



**CONSUMER AND CARER EXPERIENCES
OF STIGMA FROM MENTAL HEALTH
AND OTHER HEALTH PROFESSIONALS**

ACKNOWLEDGEMENTS

This report was prepared by the Mental Health Council of Australia (MHCA) through funding provided by the Australian Government Department of Health and Ageing.

The MHCA wishes to thank the members of the National Mental Health Consumer and Carer Forum who provided their feedback and constructive criticism in the development stages of the two surveys.

The MHCA also wishes to thank the mental health consumers and carers who took the time to complete this survey. They provided invaluable commentary about their experiences when seeking treatment from the wide range of health professionals providing mental health services.

Finally, the MCHA also acknowledges the contribution of Jeff Cheverton, Professor Helen Christensen, Tracey Davenport, Professor Kathy Griffiths, Yvonne Quadros, Ailsa Rayner, Michelle Swallow and Professor Ann Taket who provided their time and experience throughout the various stages of the project.

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Suggested reference: Mental Health Council of Australia 2011, *Consumer and carer experiences of stigma from mental health and other health professionals*. Canberra: MHCA.

ISBN 978-0-9807007-6-3

Design: Voodoo Creative

FOREWORD

It is unthinkable that health professionals would stigmatise Australians with a physical condition such as cancer or a heart condition. However, there is a widespread belief that mental health consumers encounter stigmatising attitudes from health professionals. Such stigma poses a substantial risk to the wellbeing of consumers with a mental illness. It is a potential barrier to vital help seeking from health professionals, it can further exacerbate a consumer's psychological distress and it may reduce career opportunities.

Despite the importance of the topic, to date there has been little systematically collected information about the nature and prevalence of negative attitudes and behaviours of health professionals toward Australian consumers with a mental illness. In this timely publication, the Mental Health Council of Australia reports the results of a quantitative and qualitative survey of stigma and discrimination as it is experienced by Australian mental health consumers who have sought help from health

professionals and as it is perceived by their carers. The report concludes that many consumers are subjected to stigmatising attitudes from various health professionals. For example, across diagnostic categories, almost 29% of consumers reported that their treating health professional had shunned them. These figures rose to over 54% and 57% for consumers with post-traumatic stress disorder and borderline personality disorder respectively. Similarly, over 44% of consumers agreed that health professionals treating them for a physical disorder behaved differently when they discovered their history of a mental illness.

This level of stigma is dangerous and unacceptable. The time has come to develop and deliver evidence-based mental illness destigmatisation programs in medical and other health care settings to ensure that consumers can be confident that they will be treated within the medical system with the respect they deserve. This report provides the platform from which to launch the first step towards that goal.

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CONTENTS

EXECUTIVE SUMMARY	02
INTRODUCTION AND LITERATURE REVIEW	03
Consumer and carer experiences of stigma from health professionals	04
Summary of existing research	08
SURVEY METHODOLOGY	09
Survey development and distribution	09
Participants	10
RESULTS	14
Consumer and carer experiences of stigma in the general community	15
Consumer and carer experiences of stigma from health professionals	16
Detailed analysis of relationships and associations that exist between stigma items	20
DISCUSSION	34
LIMITATIONS	40
CONCLUSION	41
APPENDIX 1	42
APPENDIX 2	43
APPENDIX 3	48
REFERENCES	54

EXECUTIVE SUMMARY

A large body of research has documented the negative affect that stigma has on a person with a mental illness. When this stigma is received from a health professional providing mental health services the impact is likely to impede recovery and result in poor outcomes for the individual. This study aimed to identify the scope and nature of stigma experienced by mental health consumers seeking treatment from mental health and other health professionals.

A convenience sample of Australian mental health consumers (n=413) and carers (n=200) completed questionnaires about their experiences and observations of stigma received by the consumer, from their treating health professionals.

Among both samples, stigma was reported, by the consumer themselves, or by carers who observed health professionals treating the consumer. The level of stigma experienced by consumers varied according to the diagnosis of the consumer and the specific profession of the health professional providing their treatment. The levels of stigma experienced were similar to those reported as being received from the general population.

The views held by health professionals providing mental health services may not differ to those of the wider community. A review of education and training material (both initial and ongoing) is recommended for all health professions that provide mental health services.

INTRODUCTION AND LITERATURE REVIEW

There are many definitions of stigma used in research and the mental health sector internationally. For the purposes of this publication, a few of the more commonly cited ones will be presented. More than fifty years ago Goffman (1963) defined stigma as an attribute that is deeply discrediting and reduces the bearer from a whole and usual person to a tainted, discounted one. This is similar to the one developed and currently used by the United States Department of Health and Human Services (1999) which defines stigma as something that deprives people of their dignity and interferes with their full participation in society. SANE Australia (2011) noted that stigma most often involves inaccurate and hurtful representations of people with a mental illness as violent, comical or incompetent, which can lead to people having an altered view of themselves. It is clear from these definitions that a person experiencing stigmatising attitudes and behaviours will undoubtedly feel discredited and devalued and is likely to have reduced ability to participate or feel socially included.

The impact of stigma is two-fold and includes public stigma and self-stigma. Public stigma is how the general population reacts to people with a mental illness; while self-stigma refers

to the prejudice, negative feelings and negative impact that discrimination has on a person with a mental illness (Corrigan & Watson 2002). Stigma impedes recovery by negatively affecting social status, self-esteem and social networks. This can result in poor outcomes for the individual, including issues such as unemployment, isolation, delayed treatment seeking and hospitalisation (Link, Morotznik & Cullan 1991; Link et al. 2002). These impediments are likely to lead to feelings of social isolation and exclusion for a person with a mental illness. Contending with this on top of a mental illness is going to affect their self-esteem and level of distress, making recovery all the more difficult (Boyd-Ritscher, Otilingam & Grajales 2003). When a person is being stigmatised by their health professional, these feelings are likely to be compounded, making treatment and recovery unlikely.

Very little research has been conducted on the attitudes of professionals providing care to patients and clients with a mental illness. The primary aim of this project was to identify the scope and nature of stigma experienced by mental health consumers seeking treatment from mental health and other health professionals.



This meant looking across the broad spectrum of workers and practitioners offering services to those experiencing mental health issues, not just limited to practitioners specialising in mental health. This issue was examined from the perspective of both mental health consumers and carers, by asking questions about their experiences of stigma from both health professionals as well as the general population. This information was collected via two online survey instruments, designed specifically for consumers and carers. Because so little research has been done in this area to date, the results of this study will provide an Australian context and base for measuring the experiences of stigma for consumers and carers of consumers receiving mental health services.

The literature reviewed for this project included Australian and internationally peer-reviewed journals and grey literature published between January 1989 and 2010 that had a focus on mental illness stigma and stigma received from various health professional groups. Specifically, 85 articles were reviewed. The majority of the articles were sourced from electronic databases, including PubMed Central, ProQuest Health and Medical Complete, BioMedCentral, EBSCOhost Electronic Journals Service and other health related sources using the Deakin University Library services. Grey literature (meaning material that was non-academic or peer-reviewed) was sought using mental health websites, including those related to government and non-government organisations. The literature review provides a broad overview of the current research findings in relation to mental health consumer and carer experiences of stigma from their health professionals, before presenting the survey findings.

