, L. and Kendig, H. (2016) Partner status and mental and physical health of independently living men aged 70 years and older, *Australasian journal on ageing*.
 14 Al-Khathami, A.D. and Ogbeide, D.O. (2002) Prevalence of mental illness among Saudi adult primary-care patients in Central Saudi Arabia, *Saudi medical journal* 23(6), pp.721-724.
 15 Braithwaite, S.R., Delevi, R. and Fincham, F.D. (2010) Romantic relationships and the physical and mental health of college students, *Personal relationships* 17(1), pp.1-12.

depression and relationship status has been investigated, with studies typically documenting lower rates of depression amongst married participants, compared to single¹⁶ or separated/divorced participants.¹⁷

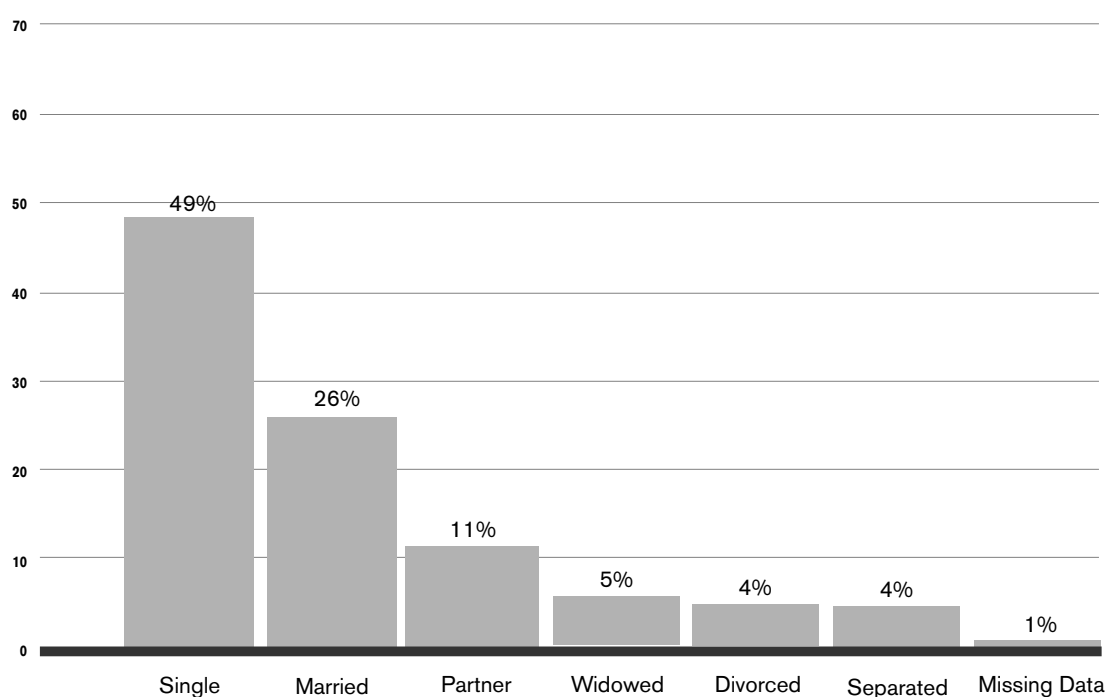


Figure 1.2 Civic Status

1.2 Diagnosis

Although the survey was collected in a mental health clinic, only three quarters of participants (76%) stated that they had been given a diagnosis for their mental health problem, with 22% reporting that they had received no diagnosis. The lack of reported diagnosis could reflect not having been given the information, or may reflect a service user not being able to remember a diagnosis that was provided.

Depression was the most common diagnosis (21% overall) with 13% of participants stating they were diagnosed with depression, and 8% reporting that they were diagnosed with comorbid depression and another diagnosis (Figure 1.3). This was followed by bipolar disorder (16%), schizophrenia (11%), schizoaffective disorder (7%), and borderline personality disorder (5%). However, as participants were only provided with four options to choose from: 'Bipolar', 'Schizophrenia', 'Schizoaffective disorder', and 'Other (please specify)', it is possible that the level of multiple diagnoses may be higher than reported.

16 Scarinci, I.C., Beech, B.M., Naumann, W., Kovach, K.W., Pugh, L. and Fapohunda, B. (2001) Depression, socioeconomic status, age, and marital status in black women: a national study, *Ethnicity & Disease* 12(3), pp.421-428.

17 Akhtar-Danesh, N. and Landeen, J. (2007) Relation between depression and sociodemographic factors, *International Journal of Mental Health Systems* 1(1), p.1.

1.3 Education level

Just over two thirds of participants (67%) had completed primary education (12%), lower second level education (28%), and upper second level education (28%) combined (Figure 1.3).

The results presented below represent the highest qualification participants attained (Figure 1.3).

In terms of third-level education, only 7.9% of the survey sample had a third level degree or higher, compared to 23.5% of the population in Census 2011.¹⁸ The proportion of males educated to a level no higher than lower secondary, at 37%, was almost exactly the same as that of the general population, which stands at 36%. However, only 22% of females were educated to a level no higher than lower secondary, which is significantly fewer than the general population, whereby 31% of females had a similar level of education.

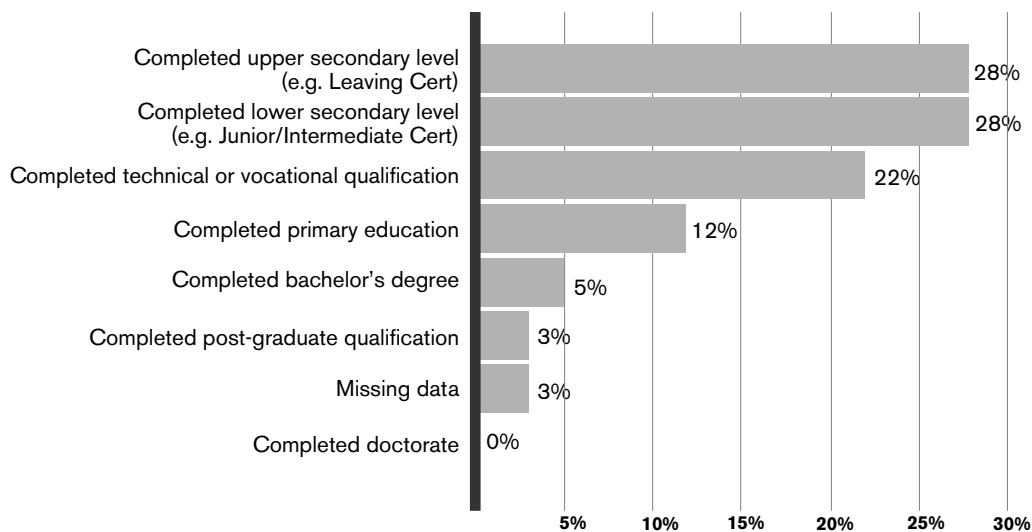


Figure 1.3 Highest qualification completed

1.4 Accommodation

Three quarters of participants (75%) (Figure 1.4), stated that they lived with family members, while just 16% lived alone, and only 7% lived with non-family members. The substantial number of participants living with others is reassuring in one way, because much research has suggested that

living alone may have negative effects on mental health.^{19,20} However, it is possible that living with family as a middle-aged adult may indicate a lack of social inclusion or lack of access to independent accommodation.

It is striking that, in terms of those who identified as being single, 22% were living alone, 68% were living with family members, and 8% were living with non-family members.

The most common type of accommodation lived in was renting from a local authority (28%), followed by living in a home which the participant owned or paid a mortgage for (24%), and living in a home that family member owns/pays a mortgage for (17%). Following this, 9% of participants were renting from a voluntary housing association and 9% were renting from a private landlord.

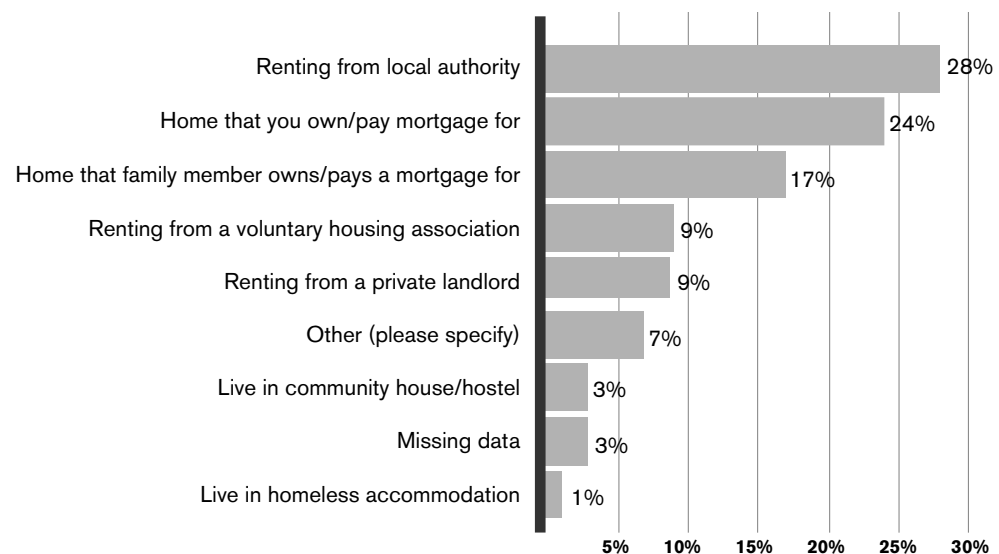


Figure 1.4 Current housing type

19 Pulkki-Råback, L., Kivimäki, M., Ahola, K., Joutsenniemi, K., Elovainio, M., Rossi, H., Puttonen, S., Koskinen, S., Isometsä, E., Lönnqvist, J. and Virtanen, M. (2012) Living alone and antidepressant medication use: a prospective study in a working-age population, *BMC Public Health* 12(1), p.1.

20 Haw, C. and Hawton, K. (2011) Living alone and deliberate self-harm: a case-control study of characteristics and risk factors, *Social psychiatry and psychiatric epidemiology* 46(11), pp.1115-1125.

1.5 Employment Status & Income

Almost two thirds of participants were out of work, with 30% (Figure 1.5) indicating that they were unemployed and 28% selecting that they were unable to work due to permanent sickness or disability. Only 16% of participants were working for payment/profit (full time or part time). A further 8% of participants were looking after their home or family, while 5% were students and 5% were retired. In comparison to the Census 2011 unemployment rate for the whole adult population of 19%,²¹ the rate in this sample was high. Irish research has shown that people with a mental health disability are nine times more likely to be outside the labour force than those without a disability.²²

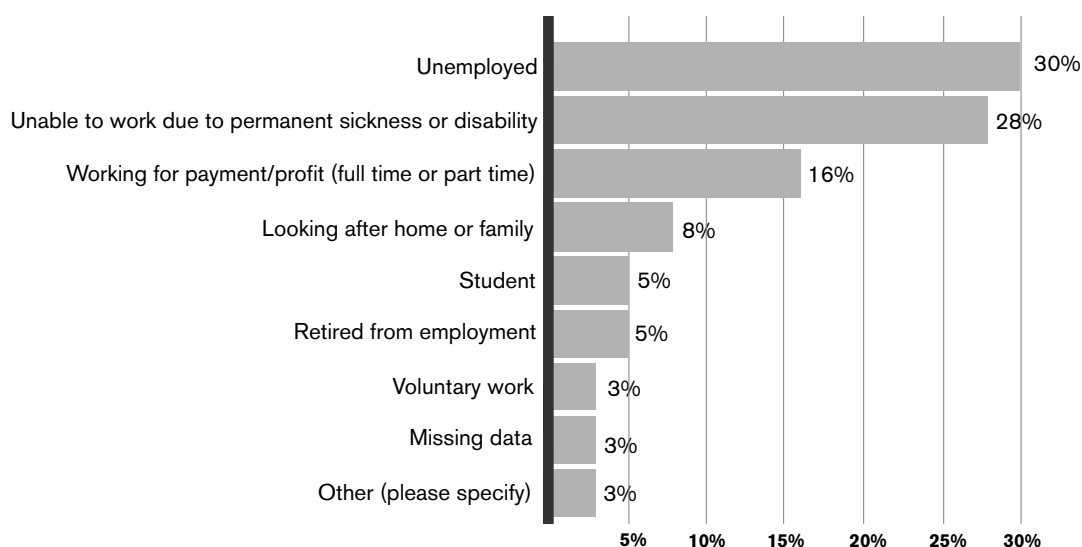


Figure 1.5 Current work status

As the majority of participants indicated that they were out of work, it is unsurprising that a substantial three quarters of participants' (76%) main source of income was social welfare payments, while only 16% of participants' main source of income came from work or self-employment (Figure 1.6). Very few participants depended on the state old age pension (3%), while none were dependent on an occupational or personal pension.