CONSUMER AND CARER EXPERIENCES OF STIGMA FROM HEALTH PROFESSIONALS

Mental health professionals often serve as role models and opinion leaders within the mental health sector, and they are the people consumers tend to see when they are at their most vulnerable and whom they rely on for help, understanding and support. In addition, many mental health professionals are educators whose attitudes and behaviours influence future professionals and carers. Therefore, how people with mental illness view the various mental health professions, and vice versa, can have serious consequences for treatment and quality of life for these people (Wahl & Aroesty-Cohen 2009).

Stigma is a major barrier to recovery for people with mental health problems, their families and those working in the field of mental health. Stigma acts as a ‘social disability’ - often contributing to at least the same amount of, if not more, stress than the original mental health issue (Rethink/ Institute of Psychiatry 2002). Tackling stigma and discrimination is therefore high on the agenda for community action. Within this broad agenda, stigma within mental health services is a major issue for mental health consumers and carers.

In its ground-breaking report, Not for Service, the Mental Health Council of Australia (2005) reported that accounts of highly negative, dismissive and stigmatising remarks by health staff towards persons with mental illness were still very common. In addition, family members often felt discounted or ignored by health workers. The Victorian Mental Illness Awareness Council (VMIAC) gave testament to this situation:

It has been the experience of the VMIAC that more often than not, if you ask a consumer if they could wave a magic wand and change something about the mental health system, what would they change? The attitude of health professionals is the most frequent answer followed by access to services (Mental Health Council of Australia 2005).

In a 2004 survey conducted by SANE Australia that asked consumers and carers to report on their experience of stigma in the previous two years, the responses suggested that unfair treatment and disrespectful behaviour by health professionals was a regular occurrence for many consumers and carers. Fifty-seven per cent responded that stigma by health professionals was the same or worse than two years ago (SANE Australia 2004).

A recurring complaint among participants in one survey on mental health consumers’ experience of stigma was that consumers felt that doctors and psychologists treated them as less competent and they were discouraged from setting high goals (Wahl 1999). In the same survey, respondents also gave examples of disparaging comments made by mental health caregivers. One respondent reported that staff in psychiatric facilities often spoke about

patients with disrespect and sometimes mocked them. One comment from a respondent, about her experience in medical school, echoed many similar statements made by mental health consumers:

The treatment of psych patients in all rotations was awful. They would laugh at them, poke fun at them on rounds, disbelieve any physical complaint they had (Wahl 1999).

Public perceptions of mental health specialists often present a barrier to effective treatment for people with mental illness. An Australian study on mental health literacy (Jorm et al. 1997) found that when people were asked their opinion about the helpfulness of various people in the health services in regards to depression and schizophrenia, GPs and counsellors were most often rated as helpful, with psychiatrists and psychologists considered less so.

This study of 2031 participants aged 18-74 years was a representative national survey conducted by the Australian Bureau of Statistics. The survey participants were split into two groups with half given a depression vignette and the other a schizophrenia vignette. Many standard psychiatric treatments such as anti-depressants, anti-psychotics and admission to a psychiatric ward, were often rated as more harmful than helpful. The results suggested that change was needed in public perceptions of mental health specialists and that negative perceptions could result in an unwillingness to accept help from mental health professionals or to adhere to advice given. Considering the importance of recognising mental disorders early and taking appropriate action, the study recommended that public mental health literacy should improve. These perceptions of the mental health sector and avoidance seeking treatment and care for fear of stigma are consistent with international research — suggesting that stigma within mental health services is not just a major issue but a universal phenomenon.

One UK report (Salter & Byrne 2002) highlighted the need for mental health professions to tackle stigma. It found that in spite of the way stigma affects the work of psychiatrists, the prevailing attitude of psychiatry towards stigma seems to be ‘one of inertia and resignation’. According to this report, none of the main texts of psychiatry mention stigma and, with only a few notable exceptions, psychiatrists have taken a low profile in local

and national debate about mental health issues. Several years after this research was conducted, people with mental illness in the UK still report encountering negative attitudes from mental health professionals. People experiencing mental illness often feel patronised, punished or humiliated and many rate mental health professionals as one of the groups that stigmatises them the most (Thornicroft, Rose & Kassam 2007).

A Swiss focus group of people with schizophrenia and their families reported stigma related to their health care accounted for nearly one quarter (22.3%) of all their stigma experiences (Schulze 2007). Group participants felt stigmatised by the lack of interest in them as individuals and had a general feeling that there is only one standard psychiatric treatment for everyone and that it revolved around drug dosage. Statements commonly made by health professionals included “you’ve got schizophrenia, you will be ill for the rest of your life” or “your illness means that you will end up committing suicide”. In addition, study participants were critical that a diagnosis was usually accompanied by a negative prognosis and that patients do not get the personal attention needed. Those questioned further articulated that there was insufficient information about their treatment or about options for follow-up care in the community. Similar findings have been reported in other studies examining service provider’s perceptions of stigma (Pinfold, Byrne & Toulmin 2005; The Royal College of Psychiatrists 2002; Walter 1998).

These findings beg the question of whether perceptions of stigma by service users mirror the actual attitudes of mental health professionals. While many studies examine the experiences of consumers, there is less known about attitudes of mental health professionals towards people with mental illness and how these attitudes differ from those of the general population (Lauber et al. 2004). Of course, if consumers are reporting experiences of stigma, then this is an issue of itself, regardless of the outcome of any research finding about the attitudes and beliefs of health professionals.



The need to fight stigma and discrimination has previously been acknowledged by the psychiatric profession. Indeed, there have been various programs to combat stigma initiated by professional bodies of psychiatrists and other health professionals. Many of these anti-stigma campaigns registered significant successes, such as an increased public awareness of and improved attitudes towards mental illness, reductions in barriers to psychiatric treatment and improved stigma-management skills and self-esteem among people with mental illness. However, programs initiated by the psychiatric profession have often been criticised as being an attempt to raise the profile of psychiatry rather than improving the conditions for people with mental illness. Moreover, many of these campaigns specifically targeted improving attitudes among the public, rather than among the health professionals themselves (Schulze 2007).

A paper from Malaysia reported that attitudes towards psychiatric work and patients among nursing staff indicated that despite the decentralisation of services, there was still an 'asylum' attitude influencing staff (Ashencaen 2003). They showed negative professional attitudes towards patients that led to issues of both moral and physical restraint. The associated attitudes of stigma and prejudice towards mental illness impacted on how attractive a career in psychiatric nursing was perceived. At the time of this report there was no formal examination in psychiatry in most medical schools in Asia. The majority of lessons took place in acute settings so student exposure was only with people experiencing severe and persistent episodes of mental illness (Lauber & Rossler 2007).

In Fiji, a survey of the attitudes of 71 nursing and orderly staff from one psychiatric hospital found that the participants expressed both positive and negative attitudes towards individuals in mental health care. Positive attitudes were expressed when participants were asked about psychosocial causations, whereas negative attitudes appeared in response to questions relating to alcohol abuse and lack of self-control (Foster et al. 2008). The study participants had a wide range of experience and education and mental health training. There was a significant difference between the two groups, with the orderlies holding both more negative and more positive attitudes than qualified staff. The results were similar to two previous studies, one looking at the attitudes of acute mental health nurses (Munro & Baker 2007) and a previous study in Fiji (Aghanawa 2004) which found that education about — and working with — people with mental illness may assist in the development of positive attitudes in this area.

In Pakistan, there were similarly mixed responses among medical students and doctors in three medical colleges in Lahore. Just over half of the respondents held negative attitudes towards people with schizophrenia, depression, drug and alcohol disorders. However, most had positive views about recovery and treatability of mental illness. This situation was broadly similar to opinions expressed by medical students and doctors in the UK (Naeem et al. 2006). This survey included 294 medical students and doctors from three medical colleges in Pakistan. The attitudes of doctors and medical students were similar, although doctors were less likely to have negative attitudes toward people with mental illness than the medical students.

A number of studies have highlighted differences between professional groups, including two that suggested psychiatrists tend to reject negative

attributes about people with mental illness such as dangerousness, individual responsibility for the illness (Kingdon et al. 2004) and unpredictability (Magliano et al. 2004). Compared to mental health nurses, psychiatrists held views that were more positive. However, other findings document that mental health professionals across the board subscribe to negative stereotypes.

In a Swiss study, professionals consistently judged negative characteristics more typical of people with mental illness than positive ones. Psychiatrists held more negative stereotypical views than any other professional group (Lauber et al. 2004). Yet another study identified case managers — mainly social workers — as reinforcing negative notions by aiming to train their clients for 'normality', thus devaluing mental illness (Magliano 2004). Research surveying the attitudes of Australian mental health nurses towards Borderline Personality Disorder (BPD) showed that the majority of them perceived patients with BPD as manipulative, and 30% stated that they tend to make them angry (Deans and Meocevic 2006). Results from an Italian survey imply that professionals endorse the view that people with mental illness are dangerous (Magliano 2004); and in the UK, psychiatrists tended to agree with the stereotype of unpredictability (Kingdon et al. 2004).

Many of the studies conducted on mental health professionals' attitudes towards mental illness compared these attitudes with those of the wider public. The majority of studies reviewed by Schulze (2007) found that the beliefs of mental health providers do not differ from those of the public. This contradicts the hypotheses of most studies that predicted better attitudes from professionals due to their knowledge about and their daily contact with people with mental illness. The studies found professionals' attitudes were better than the public, regarding psychiatric treatment and patients civil rights, but were generally in line with negative public views concerning stereotypes and social distance. While mental health professionals might have positive views regarding patients treatment and rights; these positive attitudes do not necessarily guard against stigma, as they do not encourage a greater willingness on the part of professionals to look beyond stereotypes or encourage closer interaction with people with a mental illness (Lauber, Nordt & Rossler 2006; Nordt, Rossler & Lauber 2006).

A study of Western Nigerian doctors' attitudes found they believed people with mental illness to be unpredictable, dangerous, lacking self-control and aggressive — all very similar to the perceived views of the public in both Nigeria and many

other countries (Adewuya, & Oguntade 2007). A Swiss study came to the same conclusion when comparing professional and public attitudes towards people with schizophrenia and major depression. This study found there was no difference between the two groups, concluding that the better knowledge of mental health professionals did not result in fewer stereotypes, nor signify a willingness to have closer interactions with people with mental illness (Nordt, Rossler & Lauber 2006).

A review of studies examining the attitudes of mental health professionals in the five years between 2004 and 2009 (Wahl & Aroesty-Cohen 2009) found that they held positive attitudes towards mental illness. Fourteen of the 19 studies reviewed revealed mental health professionals are more positive in comparison to community views, and only five showed predominantly negative attitudes. However, despite a more positive outlook than the wider community, these studies also revealed negative attitudes, even in those studies that showed positive results. Many mental health professionals appeared to agree with the community view that people with serious mental illness are dangerous. Many also had doubts about the possibility of recovery and expressed views that people with serious mental illness should not marry and have children. Negative attitudes also arose when discussing social distance. While many mental health professionals were optimistic and understanding of mental illness, they tended to hold similar views to the public regarding accepting people with mental illness into their social and occupational groups. Interestingly, this review concluded that many studies examining attitudes of mental health professionals towards people with mental illness fail to find consistent results (Wahl & Aroesty-Cohen 2009).

Since stigma is common in society, it is perhaps not surprising that social norms and beliefs affect all members of a society — mental health professionals included. What is surprising is that many of the attitudes of health professionals still mirror that of the community. Given their training, knowledge and involvement with people with a mental illness, wouldn't it would be reasonable to expect more positive views to be held by health professionals?

SUMMARY OF EXISTING RESEARCH

The international research discussed above show that mental health consumers often do not have positive things to say about the professionals treating them. Moreover, many studies revealed that while there are negative attitudes held by mental health specialists towards the people they treat, positive attitudes exist as well, reflecting the complex relationship between stigma and mental health services. Adding to these complexities are factors relating to different attitudes among different groups of professionals, in addition to differing outcomes in a variety of countries.

A further issue may be the fine line that exists between stigmatising beliefs and attitudes and specific characteristics or manifested behaviours that may occasionally be an inherent part of some mental disorders. For example, a person having a psychotic episode may be experiencing delusions that cause them to behave in a particular way, at a particular time. It is important to distinguish that behaviour from the person and their locus of control over it. This is an extremely sensitive issue given that the isolated incidents of consumers having episodes that rarely involve police can quickly become public when sensationalised through negative media portrayal. This does nothing to break down the entrenched stigmatising beliefs that the general community have traditionally attached to what it means to have a mental illness. It also highlights the role and responsibility of media depicting negative tragic events, and the importance of balancing this reporting with the many positive stories of recovery of people living with a mental illness.

Looking at the evidence, it is hardly surprising that there is a complicated relationship between mental health professionals' attitudes, stigma and mental illness. While a large number of the studies found that people working in the area of mental health had significant knowledge about mental illness, this did not automatically translate into better attitudes towards people with mental illness. What is clear is that the attitudes of health care professionals towards people with mental illness can influence the care provided (Lauber & Rossler 2007).

In conclusion, this literature review highlights the profoundly negative effect that stigma has upon mental health consumers, leaving little doubt that when subjected to stigmatising attitudes and behaviours by their health professional, the result is likely to be reduced self-esteem and self-perception, thereby limiting treatment and recovery. The studies presented showed that there is great variability between professions, and across countries regarding the stigma received by mental health consumers, and from whom. Negative and stigmatising remarks were commonly reported by consumers who felt disrespected and treated as less competent as a result of having a mental illness. There were no clear findings reported as to why professionals responded to mental health consumers so negatively, although some studies indicated that health professionals need further training about mental illness and stigma in the early education and learning stages of their respective professions. What emerges from this review is that the stigmatising attitudes and behaviours of health professionals are very real problems for mental health consumers and carers. A renewed focus is needed on establishing why stigma occurs and how best to eliminate it.