21 CSO (2011) *Irish Census*, CSO Publishing.

22 Watson, D., Kingston, G. and McGinnity, F. (2012) *Disability in the Irish Labour Market: Evidence from the QNHS Equality Module*, Dublin: Equality Authority/Economic and Social Research Institute, p.19.

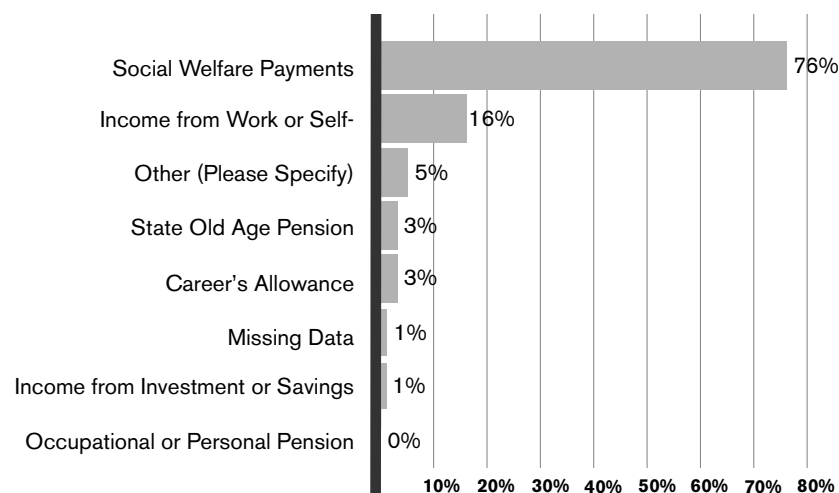


Figure 1.6 Main sources of income

More than half or 57% of all participants were dependent on a total household annual income of under €10,000. In line with the results of the previous question, 69% of those who selected that they were dependent on social welfare payments indicated that they were dependent on a total household annual income of less than €10,000, though this probably does not reflect secondary benefits that individuals may have such as housing benefit. The next category, €10,000 - €19,999, amounted to 11% of all participants, followed by 8% of all participants depending on a total household annual income of 20,000-€29,999, and 7% of dependent on €30,000-€39,999. Only 3% of all participants had a total annual income of €40,000 or more. This finding is of particular concern as research has documented a relationship between low income and increased mental health difficulties.²³

While 42% of participants did not share their income with anyone else, almost a quarter of participants (24%) shared it between 4 or more individuals. This finding is of interest in relation to research which has emphasised the relationship between low levels of household income and mental health difficulties. For example, one study found a reduction in household income to be associated with increased risk for incident mental disorders.²⁴ 21% of participants shared this income with two individuals, while 11% of participants shared it between three.

23 Sareen, J., Afifi, T.O., McMillan, K.A. and Asmundson, G.J. (2011) Relationship between household income and mental disorders: findings from a population-based longitudinal study, *Archives of General Psychiatry* 68(4), pp.419-427.

24 Sareen, J., Afifi, T.O., McMillan, K.A. and Asmundson, G.J. (2011) Relationship between household income and mental disorders: findings from a population-based longitudinal study, *Archives of General Psychiatry* 68(4), pp.419-427.

2. Life in the Community

2.1 Attendance at activities in the community

The cinema was the most popular activity which participants attended in the community (29%) (Figure 2.1), followed by pubs/clubs/restaurants (25%). However, the largest group of participants (34%) selected 'none' when given a list of possible community activities. It should be noted that this could be interpreted to mean that they attended no activities in the community, or that they attended none of those listed. The large minority indicating that they participated in none of the listed activities is of concern, as much research has documented that engaging in activities can be beneficial for mental health, with studies suggesting that individuals who engage in leisure-time physical activity,²⁵ religious practice²⁶ and outdoor activities²⁷ were less likely to have symptoms of psychological distress, compared to individuals who did not engage in these activities. Other activities attended by participants included the library (24%), social clubs (8%), religious worship (8%), community centres (7%), bingo (5%), and a mental health related support group (5%). The categories 'mental health related support group', 'class' (not specified by the participants), 'sports club' and 'volunteer work' were incorporated into the analysis following the collection of data, due to the large number of participants who wrote some form of these activities into the 'Other' option. An increased number of participants therefore may have selected these options if they had been available to choose from at the time of completing the survey.

25 Harvey, S.B., Hotopf, M., Øverland, S. and Mykletun, A. (2010) Physical activity and common mental disorders, *The British Journal of Psychiatry* 197(5), pp.357-364.

26 Jarvis, G.E., Kirmayer, L.J., Weinfeld, M. and Lasry, J.C (2005) Religious practice and psychological distress: The importance of gender, ethnicity and immigrant status, *Transcultural Psychiatry* 42(4), pp.657-675.

27 Peacock, J., Hine, R. and Pretty, J. (2007) *The mental health benefits of green exercise activities and green care*, Mind UK available at <https://www.mind.org.uk/medv ia/273470/ecotherapy.pdf>

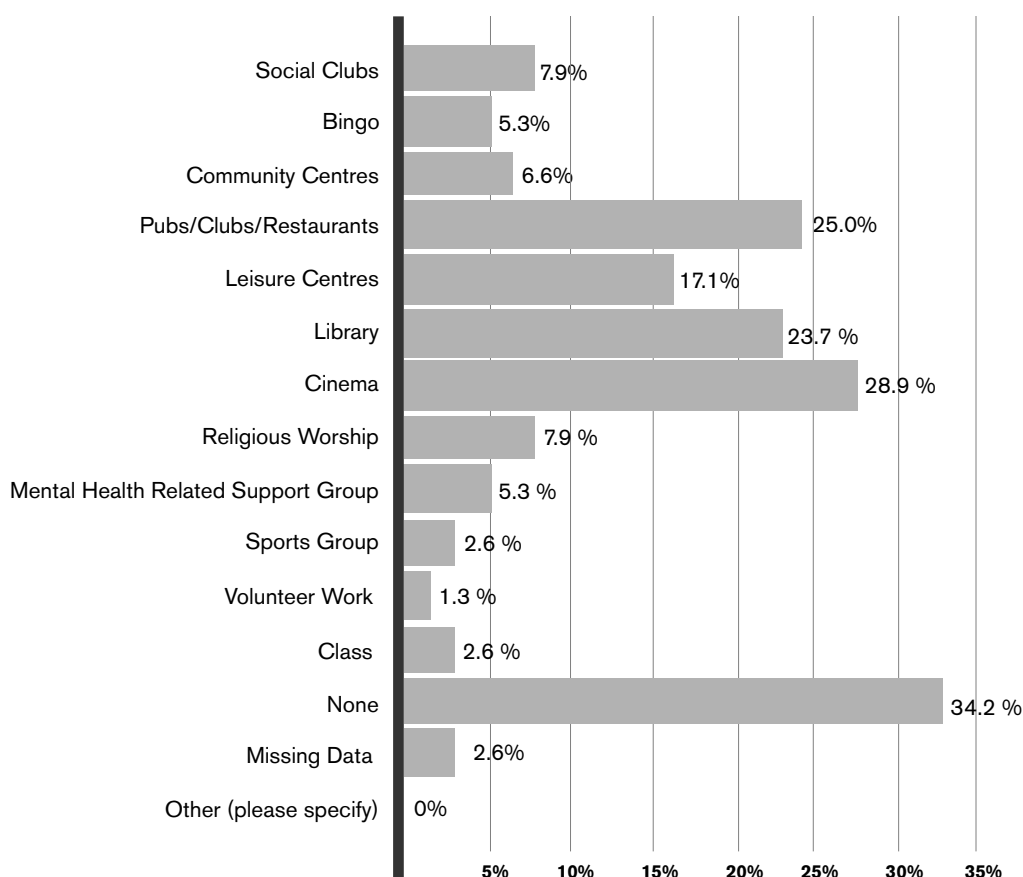


Figure 2.1 Activities attended in the community

2.2 Involvement in the community

Participants were asked five questions which related to their involvement in the community, control over their own life, satisfaction with their community mental health team, satisfaction with their GP and involvement in care planning.

Participants were also asked how happy they were with their involvement in the community. The options were as follows: not at all happy (1), slightly happy (2), happy most of the time (3), or very happy (4).

61% of participants were either not at all happy, or only slightly happy with their involvement in the community.

The average level of happiness with involvement in the community for all participants was 2.1 (n=73), indicating that participants on average are only slightly happy with their involvement in the community. In terms of the spread of responses, a third (33%) were not happy at all with their involvement in the community, while 28% were only slightly happy. Just under a third (30%) of participants were happy most of the time, however only 5% were very happy with their community involvement. Therefore, 61% of participants were either not at all happy, or only slightly happy, which is of concern because engagement in the community has been found to have benefits for developing feelings of self-efficacy and well-being.²⁸

For those who indicated that they lived alone, a quarter of participants (25%) were not happy at all with their involvement in the community, half (50%) were only slightly happy, 17% were happy most of the time, with only 8% very happy with their involvement in the community.

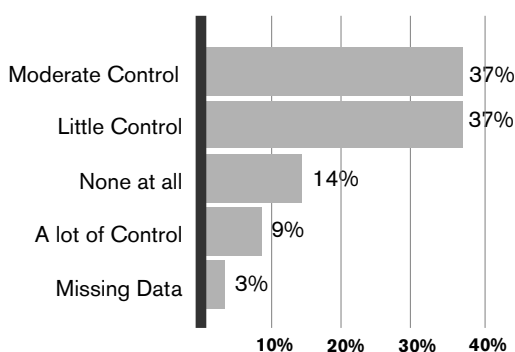


Figure 2.2 How much control do you feel you have to lead your own life as you want?

2.3 Participant perception of control to lead own life as wanted

Participants were asked how much control they felt they had to lead their own life as they wanted. The options were as follows: none at all (1), little control (2), moderate control (3), or a lot of control (4). The average of all participants was 2.4, indicating that participants on average felt that they had between little and moderate control to lead their own lives as they wanted.

More than a third or 37% of participants felt that they had little control to lead their own lives as they wanted (Figure 2.2), while 37% also felt they had moderate control to lead their own lives as they wanted; 14% however, felt that they had no control at all, and 9% felt they had a lot of control to lead their own lives as they desired. The small number of participants who felt they had a lot of control to lead their own lives as they want is of concern. A study examining the quality of life of individuals with mental health problems found that a good quality of life was characterised by the feeling of being in

control, whereas a poor quality of life was characterised by feelings of lack of control.²⁹

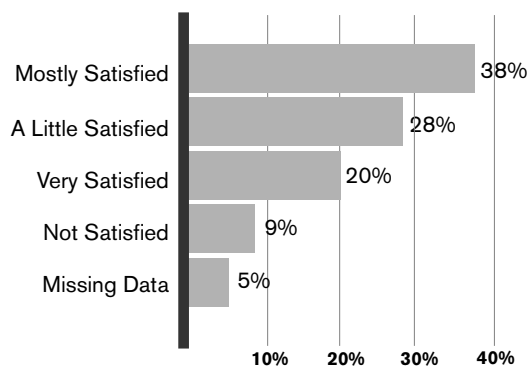


Figure 2.3 Percentage of participants satisfied with the support from their mental health team

2.4 Satisfaction with support from mental health team

In response to 'how satisfied are you with the support that you get from your mental health team?' participants selected from the following options: not satisfied (1), a little satisfied (2), mostly satisfied (3), or very satisfied (4).

The average participant score was 2.7 (n=72), indicating that on average, participants felt that they were between a little satisfied and mostly satisfied with the support they received from their mental health team.

These figures indicate that a majority of 38% were mostly satisfied with the support that they received from their mental health team (Figure 2.3), and 20% were very satisfied. However, 28% were only a little satisfied and 9% were not satisfied. A national survey on inpatient mental health

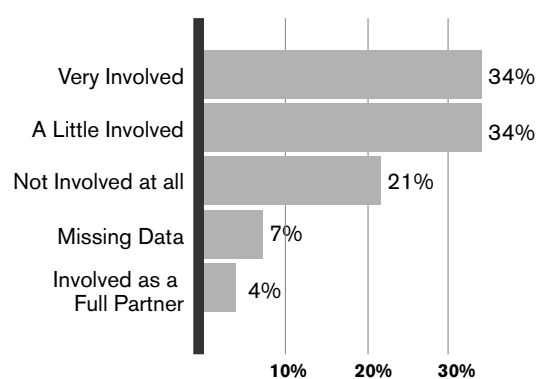


Figure 2.4 Percentage of participants' involvement in planning treatment with the mental health

29 Connell, J., Brazier, J., O'Cathain, A., Lloyd-Jones, M. and Paisley, S. (2012) Quality of life of people with mental health problems: a synthesis of qualitative research, *Health and quality of life outcomes* 10(1), p.1.

care conducted by the Mental Health Commission³⁰ asked participants about certain aspects of their mental health team. Although participants were not asked specifically about their level of satisfaction with their mental health team, they were asked about several other aspects of their experience of their team. In the inpatient study, 87% of participants stated that they trusted their healthcare team, 93% reported that members of their healthcare team were courteous, and 90% indicated that it was possible to have a private conversation with a member of their team.

2.5 Involvement with planning of own treatment with mental health team

Participants were asked to rate how involved they were in planning their own treatment with their mental health team. The options were as follows; not involved at all (1), a little involved (2), very involved (3), or involved as a full partner (4). The average score for all participants was 2.2 (n=71), suggesting that on average participants felt that they were only a little involved in the planning of treatment.

In terms of percentages, 34% of participants said they were very involved, 34% were involved a little, over a fifth (21%) selected that they were not involved at all while only 4% selected that they were involved as full partners (Figure 2.4). These findings are relatively low in comparison to the findings of the national survey of inpatients, where 76% of service users believed that they were involved in decisions made about their care and treatment as much as they would have liked, however 24% of service users would have welcomed greater involvement in the process.³¹

2.6 Satisfaction with healthcare received from GP

Participants were asked 'if you receive healthcare from a GP, how satisfied are you with the healthcare that you receive?' The options were as follows; not satisfied (1), a little satisfied (2), mostly satisfied (3), or very satisfied (4). The average score for all participants was 2.9 (n=69), suggesting that on average participants were mostly satisfied with the healthcare they received from a GP.

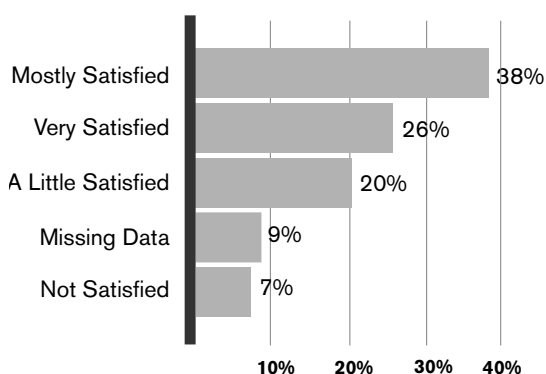


Figure 2.5 Participant satisfaction with healthcare from a GP

30 Mental Health Commission (2012) *Your views of mental health inpatient services inpatient survey 2011*, Dublin: Mental Health Commission.

31 Mental Health Commission (2012) *Your views of mental health inpatient services inpatient survey 2011*, Dublin: Mental Health Commission.

This indicates that the majority of participants (64%) (Figure 2.5) were very or mostly satisfied with the healthcare they received from a GP, a fifth (20%) were a little satisfied, while 7% were not satisfied. These results are relatively low compared to the results of a patient satisfaction study conducted by the HSE which found that 84% of GP patients rated their experience as excellent or very good, with just 3% of GP patients rating their experience as fair or poor.³²

3. Self-esteem/ self-efficacy

A subscale of the Empowerment Scale³³ was used to assess the self-esteem/self-efficacy of participants. The Empowerment Scale was originally designed to “measure the personal construct of empowerment as defined by consumers of mental health services.”³⁴ It has been suggested that the self-esteem and self-efficacy subscale has “items which measure feelings of worth, capabilities to accomplish goals, perceived ability to overcome obstacles and perseverance.”³⁵ Participants selected their response to each of the 9 items from a four point Likert scale (strongly agree (1), agree (2), disagree (3), or strongly disagree (4)).

Combined average scores per participant for the 9 items in the scale were calculated. The mean score for the scale was 2.52 (n=72) indicating that on average, participants' self-esteem was neither high nor low, but relatively neutral.

32 Boilson, A., Craven, F., Drummond, A., Fitz-Simon, N., O'Mahony, D. and Staines, A. (2007) *Insight '07—Health and Social Services in Ireland—a survey of consumer satisfaction*, HSE Dublin.

33 Rogers, E.S., Chamberlin, J., Ellison, M.L., Crean, T. (1997) A consumer-constructed scale to measure empowerment among users of mental health services, *Psychiatric Services* 48(8), pp.1042-7.

34 Ibid.

35 Walby, G.W. (2006) *Associations between Individual, Social and Service Factors, Recovery Expectations and Recovery Strategies for Individuals with Mental Illness*, University of South Florida, graduate theses and dissertations, <http://scholarcommons.usf.edu/etd/2741>.

4. Accessing services & entitlements

4.1 Accessing support

Participants were shown a list of types of services and asked if they had any difficulty accessing these services. The purpose of this question was to assess whether they had been in a situation where they may have benefited from independent advocacy support.

A quarter of participants (25%) (Figure 4.1.1) indicated that they had experienced difficulty getting/ accessing supports from mental health services, while a quarter (25%) of participants also indicated they had difficulty attaining supports from social welfare services. Closely behind this, was difficulty in getting support from local authority housing services (24%); 26% of participants did not select any of the options. This could reflect that they did not have any difficulty or that they had not attempted to access any of the services which were provided in the options. It is therefore recommended for future research that a 'no difficulty' option and a 'never attempted to access any of the above services' option are included in the survey. A total of 16% of participants had difficulty accessing supports from employment services, while 16% had difficulty attaining supports from other mental health services. Furthermore 9% had difficulty accessing supports from An Garda Síochána, and a further 9% had difficulty gaining support from education or training providers.

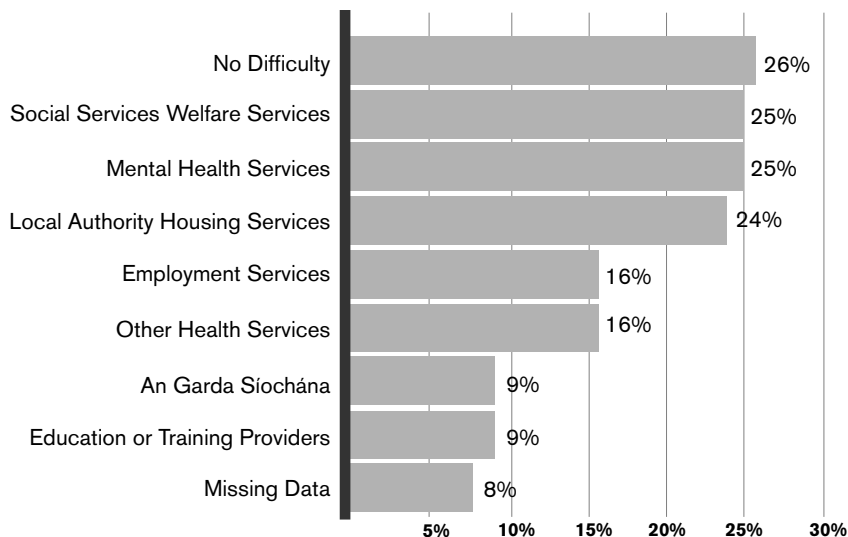


Figure 4.1.1 Have you had difficulty in getting the supports you needed from any of the following services?

Participants were then asked open questions about who they would turn to for support if they had difficulty accessing various services. During analysis, these answers were sorted into several categories which best suited the answer provided.

For help with mental health services, 30% of participants (Figure 4.1.2) stated that they would turn to a medical professional when experiencing a difficulty in getting what they needed from a mental health service. Some participants stated that they would turn to a family member (20%). There was a high response rate of 'no-one' (16%) and 'don't know' (12%), as well as a high rate of missing data (13%), which may indicate a lack of knowledge on how to access supports. A survey commissioned by the HSE in 2007 asked participants who they would turn to if they thought they had a mental health problem. Although the question differed from the current survey as the question surrounded the mental health problem rather than the service, there was a similarity between the responses, whereby the majority of participants stated they would most likely turn to a GP, followed by a husband/wife/partner.³⁶

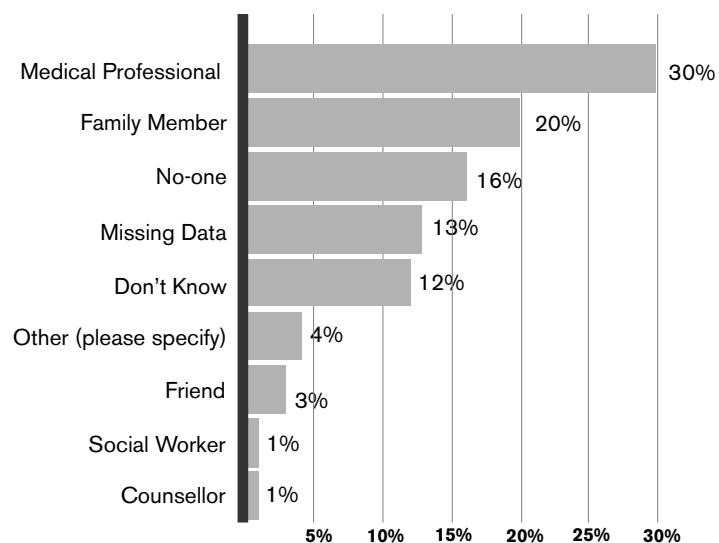


Figure 4.1.2 If you had difficulty getting what you needed from mental health services, who would you turn to for support?

With regard to housing, one quarter of participants (25%) stated that they did not know who they would turn to for support if they had difficulty getting housing (Figure 4.1.3). This was followed by a family member (14%) and the County Council (12%) while 9% stated that they would turn to 'No-one'.