SURVEY METHODOLOGY

There is a distinct lack of evidence regarding the extent of stigma by professionals providing mental health services in Australia. The bulk of research to date has focused on stigma expressed by the public towards people with a mental illness. The aim of this project was to identify the scope and nature of mental health stigma that exists by workers providing mental health services, according to the experiences of mental health consumers and carers.

Prior to commencing the survey roll-out, ethics clearance was obtained for both the consumer and carer survey from the relevant Deakin University Ethics Committees (Appendix 1). Additionally, surveys did not collect any identifying particulars, and in cases where survey participants did provide this information it was removed so that only de-identified particulars were reported.

All statistical analyses utilised the Statistical Package for the Social Sciences (SPSS 17.0.0 for Windows, Chicago, USA). Analysis of the data included simple univariate statistics to describe samples and respondent attitudes towards stigma items. Descriptive and simple inferential statistics were used to analyse the data. Multivariate analyses included the use of Chi-Square Tests where data were categorical and cell sizes were large enough for valid analysis and Kruskal-Wallis Tests when cell sizes were too small and data needed to be treated as ordinal. Other non-parametric tests included the Mann-Whitney U or Wilcoxon Rank Sum Test. The significance levels used throughout the various analyses was at the $p < .05$ level.

SURVEY DEVELOPMENT AND DISTRIBUTION

A considerable review of the literature was undertaken to try and identify an appropriate instrument for consumer and carer use. No tool was found that specifically examined consumer and carer views about health professionals attitudes and behaviours towards people being provided with, or caring for people receiving, mental health services. An instrument developed by Wahl (1996)

– *Mental Health Consumers Experience of Stigma* – measured mental health consumers' experiences of stigma within the community; however it did not specifically look at their experiences in services. Several of the stigma items from this instrument were used in the current study to obtain consumer and carer views regarding stigmatising views in the general community.

Two survey instruments were developed, one for the consumer group and one for the carer group. The consumer survey (Appendix 2) was developed first and once finalised a carer version (Appendix 3) was prepared, based on the consumer version, with slight wording changes made to reflect and capture the carer perspective. Several of the items used in the Wahl instrument were used as a basis to develop questions for this survey, with changes to reflect the focus upon stigma by the target group.

In addition, input was sought from members of the National Mental Health Consumer and Carer Forum, which is the combined national voice for consumers and carers participating in the development of mental health policy and sector development in Australia. Some 24 members provided feedback on two separate versions of the survey which lead to two instruments that were suitable for consumer and carer use.

The final instrument contained 51 questions consisting of three main sections. The first 31 questions were developed to establish mental health consumer and carer experiences of stigma when receiving mental health services from their health care professional. The next nine questions were taken directly from the Wahl study and looked at participants experiences of stigma received from the general community. The final 10 questions sought socio-demographic information including age, gender, race and ethnic group, marital status, education, employment status and living situation and mental illness diagnosis. The final question provided survey respondents with the opportunity to provide any additional information or comment.

The surveys were disseminated using MHCA membership and database contact details. The initial electronic mailing list included all MHCA

members, consisting of approximately 100 national mental health bodies as well as a few hundred non-government mental health organisations that the MHCA has previously provided funding grants to that have previously received MHCA funding grants. The majority of these bodies and organisations are involved either directly or indirectly in service provision to mental health consumers. In total, several hundred consumers and carers were sent electronic mail invitations to participate in the study. It is not known how many organisations or individuals forwarded this invitation on to others, but the number of recipients undoubtedly exceeded one thousand. The email invitation included a link to an external website that allowed individuals to take part in the study either as a consumer or carer.

PARTICIPANTS

As there were two surveys, there were two separate datasets, one for mental health consumers and another for mental health carers. Altogether, 427 completed consumer questionnaires were received between 22 November 2010 and 17 February 2011. The consumer dataset used for analysis included only those 413 respondents who identified as either a ‘mental health consumer’ or ‘both a mental health consumer and carer’. The initial carer dataset included 246 completed questionnaires, received between 22 November 2010 and 22 February 2011. The carer dataset included only those 200 respondents who identified themselves as either a ‘mental health carer’ or ‘both a mental health consumer and carer’. A complete breakdown of consumer and/or carer status for those included in the dataset is provided in Table 1.

TABLE 1: CONSUMER AND/OR CARER STATUS OF ALL SURVEY RESPONDENTS^

	Consumers, n (%)	Carers, n (%)
n	427	246
Consumer / carer status		
Mental health consumer	268 (62.8)	2 (0.8)
Mental health carer	13 (3.0)	198 (80.5)
Both a mental health consumer and carer	145 (34.0)	2 (0.8)
Neither a mental health consumer or carer	1 (0.2)	44 (17.9)

^Refers Q1 Consumer and Carer surveys.

As shown in Table 2, both consumer and carer respondents came from all eight Australian states and territories, with representation for both groups being reasonably representative of jurisdiction proportions, except the Australian Capital Territory (ACT), which had a much higher number of respondents (5.1%) than the ACT proportion of the total population proportion (1.6%). Consumer respondents had an age range of 17–84 years and carers from 22–89 years, with the mean age of consumer respondents lower than carers at 44.27 years and 59.96 years respectively.

Approximately 77% of both consumer and carer respondents were female and 33% were male. Most consumer respondents were partnered (i.e. married, de facto or in a civil union). The remaining respondents were single or never married (34.1%); divorced or separated (18.2%); or widowed (2.7%). The carer respondent relationship status was quite different to the consumers, with many more being partnered (68.5%) and far fewer divorced or separated (18%); single or never married (8%) or widowed (5.5%). Both respondent samples were predominantly Caucasian — consumers (80.1%) and carers (85.8%). Both groups tended to have at least a high school education, with many holding tertiary qualifications.

TABLE 2: DEMOGRAPHIC CHARACTERISTICS OF CONSUMER AND CARER SURVEY RESPONDENTS^

Characteristic	Consumers, n (%)	Carers, n (%)
Age in years, n	411	200
Mean	44.27 (SD=12.16)	56.96 (SD=12.78)
Range	17 – 84	22 – 89
Gender, n	412	200
Males	93 (22.6)	46 (23.0)
Females	319 (77.4)	154 (77.0)
Geographical source (proportion of total Australian population), n	412	200
Australian Capital Territory (1.6%)	21 (5.1)	8 (4.0)
New South Wales (32.4%)	123 (29.9)	50 (25.0)
Northern Territory (1.0%)	4 (1.0)	5 (2.5)
Queensland (20.2%)	77 (18.7)	45 (22.5)
South Australia (7.4%)	43 (10.4)	17 (8.5)
Tasmania (2.3%)	16 (3.9)	12 (6.0)
Victoria (24.8%)	98 (23.8)	42 (21.0)
Western Australia (10.3%)	30 (7.3)	21 (10.5)
Current marital status, n	411	200
Single, never married	140 (34.1)	16 (8.0)
Married, de facto, civil union	185 (45.0)	137 (68.5)
Divorced, separated	75 (18.2)	36 (18.0)
Widowed	11 (2.7)	11 (5.5)
Race or ethnic group†, n§	407	197
African-American	4 (1.0)	2 (1.0)
Asian	17 (4.2)	1 (0.5)
Caucasian Australian	326 (80.1)	169 (85.8)
European	14 (3.4)	7 (3.6)
Hispanic	58 (14.3)	29 (14.7)
Indian	2 (0.5)	1 (0.5)
Indigenous Australian	5 (1.2)	2 (1.0)
Maori	15 (3.7)	3 (1.5)
Middle Eastern	4 (1.0)	2 (1.0)
Torres Strait Islander	6 (1.5)	1 (0.5)

Continued on p12.