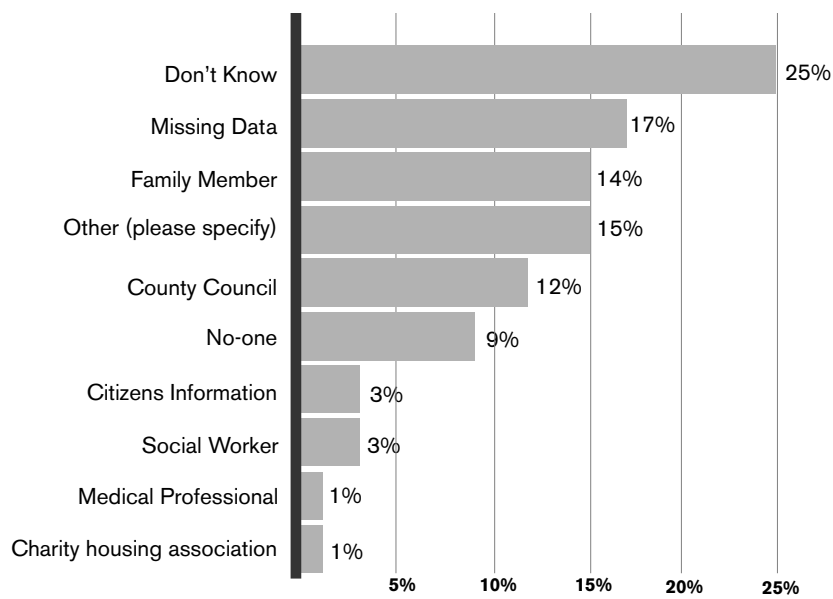


Figure 4.1.3 If you had difficulty getting housing, who would you turn to for support?

In relation to accessing social welfare benefits, similar to the previous question, a quarter of participants (25%) (Figure 4.1.4) stated that they did not know who they would turn to for support if they had difficulty in this area, 16% indicated that they would go to the Citizens Information Service, 13% said they would approach the social welfare office, and 12% stated they would turn to a family member. Furthermore 8% said that they would turn to 'no-one', while 12% left the answer to this question blank.

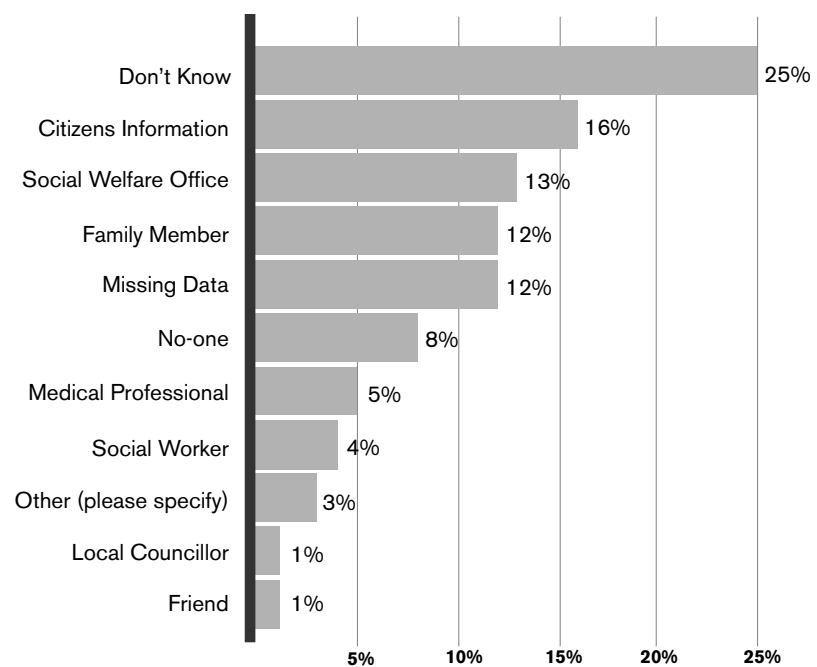


Figure 4.1.4 If you had difficulty accessing social welfare benefits, who would you turn to for support?

Almost a third of participants (32%) (Figure 4.1.5) stated that they did not know who they would turn to for support if they had difficulties in getting their needs met in employment services, followed by 13% of participants who selected 'no-one'. A further 8% stated they would turn to a family member, 8% said they would go to an employment support service, 5% said that they would go to the Citizens Information Service, and 16% of participants did not answer this question.

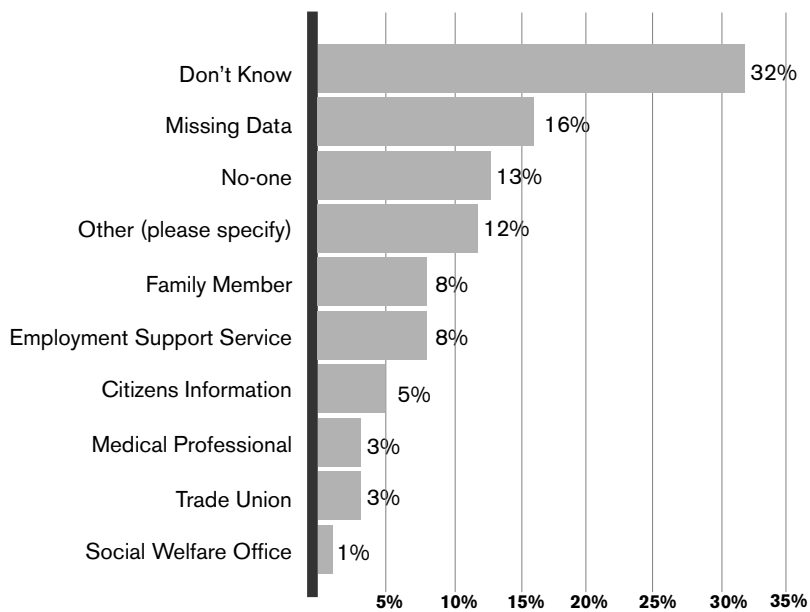


Figure 4.1.5 If you had difficulties getting your needs met in employment services, who would you turn to for support?

Over half of participants (53%) indicated that they did not know about their rights under Ireland's Employment Equality laws, while 37% selected that they knew a little about their employment rights (Figure 4.1.6). Only 1% of participants indicated that they knew a lot about their rights, however no participants were fully aware of the process for making a claim under Ireland's Employment Equality laws while 9% of left this question blank.

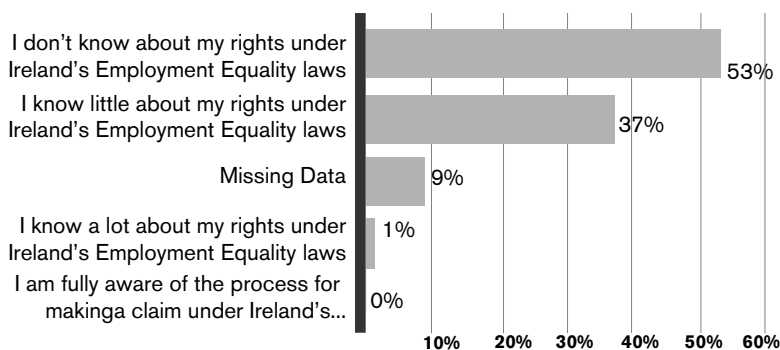


Figure 4.1.6 How would you describe your knowledge about your rights under Ireland's Employment Equality laws?

A quarter (25%) of participants (Figure 4.1.7) stated that they did not know who to turn to if experiencing difficulty in getting their needs met in relation to education or training services. More than one in ten or 11% said that they would contact an employment support service, while 7% would turn to the Citizens Information Service. However, 7% responded that they would turn to 'No-one', while 22% left the answer to the question blank.

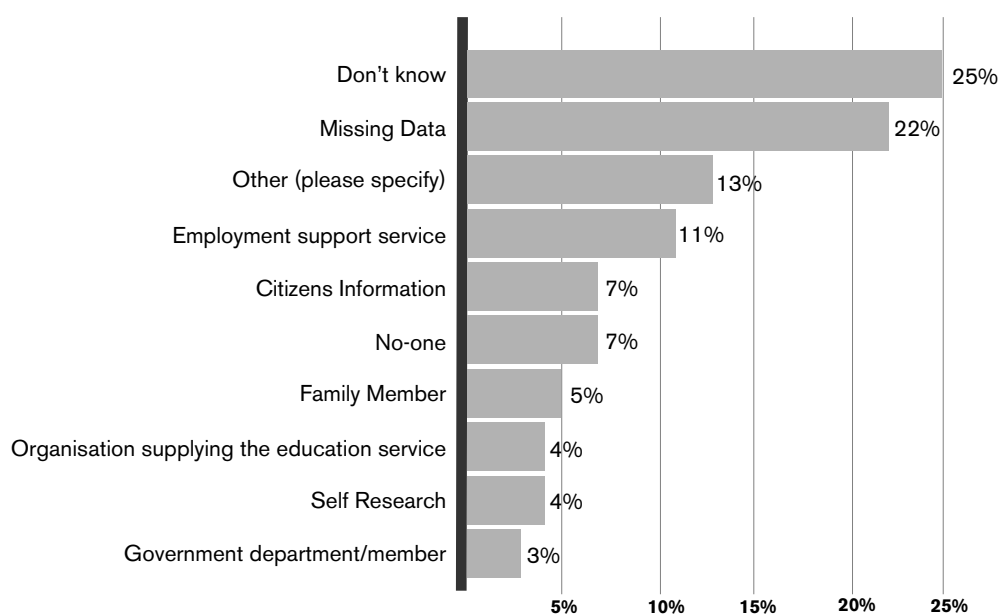


Figure 4.1.7 If you had difficulty getting your needs met in education or training services, who would you turn to for support?

Almost a quarter (24%) (Figure 4.1.8) of participants responded that they did not know who to turn to for support if they had a difficulty with An Garda Síochána, 13% would turn to a family member, 11% to a legal professional, and 9% to the Ombudsman. However, 12% stated that they would turn to 'No-one' and 17% left the answer to the question blank.

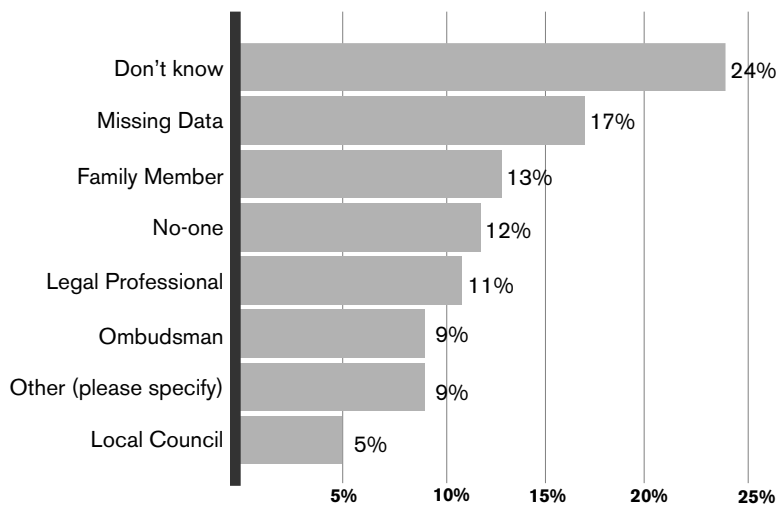


Figure 4.1.8 If you had difficulty with An Garda Síochána, who would you turn to for support?

4.2 Experience of Advocacy Services

Participants were asked if they had heard of the following advocacy services: Irish Advocacy Network, National Advocacy Service for People with Disabilities (NAS), Citizens Information Centre (CIC), Money Advice and Budgeting Service (MABS), or Other (specify). The Irish Advocacy Network is funded by the HSE, while the CICs, NAS and MABS are funded by the Citizens Information Board.

When asked, almost all participants indicated that they had heard of the Citizens Information Centre (97%) (Figure 4.2.1), while two thirds (67%) had heard of the Money Advice and Budgeting Service. 14% had heard of the Irish Advocacy Network, while 11% had heard of the National Advocacy Service for People with Disabilities (NAS). One participant also expressed knowledge of the National Service Users Executive in the 'Other' section.

These findings must be read within the context of the target scope for the various advocacy services available. The finding that almost all participants had heard of the CIC fits with the general target group for this service, while, as already mentioned, the NAS service has a special remit for individuals who are isolated from their community and services, have communication differences, are inappropriately accommodated, live in residential services, attend day services and have limited informal or natural supports. As a service providing advocacy support to very vulnerable people, NAS is not intended as a first port of call for information or advocacy.

Similarly, it may be that the participants in this study had not had an inpatient experience where they may have been more likely to hear about the Irish Advocacy Network.

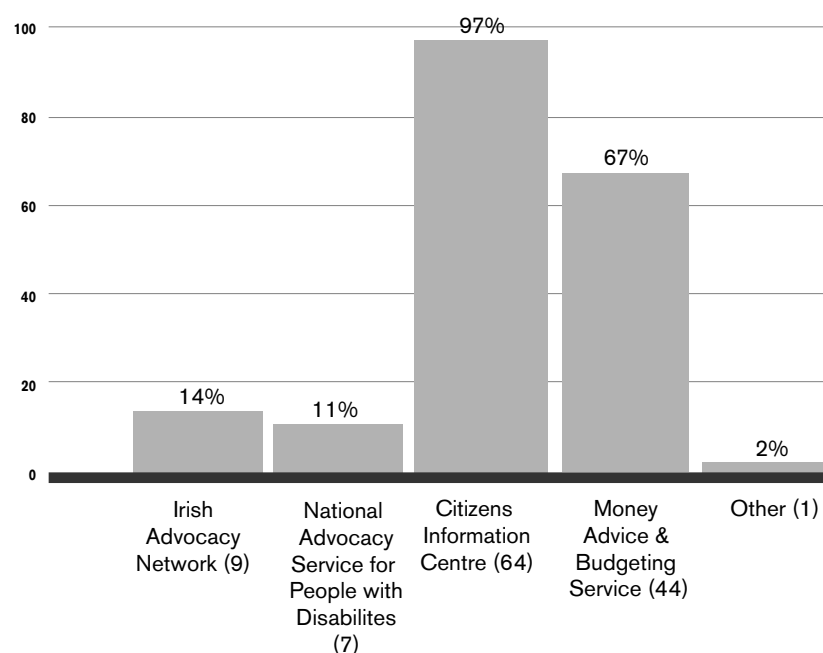


Figure 4.2.1 Have you heard of any of the following advocacy services?

When asked about usage of these services, a large majority of participants had used the Citizens Information Centre (92%) (Figure 4.2.2), while a quarter of (25%) had used the Money Advice & Budgeting Service; 4% of participants had used the National Advocacy Service for People with Disabilities, and 2% had used the Irish Advocacy Network.

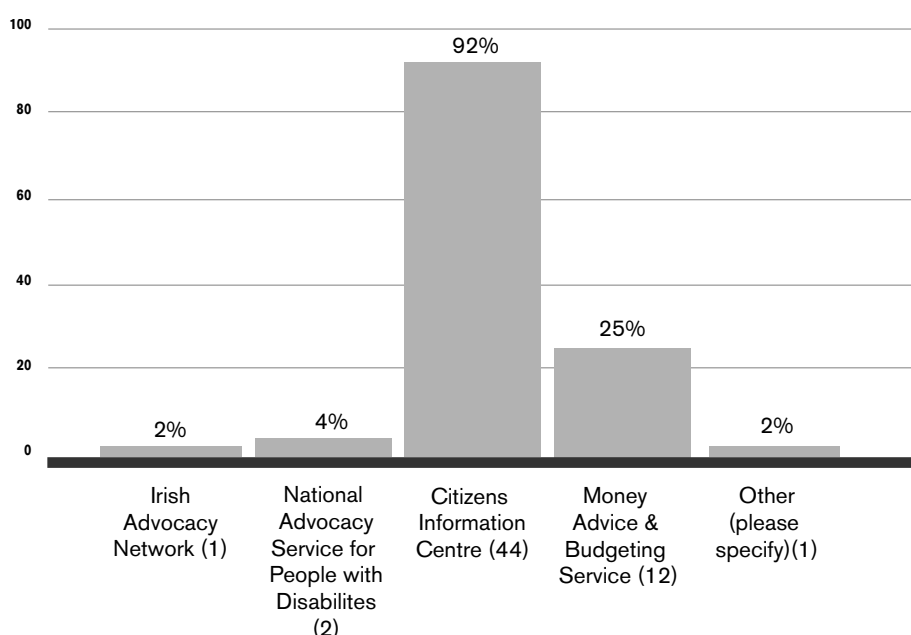


Figure 4.2.2 Have you used any of the following advocacy services?

In relation to satisfaction with the services accessed, although only one participant had stated in the previous question that s/he had used the Irish Advocacy Network three participants answered the question asking how satisfied they were with the service, so these responses should be treated with caution. Of these three participants, two selected 'satisfied' while one selected 'not at all satisfied' (Figure 4.2.3).

Of the two participants who had used the National Advocacy Service for People with Disabilities, one was 'satisfied' while one participant was 'not satisfied at all'.

Thirty-eight participants out of the forty-four who stated that they had used the Citizens Information Centre, answered this question. Of these 38 participants, 36 said that they were satisfied to some extent, with 18 having selected 'satisfied', 11 'very satisfied' and 7 reported that they were 'fully satisfied'. Meanwhile 2 participants selected that they were 'not at all satisfied'.

Although only 12 participants selected in the previous question that they had used the Money Advice and Budgeting Service, 13 participants expressed their level of satisfaction with the service. Overall 10 were satisfied to some extent, with 5 'satisfied', 3 'very satisfied', and 2 'fully satisfied' Three participants were 'not satisfied at all'.

Although only one participant had selected in the previous question that s/he had used another advocacy service (the National Service Users Executive), 3 participants supplied answers as to how satisfied they were with 'Other' advocacy services, however the names of these services were not provided. Of these 3 participants one was not satisfied at all, one was 'very satisfied' and one was 'fully satisfied'.

It is clear however from these questions, that there is a good level of knowledge about the existence of the Citizens Information Centre and a strong level of satisfaction with the service. Following this in terms of knowledge is the Money Advice and Budgeting Service. However it is evident that there is little knowledge of the services provided by the Irish Advocacy Network and the National Advocacy Service for People with Disabilities which may be in keeping with the small proportion of mental health service users for which these services are relevant.

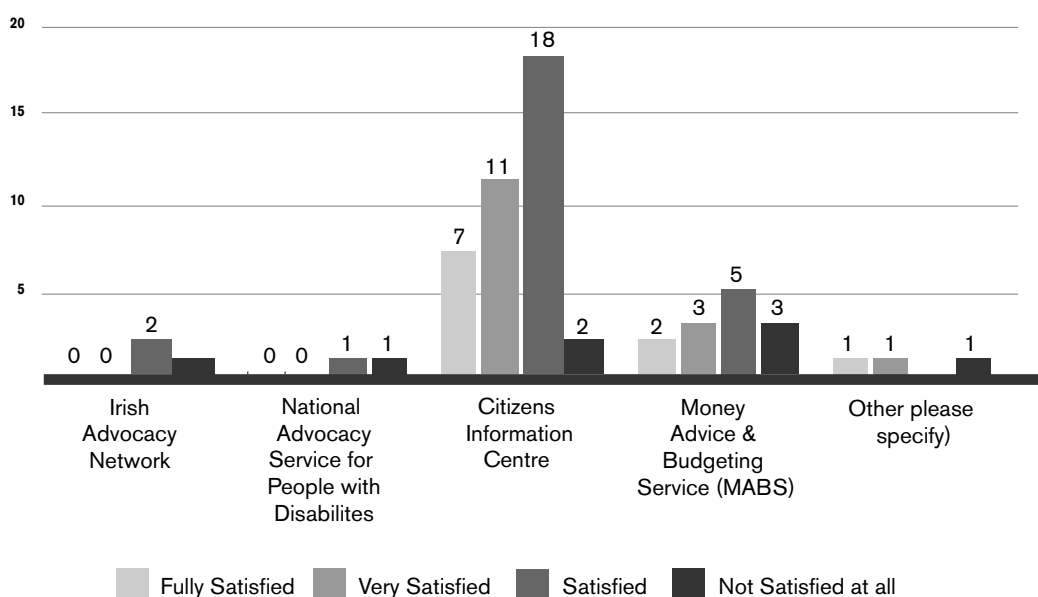


Figure 4.2.3 If you have used an advocacy service before, how satisfied were you with the support you received?

4.3 Complaints procedures

Participants were asked about their knowledge of how to make a complaint about public mental health services. Two thirds of participants (67%) stated that they did not know how to make a complaint about mental health services, while 19% selected that they knew a little about how to make a complaint. Only 5% selected that they knew a lot about how to make a complaint; no participant was fully aware of the process for making a complaint and 9% did not provide any answer for this question.

When asked about the HSE's 'Your Service Your Say' feedback process, 78% of participants had not heard of the 'Your Service Your Say', while only 12% had heard of it and 11% did not answer this question.

When asked about the ease of making a complaint about a health service,³⁷ the majority of participants indicated that it was difficult or very difficult to make a complaint (62%), just 3% of participants reported that they thought it was 'very easy', while 17% said it was 'easy'. Meanwhile 19% of participants did not answer this question.

5. Self-advocacy

5.1 Patient Self-Advocacy Scale

As described in the methodology section, participants completed the Patient Self-Advocacy Scale, a 12 item scale in 4-point Likert format, ranging from 'Strongly agree' (1) to 'Strongly disagree' (4). There are three domains within this scale, each represented by four items: a) increased 'illness' education (b) increased assertiveness and (c) potential for mindful non-adherence.³⁸ The overall mean among all participants for the patient self-advocacy scale was 2.65 (n=67), indicating that this group of participants were more likely to disagree than to agree that they are able to self-advocate.

37 This question in the survey referred to 'health service' and did not specify 'mental health service'.

38 Brashers, D.E., Haas, S.M. & Neidig, J. (1999) 'The Patient Self-Advocacy Scale: Measuring patient involvement in health Care decision-making interactions', *Health Communication* 11:2, 97-121.

5.2 Confidence in self-advocacy

Supporting the findings from the Patient Self-Advocacy Scale, participants were then asked how confident they would feel advocating for themselves in nine different situations. Participants selected their response from a 4-point Likert Scale; not confident at all (1), a little confident (2), mostly confident (3), or fully confident (4). The results for each situation are shown in Figure 5.1.