Continued from p11.

Characteristic	Consumers, n (%)	Carers, n (%)
Highest Educational level, n	411	199
Primary school	5 (1.2)	0 (0)
High school	64 (15.6)	22 (11.1)
TAFE/ CIT course completion	96 (23.4)	37 (18.6)
Professional course	32 (7.8)	30 (15.1)
Undergraduate degree	111 (27.0)	46 (23.1)
Postgraduate degree	103 (25.0)	64 (32.2)
Employment status†, n§	407	200
I am employed full-time	137 (33.7)	60 (30.0)
I am employed part-time or casually	142 (34.9)	61 (30.5)
I am not currently employed	36 (8.8)	5 (2.5)
I am in receipt of a pension	87 (21.4)	26 (13.0)
I am currently employed but on leave due to a health condition	7 (1.7)	0 (0)
I am unable to work due to a health condition	18 (4.4)	2 (1.0)
I am retired	9 (2.2)	50 (25.0)
I cannot work due to my role as carer	6 (1.5)	17 (8.5)
I am a volunteer worker	71 (17.4)	26 (13.0)
Current living situation, n	410	194
Living alone in a house or apartment	126 (30.7)	3 (1.5)
Living with parents/ other family members	240 (58.5)	146 (75.3)
Living with friends/ acquaintances	37 (9.0)	5 (2.6)
Semi-independent living in a supervised home/ apartment	4 (1.0)	37 (19.1)
Currently under hospital care	0 (0)	1 (0.5)
No current residence	3 (0.7)	1 (0.5)
Other	0 (0)	1 (0.5)

Notes: Denominators vary with missing data. SD = standard deviation. ^Refers Qs 41–50 Consumer survey and Qs 39–48 Carer survey. †Percentages do not add to 100%, as survey respondents could provide more than one response. §n pertains to number of respondents.

Approximately one quarter of consumers (27%) and carers (23%) hold an undergraduate degree and a similar number of consumers (25%) and carers (32.2%) also have postgraduate qualifications. The majority of consumers indicated that they were employed either full-time (33.7%) or part-time (34.9%). This was slightly higher than the number of carer respondents who were employed either full-time (30%) or part-time (30.5%). Relatively few consumers were unemployed (8.8%), however this number could be explained by other consumer responses indicating they were in receipt of a pension (21.4%), unable to work due to a health condition (4.4%) or were volunteer workers (17.4%). Very few carers were unemployed (2.5%), although many indicated they were retired (25%), in receipt of a pension (13%), were volunteer workers (13%), or were unable to work due to their role as a carer (8.5%).

When respondents were asked about their living situation, consumers and carers responded quite differently. The majority of consumers were living with parents or other family members (58.5%), living alone in a house or apartment (30.7%), or living with friends or acquaintances (9%). Similarly, the majority of carers were living with parents or other family members (75.3%), but most

of the remaining carers indicated living semi-independently in a supervised home or apartment (19.1%) and only a few of them lived alone in a house or apartment (1.5%).

In summary, both the consumer and carer survey respondents tended to be female, Caucasian, well-educated and employed full or part-time. Consumers were more likely to be single or never married and living alone. The carers were mostly older than the consumers, and were more likely to be married, de factor or in a civil union (Table 2).

Consumer and carer respondents were asked several open-style questions allowing for more detail in their responses. There was an incredible richness to the comments made in response to these questions, particularly the last one which allowed survey participants to provide any other information that they felt they had not been able to while completing the survey. Wherever possible, quotes and comments provided by consumers and carers have been incorporated to support the results of analyses. Unfortunately the confines of this publication prevented all comments being included, although efforts have been made to ensure that those presented represent the range of views present in the sample.



RESULTS

The majority of the 413 consumers and 200 carers taking part in this study reported experiencing stigma from both the community and the professionals providing their mental health services or those of the person they care for. The questions asked of participants related to the nature of the stigma experienced, where it was received from and whether there were any interrelated variables that would make any negative experiences more likely. This chapter provides detailed information about the analyses conducted, including reporting upon the compared variables and the results and significance of the analysis used for each test. A series of descriptive statistics have been presented in relation to consumer and carer experiences of stigma from both the general community and health professionals.

The results of more detailed analyses are then provided to highlight significant relationships and associations that existed between individual stigma items.

When consumer respondents were asked whether they had been diagnosed with a mental illness, a diverse clinical picture emerged indicating that many consumers have co-occurring mental disorders. The overwhelming majority of respondents indicated being diagnosed with depression (72.0%), anxiety disorder (including obsessive compulsive disorder) (49.9%) and/or bipolar disorder (28.7%). As outlined in Table 3, other commonly listed diagnoses included schizophrenia (including psychosis) (14.3%), borderline personality (12%) and post-traumatic stress disorder (11.3%).

TABLE 3: MENTAL ILLNESSES WITH WHICH CONSUMER SURVEY RESPONDENTS HAVE BEEN DIAGNOSED^

	Consumers, n (%)
Diagnosis†, n§	407
Depression	293 (72.0)
Anxiety disorder (including obsessive compulsive disorder)	203 (49.9)
Bipolar disorder	117 (28.7)
Schizophrenia (including psychosis)	58 (14.3)
Borderline personality disorder	49 (12.0)
Post traumatic stress disorder	46 (11.3)
Other‡	16 (3.9)

Notes: †Percentages do not add to 100%, as respondents could provide more than one response. §n pertains to number of respondents. ‡Other includes a summation of responses proffered by less than 5% of the sample such as dissociative identity disorder and eating disorders (e.g. bulimia). ^Refers Q2 Consumer survey.



CONSUMER AND CARER EXPERIENCES OF STIGMA IN THE GENERAL COMMUNITY

Experiences of stigma (Table 4) were common amongst consumers, with the majority of respondents (55.4%) reporting that they were often or very often reluctant to tell anyone outside of their close family and friends that they were a mental health consumer. Generally, friends and family (48.0%) were seen as understanding and supportive, however, consumers frequently reported being treated as less competent once others learned that they had a mental illness (34.7%) and had been shunned and avoided (20.6%). In addition, consumers frequently reported experiencing negative, hurtful and offensive attitudes and comments from both the general population (60.2%) and from the media (48.3%). Many worried that their illness would impact on how others viewed them (54.6%), and using the Mann Whitney U Test, there was a significant difference between the responses of those with or without schizophrenia ($z=-2.22$, $p<.05$) or an anxiety disorder ($z=-2.02$, $p<.05$), with these two groups avoiding telling others that they have a mental illness.