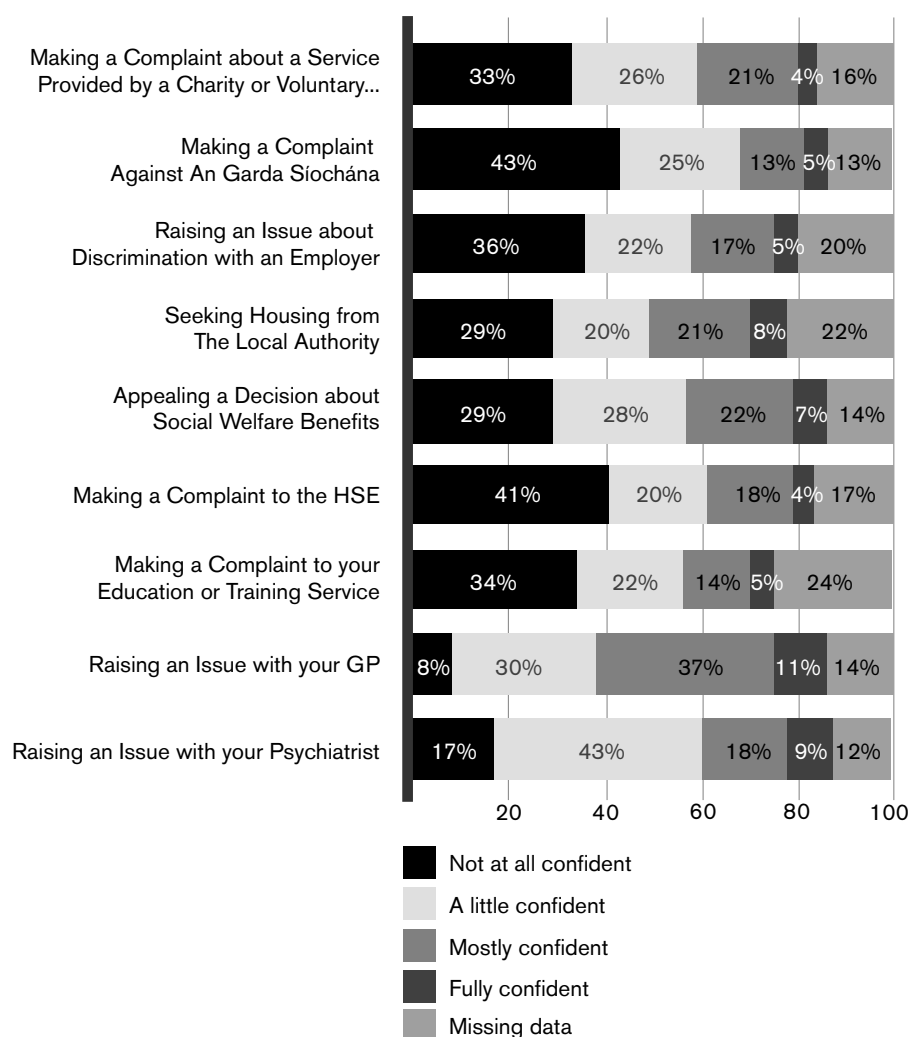


Figure 5.1 Level of confidence in self-advocacy

With regard to 'Making a complaint about a service provided by a charity or voluntary organisation', a third of participants (33%) selected 'not at all confident', 26% selected 'a little confident', 21% selected 'mostly confident', and 4% selected 'fully confident'.

In response to 'Making a complaint against An Garda Síochána', 43% of participants would not be confident at all, 25% would be a little confident, 13% would be mostly confident and 5% would be fully confident.

With regard to 'Raising an issue about discrimination with an employer', 36% of participants selected 'not at all confident', 22% chose 'a little confident', 17% selected 'mostly confident' and only 5% indicated that they would be 'fully confident'.

In response to the situation 'Seeking housing from the local authority', 29% of participants would not be confident at all, 20% would be a little confident, 21% would be mostly confident, and 8% would be fully confident.

When presented with the situation 'appealing a decision about social welfare benefits', 29% of participants selected that they would be 'fully confident', 28% selected that they would be 'confident', 22% selected that they would be 'mostly confident', and 7% selected that they would be 'fully confident'.

In response to 'making a complaint to the HSE', 41% of participants were not confident at all, 20% were a little confident, 18% were mostly confident, and only 4% were fully confident.

In response to 'making a complaint to your education or training service', 34% of participants were 'not at all confident', 22% were 'a little confident', 14% were 'mostly confident', and only 5% were 'fully confident'.

In relation to 'raising an issue with your GP', 8% of participants were not confident at all, 30% were a little confident, 37% were mostly confident, and 11% were fully confident.

Finally, in relation to 'raising an issue with your psychiatrist', 17% of participants selected that they were 'not confident at all', 43% selected that they were 'a little confident', 18% that they were 'mostly confident', while only 9% selected that they were 'fully confident', (Figure 5.1).

5.3 Types of support from an advocate

When participants were asked to select from a list the types of support they would like an advocate to provide, the majority of participants (68%) selected that they would like an advocate to listen to their concerns, followed by receiving advice and support on making a complaint (64%). More than half or 58% selected that they would like an advocate to assist with filling out forms and 53% of participants selected that they would like an advocate to provide emotional support. Other situations suggested by participants were for the advocate to provide information regarding entitlements, housing, and services (4%) and attending appointments (1%). This question was not answered by 15% of participants.

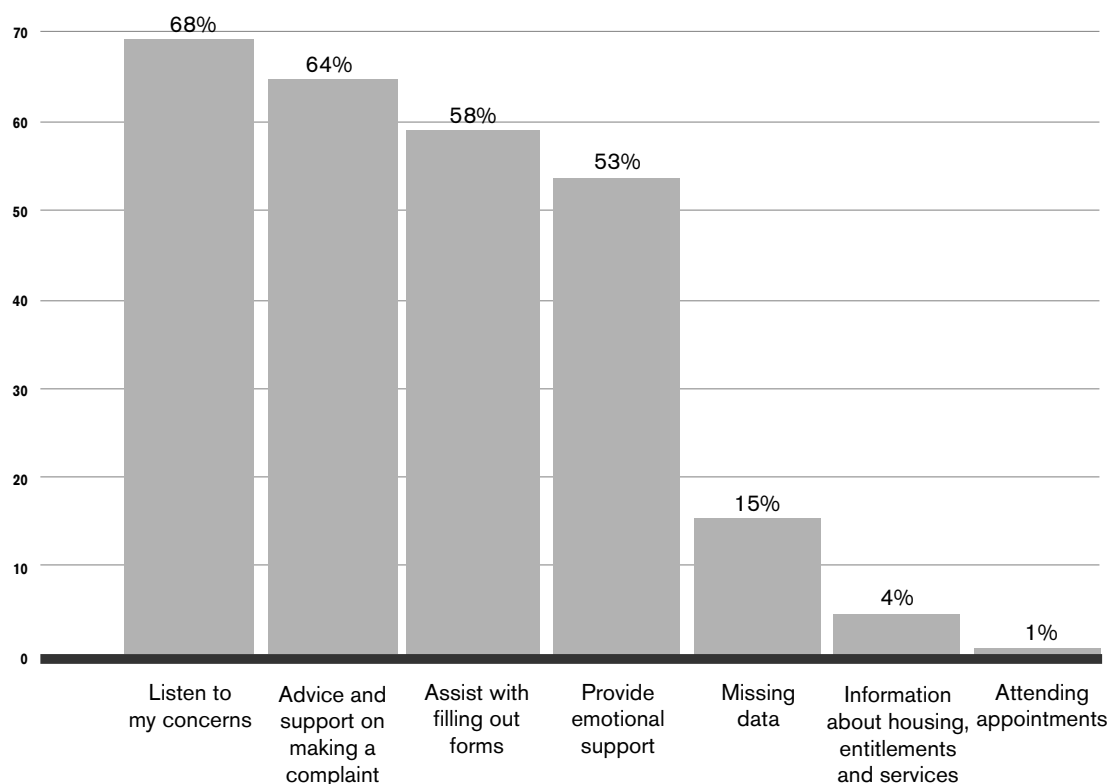


Figure 5.2 Types of Support Preferred from an Advocate

5.4 Family members as advocates

When asked how comfortable they would feel asking a family member to advocate on their behalf, 38% of participants selected that they would not be at all comfortable, 24% selected that they would be somewhat comfortable, 14% selected that they would be fairly comfortable, and 12% selected that they would be absolutely comfortable (Figure 5.3). This question was not answered by 12% of participants.

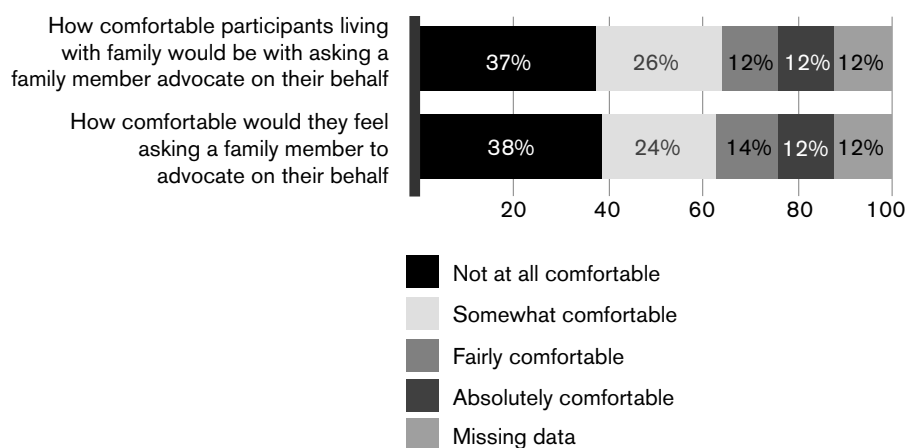


Figure 5.3 Levels of comfort with family acting as an advocate

Of the participants who were living with family members and had been given a diagnosis for their mental health difficulty, 38% selected that they were not at all comfortable asking a family member to advocate on their behalf, while 31% were only somewhat comfortable.

Of those participants who were living with family members (regardless of diagnosis), only a fifth (21%) were either fairly comfortable or absolutely comfortable asking a family member to advocate on their behalf.

For all those who indicated that they lived with family members, 38% would not be comfortable at all in asking a family member to advocate on their behalf, just over a quarter (26%) would be somewhat comfortable, 12% would be fairly comfortable, and 12% would be absolutely comfortable. More than one in ten or 12% of participants who lived with family members left the answer to this question blank, possibly indicating uncertainty.

6. Comments, Questions, Concerns

The final question of the survey asked participants whether they had any other comments, questions, or concerns. The most frequent comments were that participants found the survey helpful, useful, or interesting, and they were glad to have had the opportunity to participate. Other frequent themes in the responses were that participants expressed their hope that the results of the survey would assist in the reform of services, and they also expressed the desire to have an advocate. Other themes included concerns around the need for more supports and services, comments that the Research Assistant was a useful asset in assisting with completion of the survey, and questions as to why patients endure a constant changing of doctors. Some participants also expressed their gratitude to the clinic for all the support provided. Below are examples of the responses provided (Figure 6.1).

'I hope the survey goes some way towards the reform of services.'

'Glad to know you exist and hope this information is useful and things improve, not only in mental health services, but across the HSE, but I don't hold out much hope.'

'I think there is a need to reform mental health, we can all work together to work it out and as much help is needed as possible, including an independent advocate.'

'Every time I go to my local psychiatric clinic to an appointment, I see a different psychiatrist each time for no more than 15 minutes. It makes it difficult to trust and fully open up about my problems so it becomes pointless.'

'Only for this place, I wouldn't be here now.'

Discussion

Independent, one-to-one advocacy is about having someone available to help a person make decisions or access their rights and entitlements. These could be decisions about health care or other services, or access to social welfare, housing or other social entitlements or services. Independent one-to-one advocates can also help an individual to make a complaint or seek redress, thereby holding public services to account. An independent advocate is not the same as a health worker, social worker or doctor. Independent advocates are people whose primary role is to support an individual around decision making or having their voice heard.

The Community Advocacy Needs (CAN) survey was developed in order to investigate the level and nature of mental health service users' need for independent, one-to-one advocacy support.

Drawing upon some questions from previous surveys as well as developing new questions, the CAN survey focussed on the following questions about people who use secondary mental health services:

- The level and nature of their need for representative advocacy
- The level of their need for support for self-advocacy
- The level of their awareness of rights
- The level of their awareness of existing advocacy services
- The level of their awareness of existing complaints and redress mechanisms
- Who they would turn to for support

How was the survey carried out?

The aim of this research project was to pilot the CAN survey questionnaire in order to determine if it is an effective tool for measuring mental health service users' need for one-to-one advocacy support.

The survey was conducted in an urban mental health outpatient clinic. The area concerned is one of deprivation with high levels of unemployment and poverty. The general adult mental health team in the study area serves a population of 79,062. The general adult services in the region are largely community-oriented with an emphasis on delivering care in the community and have well developed community mental health and homecare teams (CMHTs) and also an Assertive Outreach Team (which also covers other general adult mental health teams within the CHO area).

In order to facilitate individuals to be able to complete the survey, a Peer Research Assistant (PRA) was employed to assist participants. The PRA invited individuals attending the clinic to complete the survey, obtained consent from participants, and offered assistance in completing the survey. Individuals were offered the opportunity to complete the survey in the clinic or to take it home and return by pre-paid envelope. The value of having assistance from a PRA is demonstrated by the fact that very few surveys that were not completed in the clinic were returned, while most of the participants availed of the PRA's support.

A total of 76 participants completed the survey. Relative to the general population, participants lived in social isolation, poverty and exclusion. They were more likely to be single, have a lower education level, live with family into adulthood and be reliant on social welfare benefits for their income.

Compared to the general population, the participants were 3 times less likely to own their own homes, only half as likely to be in private rented accommodation and more than 3 times more likely to be in social housing.

A higher proportion of women (59%) than men (39%) completed the survey and this should be taken into account in interpreting the findings.

In order to gauge participants' level of satisfaction with their overall level of participation in their local community, participants were asked how happy they were with their level of involvement in their local community. Many participants were not entirely happy with their level of involvement in their local community. More than half or 61% of participants reported they were either not happy at all or only slightly happy with their involvement in the community.

How satisfied are mental health service users with the services they receive?

Just over half of participants reported satisfaction with the support they receive from their mental health team, with 58% being either mostly or very satisfied with their mental health team's support. However, 28% of participants were only a little satisfied and 9% were not satisfied, indicating a large minority of mental health service users in the area for whom the service could be improved.

Satisfaction levels with mental health support may have been influenced by level of involvement. More than a fifth of participants said they were not involved at all in planning their own treatment, while a further 34% said they were involved a little. These figures suggest there is a significant journey to travel yet within this mental health service to put into practice a partnership approach to mental health care.

Extent of difficulty accessing public services

About a quarter of participants indicated having had difficulty with at least one of a number of public services including mental health services, local authority housing and social welfare. Among other services, 16% of participants had difficulty accessing supports from employment services, while 16% had difficulty getting other health services, 9% had difficulty getting assistance from An Garda Síochána and 9% had difficulty with education or training providers. However, 26% of participants did not indicate difficulty with any of the services listed, which could mean either that they had no difficulty, or had not sought access to any particular service.

Involvement in the community

It is particularly worrying that a third (33%) of participants were not at all happy with their involvement in the community. Involvement in the community is widely reported to have benefits for well-being, while lack of participation can lead to very poor social outcomes and a high potential for social

isolation which negatively impacts mental health. Indicators of isolation such as living alone³⁹ and having a small social network⁴⁰ have been associated with poorer health. Poorer mental health is associated with people who have weak social support.⁴¹ Conversely, Sheridan, et al. found that people with enduring 'mental illness' who were supported to socialise by a volunteer demonstrated an increase in recreational social functioning and a decrease in levels of social loneliness and depression.⁴² For individuals with mental health difficulties like the participants in this CAN survey the fact that such a high percentage report a high rate of unhappiness with their involvement in the community highlights this group's vulnerability for both poor social and health outcomes. The CAN survey results indicate a need for improved support in accessing community activities for people with mental health difficulties in the service area studied.

How confident are mental health service users in advocating for themselves?

Participants had a relatively low level of confidence in their own ability to advocate for themselves. When asked about their confidence in raising issues within a variety of services, on average participants said they were only 'a little confident' compared to the other options of 'not confident at all', 'mostly confident' or 'fully confident'.

Importantly for a group of mental health service users, participants' levels of confidence in raising issues with their psychiatrist were low. Only 9% of participants reported being 'fully confident' in raising an issue with their psychiatrist, while 18% were 'mostly confident', 43% were 'a little confident' and 17% were 'not confident at all'. In comparison, much higher levels of confidence were reported in relation to raising an issue with their GP, with 11% 'fully confident', 37% 'mostly confident', 30% 'a little confident' and only 8% 'not confident at all'.

Do mental health service users know how to make a complaint about mental health services?

Two thirds of participants (67%) stated that they did not know how to make a complaint about mental health services, while almost four fifths (78%) had not heard of the HSE's 'Your Service, Your Say' feedback process. This strongly indicates the need for the HSE to increase efforts to promote awareness of 'Your Service, Your Say' to ensure that their service users are familiar and comfortable with this feedback process.

39 Dean A, Kolody, B., Wood, P., & Matt, G.E. (1992) The Influence of Living Alone on Depression in Elderly Persons, *Journal of Aging and Health* 4:3-18.

40 Berkman, L. F and Syme, S. L. (1979) Social networks, host resistance and mortality: A nine year follow up study of Alameda County, *American Journal of Epidemiology* 109(2), pp.186-204.

41 Lehtinen, V., Sohlman, B., Kovess-Masfety, V. (2005) Level of positive mental health in the European Union: Results from the Eurobarometer 2002 survey, *Clinical Practice & Epidemiology in Mental Health* 1(9), pp.1-7.

42 Sheridan, A.J, Drennan, J, Coughlan, B., O'Keeffe, D., Frazer, K., Kemple, M., Alexander, D., Howlin, F., Fahy, A., Kow, V., & O'Callaghan, E. (2015) Improving social functioning and reducing social isolation and loneliness among people with enduring mental illness: Report of a randomised controlled trial of supported socialisation, *International Journal of Social Psychiatry* 61(3), pp.241-50.

Do mental health service users know about existing advocacy support services?

Almost all of the participants reported that they knew about Citizen Information Centres (CICs), which is a very positive finding. A very small number of participants were familiar with the specialist peer advocacy service for people with mental health difficulties (the Irish Advocacy Network) or the National Advocacy Service for People with Disabilities. This may reflect the targeted focus of these advocacy services, with IAN being focussed on inpatients and NAS focussed on individuals with disabilities who are isolated from their community and services. However, given that a significant proportion of participants did not know who to turn to for support in relation to specific issues of housing, social welfare or mental health care (see below), there appears to be some gap in awareness among this group of mental health service users of the role that CICs can play in providing advocacy support on such issues.

Other sources of one-to-one advocacy support

In terms of other sources of support, participants identified a range of individuals who they might turn to if they needed help accessing different types of services.

With regard to help with getting mental health support, 30% of participants stated that they would turn to a medical professional for assistance, while 20% said they would turn to a family member (20%). Just 1.3% said they would turn to a counsellor or social worker for help in this situation. Importantly, a total of 28% said either 'no-one' (16%) or 'don't know' (12%), indicating that a large group of service users in this group did not have someone to turn to for support in accessing better mental health care.

Of serious concern given the levels of social inclusion in the participant group, is that a quarter of participants did not know who to turn to for help with housing, and a similar proportion for social welfare. For assistance with housing, 14% said they would turn to a family member, while 11.8% said they would turn to the county council and just 2.6% reported that they would turn to a social worker. For assistance with social welfare, 29% said they would turn to a social welfare office or Citizens Information Centre, however interestingly, more said they would turn to a medical professional (5.3%) than a social worker (3.9%).

Given the key role that employment plays in reducing social exclusion, it is noteworthy that 53% of participants said that they did not know about their rights under Ireland's Employment Equality law and 32% said that they would not know who to turn to if they had a difficulty with employment services.

It is widely recognised that family members can play a role in providing advocacy support for their relative. It is therefore interesting that when asked how comfortable they would feel asking a family member to advocate on their behalf, 38% of participants said that they would 'not be at all comfortable' and 24% 'somewhat comfortable', while on the other side of this scale, 14% said 'fairly

comfortable', and 12% selected that they would be absolutely comfortable. This question was not answered by 12% of participants.

Conclusion

The Community Advocacy Needs Survey has shown that in at least one mental health service catchment area, there is a shortfall in advocacy support for individuals who use mental health services. For a group with high levels of social exclusion, significant dissatisfaction with the services they receive and low levels of confidence in advocating for themselves, it is clear that there is a lack of knowledge among a significant minority of participants about existing advocacy services. Also of concern is the low level of knowledge about the HSE's complaints procedures, particularly given that communicating this information is a requirement under the regulations for approved inpatient units. Interestingly, relatively few participants said that they would be comfortable having a family member advocate on their behalf, pointing to the need to avoid any presumption that family members can substitute for an independent advocacy service.

While this survey was conducted in only one mental health service area, it should give rise to concern about mental health service users' ability to avail of their human rights to quality mental health and related social support services across the country. Clearly more research is needed to establish whether these results are unique to a particular catchment area or reflect a national situation. The pilot project has shown that the CAN survey can illicit valuable information on advocacy needs among this social group; it should be replicated nationally. In the absence of such research, however, it would be prudent to presume the likelihood that mental health service users may need advocacy support in order to raise issues of concern with medical professionals, to make a complaint about services or to avail of their rights to social welfare, housing and other supports.

The mental health policy *A Vision for Change*⁴³ states that advocacy should be available as a right to people who use mental health services. Advocacy support also forms a fundamental underpinning of the human rights set out in the UN Convention on the Rights of Persons with Disabilities to which Ireland is a signatory. The findings from the Community Advocacy Needs survey show that the right to advocacy support has not yet been fulfilled and requires urgent attention.

Recommendations

The following recommendations are based on the findings of the CAN survey and relate to:

1. actions to respond to the need for community advocacy
2. the methodological process of involving a Peer Research Assistant in carrying out research, and
3. areas for follow-on research

Recommendations on meeting community advocacy needs

- Based on this study in one Dublin urban location a need has been identified for independent, one-to-one advocacy for mental health service users living in the community. A national needs assessment for independent one-to-one advocacy services for mental health service users should be conducted utilising the CAN survey instrument.
- Awareness of how to make a complaint about mental health services was surprisingly low given the requirement that all inpatient units must post information on how to make a complaint. The HSE mental health services should be proactive in explaining to service users how they can make a complaint and encourage both negative and positive feedback. Related to this finding there was an extraordinarily high percentage of participants (78%) who reported no knowledge of the Health Service Executive's 'Your Service, Your Say' feedback process. This indicates a critical need for the HSE to increase efforts to promote awareness of this process in order to increase awareness and ensure service users are familiar and comfortable with sharing feedback.
- Awareness of individuals' rights under employment legislation in Ireland was also low. The Irish Human Rights and Equality Commission should engage in proactive, targeted activity to boost mental health service users' awareness of their rights under Ireland's anti-discrimination legislation.
- Participants reported a low level of involvement in the community. Recovery orientated mental health services link individuals with community supports and activities. Mental health services should evaluate the level of community participation of their service users and services should also look at their role in facilitating access to community activities.
- Participants also reported low levels of involvement in decisions about their own mental health treatment. In a recovery orientated service, service users are involved as full partners in planning their own treatment. Mental health services should audit the level of involvement of their service users in recovery/care planning and change practice to build partnership.
- In terms of situations in which people may benefit from advocacy, it is clear that people may need assistance within mental health and other health services, housing, social welfare, employment and training services as well as when in contact with the Gardai.

- While the question of level of confidence in raising an issue was posed only in relation to the mental health discipline of psychiatry, the response that 17% were not confident at all indicates the importance of not only psychiatrists, but all mental health professionals encouraging service users to raise issues of concern.
- The Citizens Information Board, under the remit of the Department of Social Protection, has the statutory responsibility within the state to provide advocacy services. The HSE funds the national peer advocacy service for mental health service users.
- The Minister of Social Protection, the Minister of State for Mental Health and the relevant agencies (Citizens Information Board and HSE) should review the findings of this report and consider how they can ensure that the scope and capacity of publicly-funded advocacy services are adequate to provide the necessary support to mental health service users so that they can avail of their rights and entitlements.
- A large minority (38%) of participants said they would not be comfortable having their family member advocate on their behalf. Mental health services should recognise that family members may not be suitable advocates for their relative with a mental health difficulty and should ensure that service users are aware of, and linked with, independent advocacy support, where available.
- Independent one-to-one advocacy support should be available as a right to all mental health service users.