Almost a quarter of consumers (22.5%) reported that they had been advised to lower their expectations in life *often* or *very often*. Again

using the Mann-Whitney U Test to examine this by diagnosis, there was a significant difference between those with or without bipolar disorder ($z=4.39$, $p<.001$), borderline personality disorder ($z=3.59$, $p<.001$), or post-traumatic stress disorder ($z=2.12$, $p<.05$). In contrast, the majority reported being treated fairly by those who knew they were a consumer (52.9%), with significant differences in the responses between those with and without post-traumatic stress disorder ($z=2.25$, $p<.05$).

Carers' experiences were similar to consumers' (Table 5), with almost one in three (30%) expressing they were *often* or *very often* reluctant to tell people outside their close family and friends they were a mental health carer. As with the consumer respondents, carers generally found their friends and family supportive (52.8%). While there was a perception of negative attitudes by others (10.6%) and being shunned and avoided at times (8.1%), these rates were less than half to a third of those experienced by consumers in the parallel questions. Carers also reported their observations of consumers experiencing negative, hurtful and offensive attitudes from both the general population (49.5%) and the media (49.0%). Although one in eight carers (12.0%) worried about how others would view them because of their role, more than half (58%) reported *seldom* or *never worrying* about this. These figures were different from those reported by consumers.

TABLE 4: CONSUMER EXPERIENCES OF STIGMA FROM THE GENERAL COMMUNITY^

Stigma item ^	n	n (%)				
		Never	Seldom	Sometimes	Often	Very often
I have avoided telling others outside my immediate family (or intimate circle of friends) that I am a mental health consumer	408	27 (6.6)	49 (12.0)	106 (26.0)	102 (25.0)	124 (30.4)
I have been treated as less competent by others when they learned that I am a mental health consumer	406	38 (9.4)	76 (18.7)	151 (37.2)	96 (23.6)	45 (11.1)
Family and friends who learned I am a mental health consumer have been understanding and supportive	406	15 (3.7)	49 (12.1)	147 (36.2)	126 (31.0)	69 (17.0)
I have been shunned or avoided by others when it was revealed that I am a mental health consumer	404	72 (17.8)	102 (25.2)	147 (36.4)	50 (12.4)	33 (8.2)
I have been in situations where I have heard others say unfavourable or offensive things about mental health consumers and their illnesses	407	14 (3.4)	32 (7.9)	116 (28.5)	138 (33.9)	107 (26.3)
I have been advised to lower my expectations for accomplishments in life because I am a mental health consumer	405	117 (28.9)	75 (18.5)	122 (30.1)	60 (14.8)	31 (7.7)
I have been treated fairly by others who know I am a mental health consumer	406	8 (2.0)	43 (10.6)	140 (34.5)	165 (40.6)	50 (12.3)
I have seen or read things in the mass media (e.g. television, movies, books) about mental health consumers and mental illnesses which I find hurtful or offensive	410	15 (3.7)	54 (13.2)	143 (34.9)	103 (25.1)	95 (23.2)
I have worried that others will view me unfavourably because I am a mental health consumer	409	20 (4.9)	35 (8.6)	131 (32.0)	107 (26.2)	116 (28.4)

^Refers Qs 32–40 Consumer survey.

CONSUMER AND CARER EXPERIENCES OF STIGMA FROM HEALTH PROFESSIONALS

Consumer experiences of stigma were not restricted to general community experiences, with many reporting stigmatising attitudes and behaviour from their health professional and/or mental health service provider. More than one-third of consumers *agreed* or *strongly agreed* they had been advised to lower their expectations for accomplishments in life (34.1%) and/or had been shunned or avoided (29.0%) by the professional treating their mental illness. Almost half of the respondents (44.7%) indicated that their service provider had changed their behaviour toward them once finding out about their mental illness, whilst

more than one-quarter of consumers (28.7%) reported that professionals were not comfortable talking to them. The majority of consumers (61.1%) reported a lack of understanding about the lived experience of mental illness from their service providers, while over half (50.8%) worried that professionals have an unfavourable perception of them due to their mental illness.

In contrast, most consumers reported that their health professional had treated them fairly (60.6%), with dignity and respect (59.8%), and had been understanding and supportive (64.7%). Over half of the consumers also reported that their health professional had been optimistic about their recovery (55.2%) and had encouraged them to make plans for the future (58.5%). Approximately one-third of consumers (31.4%) felt more listened to by

TABLE 5: CARER EXPERIENCES AND OBSERVATIONS OF STIGMA FROM THE GENERAL COMMUNITY^

Stigma item	n	n (%)				
		Never	Seldom	Sometimes	Often	Very often
I have avoided telling others outside my immediate family (or intimate circle of friends) that I am a mental health carer	200	53 (26.5)	29 (14.5)	58 (29.0)	28 (14.0)	32 (16.0)
I have been treated as less competent by others when they learned that I am a mental health carer	198	82 (41.4)	48 (24.2)	47 (23.7)	14 (7.1)	7 (3.5)
Family and friends who learned I am a mental health carer have been understanding and supportive	199	6 (3.0)	22 (11.1)	66 (33.2)	61 (30.7)	44 (22.1)
I have been shunned or avoided by others when it was revealed that I am a mental health carer	198	79 (39.9)	54 (27.3)	49 (24.7)	12 (6.1)	4 (2.0)
I have been in situations where I have heard others say unfavourable or offensive things about mental health consumers and their illnesses	200	18 (9.0)	17 (8.5)	66 (33.0)	55 (27.5)	44 (22.0)
I have been treated fairly by others who know I am a mental health carer	197	7 (3.6)	7 (3.6)	50 (25.4)	88 (44.7)	45 (22.8)
I have seen or read things in the mass media (e.g. television, movies, books) about mental health consumers and mental illnesses which I find hurtful or offensive	198	8 (4.0)	34 (17.2)	59 (29.8)	51 (25.8)	46 (23.2)
I have worried that others will view me unfavourably because I am a mental health carer	200	85 (42.5)	31 (15.5)	60 (30.0)	11 (5.5)	13 (6.5)

Note: Denominators vary with missing data. ^Refers Qs 31–38 Carer survey.

professionals treating their mental illness than by professionals treating their other illnesses, although almost half of respondents (40.2%) *disagreed* or *strongly disagreed* with this statement (Table 6).

Carers similarly reported that the person they care for experienced stigmatising attitudes and behaviour from their service provider. Almost half of carers (43.8%) *agreed* or *strongly agreed* that the person they care for was treated as less competent, had been told to lower their expectations (40.6%), and/or had been treated differently (43.9%) once their health professional found out about their mental illness. They also reported that the majority of professionals (61.4%) treating consumers did not understand what it meant to have a mental illness, while more than one-third of carers (35.0%) felt that professionals were uncomfortable talking to the consumer. In contrast,

the majority of carers felt that health professionals had treated the person they care for fairly (56.7%), with dignity and respect (49.2%), were understanding and supportive (49.2%), encouraged them to make plans about the future (45.9%) and were optimistic about their recovery (28.0%). Although many carers worried about health professionals viewing the person they care for unfavourably (38.9%), they also reported feeling hopeful about the consumer’s future as a result of the care they receive from their service provider (53.6%). Whilst one-quarter (25.0%) of carers felt that they were an equal member of the care team for the consumer, more than half (60.5%) indicated that they did not. Similarly, while one in five carers (20.1%) indicated that they felt more listened to by professionals treating the consumer’s mental illness than their other illnesses, the majority (54.3%) did not (Table 7).

TABLE 6: CONSUMER EXPERIENCES OF STIGMA FROM HEALTH PROFESSIONALS^

Stigma item	n	n (%)				
		Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I am treated as less competent by professionals treating my mental illness than by professionals treating other illnesses that I have had	410	75 (18.3)	154 (37.6)	61 (14.9)	80 (19.5)	40 (9.8)
Professionals who have treated my mental illness have been understanding and supportive	410	27 (6.6)	53 (12.9)	65 (15.9)	188 (45.9)	77 (18.8)
I have been shunned or avoided by professionals when it was revealed that I had a mental illness	411	75 (18.2)	168 (40.9)	49 (11.9)	73 (17.8)	46 (11.2)
I have been advised by professionals treating my mental illness to lower my expectation for accomplishments in life	405	98 (24.2)	112 (27.7)	57 (14.1)	94 (23.2)	44 (10.9)
I have been treated fairly by professionals treating my mental illness	409	35 (8.6)	54 (13.2)	72 (17.6)	176 (43.0)	72 (17.6)
I have worried that professionals will view me unfavourably once they find out they will be treating me for a mental illness	405	51 (12.6)	102 (25.2)	46 (11.4)	141 (34.8)	65 (16.0)
I think that the professional/s treating my mental illness are optimistic about my recovery	406	24 (5.9)	61 (15.0)	97 (23.9)	160 (39.4)	64 (15.8)
Seeing a professional about my mental illness makes me feel more hopeful about my future	406	18 (4.4)	76 (18.7)	81 (20.0)	150 (36.9)	81 (20.0)
I find that the professionals treating my mental illness encourage me to make plans about my future	410	16 (3.9)	66 (16.1)	88 (21.5)	171 (41.7)	69 (16.8)
Health professionals treating my physical illnesses behave differently when the find out I have a mental illness	408	46 (11.3)	113 (27.7)	67 (16.4)	121 (29.7)	61 (15.0)
I sometimes feel that the professionals treating my mental illness don't really understand what it means to have a mental illness	406	31 (7.6)	86 (21.2)	41 (10.1)	146 (36.0)	102 (25.1)
The professionals treating my mental illness afford me the same dignity and respect that I see given to people with physical illnesses	406	45 (11.1)	65 (16.0)	53 (13.1)	180 (44.3)	63 (15.5)
Sometimes I get the feeling that the professionals treating my mental illness don't feel comfortable talking to me	411	72 (17.5)	165 (40.1)	56 (13.6)	88 (21.4)	30 (7.3)
I feel more listened to by professionals treating my mental illness than by professionals treating other illnesses that I have had	410	35 (8.5)	130 (31.7)	116 (28.3)	99 (24.1)	30 (7.3)
When talking to professional/s about my mental illness, I feel that I am an equal member of the team deciding on my treatment plan	409	53 (13.0)	100 (24.4)	72 (17.6)	130 (31.8)	54 (13.2)

Note: Denominators vary with missing data. ^Refers Qs 3–17 Consumer survey.

TABLE 7: CARER EXPERIENCES AND OBSERVATIONS OF STIGMA FROM HEALTH PROFESSIONALS^

Stigma item	n	n (%)				
		Strongly disagree	Disagree	Neutral	Agree	Strongly agree
The person I care for is treated as less competent by professionals treating his/her mental illness than by professionals treating other illnesses that he/she has had	199	19 (9.5)	50 (25.1)	43 (21.6)	64 (32.2)	23 (11.6)
Professionals who have treated the mental illness of the person I care for have been understanding and supportive	197	22 (11.2)	42 (21.3)	42 (21.3)	74 (37.6)	17 (8.6)
I have seen the person I care for shunned or avoided by professionals when it was revealed they had a mental illness	198	26 (13.1)	78 (39.4)	32 (16.2)	38 (19.2)	24 (12.1)
I have heard professionals treating the mental illness of the person I care for tell them that they should lower their expectation of accomplishments in life	197	24 (12.2)	62 (31.5)	31 (15.7)	55 (27.9)	25 (12.7)
I have seen the person I care for treated fairly by professionals when treating their mental illness	196	15 (7.7)	42 (21.4)	28 (14.3)	95 (48.5)	16 (8.2)
I have worried that professionals will view the person I care for unfavourably once they find out they will be treating them for a mental illness	198	19 (9.6)	67 (33.8)	35 (17.7)	52 (26.3)	25 (12.6)
I think that the professional/s treating the mental illness of the person I care for are optimistic about his/her recovery	200	19 (9.5)	69 (34.5)	56 (28.0)	42 (21.0)	14 (7.0)
Knowing the person I care for is seeing a professional about his/her mental illness makes me feel more hopeful about their future	198	10 (5.1)	33 (16.7)	49 (24.7)	76 (38.4)	30 (15.2)
I find that the professionals treating the mental illness of the person I care for encourage him/her to make plans about their future	198	17 (8.6)	43 (21.7)	49 (24.7)	75 (37.9)	14 (7.1)
Health professionals treating the physical illnesses of the person I care for behave differently when the find out he/she has a mental illness	198	14 (7.1)	56 (28.3)	41 (20.7)	63 (31.8)	24 (12.1)
I sometimes feel that the professionals treating the mental illness of the person I care for don't really understand what it means to have a mental illness	197	7 (3.6)	44 (22.3)	25 (12.7)	76 (38.6)	45 (22.8)
The professionals treating the mental illness of the person I care for afford him/her the same dignity and respect that I see given to people with physical illnesses	199	24 (12.1)	47 (23.6)	30 (15.1)	81 (40.7)	17 (8.5)
Sometimes I get the feeling that the professionals treating the mental illness of the person I care for don't feel comfortable talking to him/her	200	23 (11.5)	78 (39.0)	29 (14.5)	56 (28.0)	14 (7.0)
I feel more listened to by professionals treating the mental illness of the person I care for than by professionals treating other illnesses that he/she has had	199	39 (19.6)	69 (34.7)	51 (25.6)	33 (16.6)	7 (3.5)
When talking to professional/s about the mental illness of the person I care for, I feel that I am an equal member of the team deciding on his/her treatment plan	200	49 (24.5)	72 (36.0)	29 (14.5)	39 (19.5)	11 (5.5)

Note: Denominators vary with missing data. ^Refers Qs 3-17 Consumer survey.



DETAILED ANALYSIS OF RELATIONSHIPS AND ASSOCIATIONS THAT EXIST BETWEEN STIGMA ITEMS

Consumers and carers were asked how recently they had visited a GP or mental health professional, and whether they *agreed* that they or the person they cared for had been treated with respect and provided with good care (Table 8). The analysis examined whether respect and good care varied depending on the health profession. Using the Kruskal-Wallis Test (treating the consumers level of agreement as an ordinal variable) to examine whether respect and good care varied depending on health profession, there was a significant association between type of health professional and level of respect and care received by the consumer (Kruskal-Wallis $\chi^2 = 11.77$, $df = 5$, $p < 0.05$). This analysis was applicable for six groups with social workers receiving the lowest median score. However this was based on only six ratings and the base rates for mental health nurses and the ‘other’ professions were extremely low. There were no differences by diagnosis in the degree to which consumers felt that they were treated with respect and received good care from a mental health professional. This test was conducted by comparing each mental health professional group with each mental disorder.