Recommendations for involvement of Peer Research Assistants in research

- The participation of a Peer Research Assistant reaped clear benefits for this project by facilitating participation of individuals who might not otherwise have been able to or felt comfortable completing the survey. Peer Research Assistants should be employed for data collection within mental health services in order to maximise participation.
- Peer Research Assistants should be trained in advance in undertaking data collection and their reflections on the participation in data collection should be included in research reporting.

Follow-on areas of research

- A key recommendation is to roll out the CAN survey on a national basis to assess the need for independent community advocacy services across the Republic of Ireland. Related to this recommendation is the need for this process to be supported by the Health Service Executive to enable access to other outpatient clinics. This is vital to ensure that more hard-to-reach individuals, who may most need advocacy support, have the opportunity to participate in such a study.
- It was evident that a substantial number of participants did not understand particular survey questions concerning the nature of their need for advocacy or the types of support that could benefit them. The CAN survey questions should be revised on foot of this learning. In addition, there is a need for qualitative research to understand more fully the nature of the need and preferences for independent advocacy services.
- Given the high rate of participants' unhappiness with their involvement in the community and the known association between isolation and higher risk to mental health, a national study investigating mental health service users' existing supports into community life should be conducted to identify existing best practices and gaps across the Republic of Ireland.
- As a substantial minority of participants expressed discomfort with having family members advocate on their behalf, further research should be conducted into the challenges associated with reliance on family members as advocates.



Community Advocacy Needs of Mental Health Service Users

Introduction

Thank you for agreeing to complete this survey.

This survey is being carried out by Mental Health Reform, the national coalition promoting improved mental health services and social inclusion of people with mental health difficulties. Mental Health Reform is a charity with more than fifty member organisations, all of which are not-for-profit organisations.

The purpose of this survey is to find out your views on independent advocacy support available in the community. We are interested in getting the views of people who are current users of mental health services.

We expect that the survey will take 15-20 minutes to complete.

Information you provide in this survey will be kept confidential.

You will have the assistance of a Research Assistant available while you take this survey.

You can stop the survey at any time. If you become emotionally distressed while completing this survey, we would encourage you to seek support. You can contact the Samaritans anytime on 116 123. The Research Assistant will also have a list of support groups and helplines. We would also encourage you to get in touch with your mental health team.

The information from this survey will be used by Mental Health Reform to advise Government on their provision of advocacy services.

This survey has been granted ethical approval by the Tallaght/St. James Hospitals Joint Ethics Committee and by the Tallaght Hospital area mental health services.

If you have any questions about the survey, please contact Shari McDaid at Mental Health Reform, telephone 01 874 9468.



Community Advocacy Needs of Mental Health Service Users

Background information

We would like to begin by asking you some questions about yourself.

1. What is your gender?

Female

Male

2. What is your age (in years)?

3. What is your civic status (please tick the most appropriate option)?

Single

Married

Separated

Divorced

Widowed

Partner

I prefer not to classify myself

4. Have you been given a diagnosis for your mental health problem?

Yes

No

5. If yes, what is the most recent diagnosis you have been given? (please choose the most appropriate option)

Bipolar

Schizophrenia

Schizoaffective disorder

Other (please specify)

6. How much schooling have you completed (please choose the highest qualification completed)?

- Completed primary education
- Completed lower secondary level (e.g. Junior/Intermediate Cert)
- Completed upper secondary level (e.g. Leaving Cert)
- Completed technical or vocational qualification
- Completed bachelor's degree
- Completed post-graduate qualification
- Completed Doctorate

7. Who do you currently live with?

- Live alone
- Live with family members
- Live with non-family members

8. Could you please indicate what type of housing you currently live in?

- Home that you own/pay a mortgage for
- Home that family member owns/pays a mortgage for
- Renting from local authority
- Renting from a voluntary housing association
- Renting from a private landlord
- Live in a community house/hostel
- Live in homeless accommodation
- Other (please specify)

9. How would you describe your current work status?

- Working for payment/profit (full time or part time)
- Looking after home or family
- Unemployed
- Student
- Unable to work due to permanent sickness or disability
- Retired from employment
- Other (please specify)

10. What are your main sources of income? (Please select all that apply to you)

- Income from work or self-employment
- Occupational or personal pension
- State old age pension
- Income from investment or savings
- Carer's allowance
- Social welfare payments
- Other (please specify)

11. Which of the following best describes the total annual income for your household? This means the total income after tax for yourself plus income from anyone else who you share income with.

- Under €10,000 (for example, €188 per week Disability Allowance or Illness Benefit is less than €10,000 per year)
- €10,000-€19,999 (for example, €193.50 Invalidity Pension per week is just over €10,000 per year)
- €20,000-€29,999
- €30,000-€39,999
- €40,000-€49,999
- €50,000 or more
- I prefer not to say

12. Including yourself, how many individuals share this income in your household?

- Only myself
- 2 individuals
- 3 individuals
- 4 individuals
- 5 or more individuals



Community Advocacy Needs of Mental Health Service Users

Life in the community

13. Do you attend any of the following activities in the community?

- Social clubs
- Bingo
- Community centres
- Pubs/clubs/restaurants
- Leisure centres
- Library
- Cinema
- Religious worship
- None
- Other (please specify)

14. How happy are you with your involvement in the community?

Not at all happy

Slightly happy

Happy most of the time

Very happy

15. How much control do you feel you have to lead your own life as you want?

None at all

Little control

Moderate control

A lot of control

16. How satisfied are you with the support that you get from your mental health team?

Not satisfied

A little satisfied

Mostly satisfied

Very satisfied

17. How involved were you in planning your own treatment with your mental health team?

Not involved at all

A little involved

Very involved

Involved as a full partner

18. If you receive healthcare from a GP, how satisfied are you with the healthcare that you receive?

Not satisfied

A little satisfied

Mostly satisfied

Very satisfied



Community Advocacy Needs of Mental Health Service Users

Self-esteem/self-efficacy

19. Self-esteem/self-efficacy

| | Strongly disagree | Disagree | Agree | Strongly agree |
|-----------------------------------------------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I generally accomplish what I set out to do | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I have a positive attitude about myself | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| When I make plans, I am almost certain to make them work | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am usually confident about the decisions I make | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am often able to overcome barriers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I feel I am a person of worth, at least on an equal basis with others | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I see myself as a capable person | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to do things as well as most other people | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I feel I have a number of good qualities | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |



Community Advocacy Needs of Mental Health Service Users

Accessing services and entitlements

20. Have you had difficulty in getting the supports you needed from any of the following services?

- Mental health services
- Other health services
- Local authority housing services
- Social welfare services
- Employment services
- Education or training providers
- An Garda Siochana

21. If you had difficulty getting what you needed from mental health services, who would you turn to for support?

22. If you had difficulty getting housing, who would you turn to for support?

23. If you had difficulty accessing social welfare benefits, who would you turn to for support?

24. If you had difficulties getting your needs met in employment services, who would you turn to for support?

25. How would you describe your knowledge about your rights under Ireland's Employment Equality laws?

I don't know about my rights under Ireland's Employment Equality laws

I know a little about my rights under Ireland's Employment Equality laws

I know a lot about my rights under Ireland's Employment Equality laws

I am fully aware of the process for making a claim under Ireland's Employment Equality laws

26. If you had difficulty getting your needs met in education or training services, who would you turn to for support?

27. If you had difficulty with An Garda Siochana, who would you turn to for support?

28. Independent advocacy is about having someone to help you make personal decisions. These could be decisions about your health and well being, treatment, etc. An independent advocate is not the same as a health worker, social worker or doctor. Independent advocates are people who are trained just to support you around decision making. Independent advocates can also help you to access a service, make a complaint, attend meetings with you, etc.

In what types of situations do you think you would find the assistance of an independent advocate valuable?

29. Have you heard of any of the following advocacy services?

- Irish Advocacy Network
- National Advocacy Service for People with Disabilities
- Citizens Information Centre
- Money Advice & Budgeting Service (MABS)
- Other (please specify)

30. Have you used any of the following advocacy services?

- Irish Advocacy Network
- National Advocacy Service for People with Disabilities
- Citizens Information Centre
- Money Advice & Budgeting Service (MABS)
- Other (please specify)

31. If you have used an advocacy service before, how satisfied were you with the support you received?

| | Not satisfied at all | Satisfied | Very satisfied | Fully satisfied |
|--------------------------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Irish Advocacy Network | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| National Advocacy Service for People with Disabilities | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Citizens Information Centre | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Money Advice & Budgeting Service (MABS) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (please specify) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

32. How would you describe your knowledge about how to make a complaint about public mental health services?

| I don't know how to make a complaint about mental health services | I know a little about how to make a complaint about mental health services | I know a lot about how to make a complaint about mental health services | I am fully aware of the process for making a complaint about mental health services |
|-------------------------------------------------------------------|----------------------------------------------------------------------------|-------------------------------------------------------------------------|-------------------------------------------------------------------------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Other (please specify)

33. Have you ever heard of the HSE's Your Service, Your Say feedback process?

- Yes
- No

34. How easy do you think it is to make a complaint about a health service?

| Very easy | Easy | Difficult | Very difficult |
|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |



Community Advocacy Needs of Mental Health Service Users

Self-advocacy

35. Please indicate your level of agreement/disagreement with the following statements:

| | Strongly agree | Agree | Disagree | Strongly disagree |
|-----------------------------------------------------------------------------------------------------------------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I believe it is important for people with mental health difficulties to learn as much as they can about their condition and treatments. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I actively seek out information on my mental health condition. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am more educated about my mental health than most people. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I have full knowledge of the problems of people like myself. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I don't get what I need from my psychiatrist because I am not assertive enough. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am more assertive about my mental healthcare needs than most people in Ireland. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I frequently make suggestions to my psychiatrist about my mental healthcare needs. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| If my psychiatrist prescribes something I don't understand or agree with, I question it. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Sometimes there are good reasons not to follow the advice of a psychiatrist. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Strongly agree

Agree

Disagree

Strongly disagree

Sometimes I think I have a better grasp of what I need medically than my psychiatrist does.

If I am given a treatment by my psychiatrist that I don't agree with, I am likely to not take it.

I don't always do what my psychiatrist or health care worker has asked me to do.



Community Advocacy Needs of Mental Health Service Users

Confidence in self-advocacy

36. How confident would you feel advocating for yourself in the following situations?

| | Not at all confident | A little confident | Mostly confident | Fully confident |
|------------------------------------------------------------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Raising an issue with your psychiatrist | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Raising an issue with your GP | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Making a complaint to your education or training service | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Making a complaint to the HSE | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Appealing a decision about welfare benefits | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Seeking housing from the local authority | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Raising an issue about discrimination with an employer | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Making a complaint against An Garda Síochána | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Making a complaint about a service provided by a charity or voluntary organisation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |



Community Advocacy Needs of Mental Health Service Users

Types of support from an advocate

37. If you had a situation where you wanted independent advocacy support, what would you like the advocate to do?

- Assist with filling out forms
- Advice and support on making a complaint
- Provide emotional support
- Listen to my concerns
- Other (please specify)

38. How comfortable would you feel asking a family member to advocate on your behalf?

Not at all comfortable

Somewhat comfortable

Fairly comfortable

Absolutely comfortable



Why?



Mental Health Reform
Promoting Improved Mental Health Services

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

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

 [mentalhealthreform](https://www.facebook.com/mentalhealthreform)
 [@MHReform](https://twitter.com/MHReform)

Reg number: 506850
CHY:19958