Again using the Kruskal-Wallis Test for the carers, there was a significant association between the type of mental health professional and degree of respect or care given to the consumer. Carers reported the level of respect and good care shown to the consumer as differing according to the type of mental health professional visited, (Kruskal-Wallis $2 = 14.75$, $df = 5$, $p < 0.05$), with the ‘other’ group being rated lowest.

Consumers were asked whether the level of respect and good care received from their general practitioner varied depending on whether they were being treated for a physical or mental illness. Respondents who indicated that they visited the GP for a physical and mental illness were excluded from the analysis. There was no significant difference between visits for a physical or mental illness regarding whether the consumer felt they had been treated with respect or received good care. Similarly, when carers were asked about whether their last visit to the GP (for a physical or mental illness) saw the person they care for treated with respect and good care, the nature of the visit did not impact significantly on whether the carer felt the GP had treated the consumer with respect or provided good care.

Analysis was conducted to compare the differences in levels of respect and good care received between GPs and mental health professionals

TABLE 8: REASON FOR LATEST VISIT TO A HEALTH PROFESSIONAL AND WHETHER CONSUMER WAS TREATED WITH RESPECT AND PROVIDED WITH GOOD CARE ^

HP visited	Reason for visit	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree	
		Con	Car	Con	Car	Con	Car	Con	Car	Con	Car
GP	Physical	6 (3%)	6 (9%)	7	6	24	6	91	34	91	12 (19%)
GP	MI	15 (8%)	10 (8%)	13 (7%)	12 (10%)	18 (9%)	13 (11%)	76 (40%)	56 (45%)	69 (36%)	33 (27%)
Counsellor	MI	2 (6%)	0 (0%)	4 (11%)	1 (9%)	5 (14%)	3 (27%)	12 (33%)	6 (55%)	13 (36%)	1 (9%)
Psychiatrist	MI	7 (4%)	13 (11%)	11 (7%)	16 (14%)	20 (12%)	18 (16%)	68 (42%)	46 (40%)	57 (35%)	21 (18%)
Psychologist	MI	5 (3%)	1 (4%)	5 (3%)	0 (0%)	14 (8%)	2 (8%)	71 (41%)	11 (42%)	77 (45%)	12 (46%)
Social worker	MI	0 (0%)	1 (7%)	1 (17%)	3 (21%)	2 (33%)	3 (21%)	1 (17%)	5 (36%)	2 (33%)	2 (14%)
Totals for MH professional	MI	17 (4%)	20 (11%)	23 (6%)	22 (12%)	43 (11%)	32 (17%)	157 (40%)	74 (39%)	153 (39%)	41 (22%)

Notes: ^Refers Qs 19 and 20 Consumer survey and Qs 18 and 19 Carer survey. HP-Health Professional, Con-consumer, Car-Carer, MH-mental health, MI-Mental Illness, MH professionals – includes counsellor, psychiatrist, psychologist, social worker, mental health nurse and ‘other’.

treating their mental illness, from both the consumer and carer perspective. Of the consumers, 183 had seen both a GP and a mental health professional for a mental health problem. Using a non-parametric paired-samples analysis (Wilcoxon signed-ranks test), there was no statistically significant difference between ratings for the two groups. As with the consumer sample, only carers who had visited both a GP and a mental health professional with the person they care for with a mental health problem were included. Including the 119 responses and conducting analysis using the paired-samples analysis (Wilcoxon signed-ranks test) there was not a statistical difference between carer ratings for the two professional groups.

Using the Mann-Whitney U Test, there was a statistically significant difference between

consumer and carer reported levels of respect and good care received from GPs treating their physical health problems ($z=3.47$, $p<0.001$), with consumers rating GPs higher than carers. In contrast there was no statistically significant difference between consumers and carers regarding GPs treating the consumer’s mental health problem ($z=1.45$, $p<.05$). When examining the difference between consumer and carer reported levels of respect and good care received from a mental health professional treating the consumer, the results were statistically significant ($z=5.25$, $p<.001$), with consumers providing higher ratings than carers (Table 9). There was no significant difference by diagnosis regarding whether consumers felt they were treated with respect and had received good care from their mental health professional.

TABLE 9: CONSUMER AND CARER VIEWS ABOUT WHETHER THE MENTAL HEALTH PROFESSIONAL TREATED THE CONSUMER WITH RESPECT, AND PROVIDED THEM WITH GOOD CARE^

Type of professional	Group		
	Consumer, n (%)	Carer, n (%)	Total
Strongly disagree	17 (4.3)	20 (10.5)	37 (6.3)
Disagree	23 (5.9)	22 (11.5)	45 (7.7)
Neutral	43 (10.9)	32 (16.8)	75 (12.8)
Agree	157 (39.9)	76 (39.8)	233 (39.9)
Strongly agree	153 (38.9)	41 (21.5)	194 (33.2)
Total	393 (100)	191 (100)	584 (100)

^Refers Q24 Consumer survey and Q23 Carer survey.

TABLE 10: OCCASIONS OF PARTICULARLY GOOD AND/OR POOR CARE RECEIVED BY THE CONSUMER FROM A PROFESSIONAL TREATING THEIR MENTAL ILLNESS DURING THE PAST TWO YEARS^

Type of professional	Experience of care, n (%)	
	Good†	Bad
n	379§	314
Counsellor	48 (12.7)	9 (2.9)
GP	153 (40.4)	89 (28.3)
Nurse (incl. MH Nurse)	47 (12.4)	43 (13.7)
Psychiatrist	141 (37.2)	82 (26.1)
Psychologist	147 (38.8)	29 (9.2)
Social worker	30 (7.9)	10 (3.2)
Other	32 (8.4)	52 (16.6)

Notes: Denominators vary with missing data. †Percentages do not add to 100%, as survey respondents could provide more than one response. §n pertains to number of respondents. ^Refers Qs 26 and 29 Consumer survey.

Consumers were asked to think about an occasion during the previous two years that they had received particularly good and/or poor care from a professional treating their mental illness (Table 10). The professionals most often nominated as providing particularly ‘good’ care included GPs (40.4%), psychologists (38.8%) and psychiatrists (37.2%). However, consumers also frequently identified GPs (28.3%) and psychiatrists (26.1%) as providing particularly ‘poor’ care.

Consumers and carers were asked whether the consumer is treated as less competent by health professionals treating their mental illness (compared with professionals treating their other illnesses) (Table 11); and the frequency of being treated as less competent by others who learned that the consumer had a mental illness (Table 12). Using Chi-Square tests, there was a significant association between the responses about professionals treating the consumer’s mental illness and responses about the frequency of general population treating them as less competent due to them having a mental illness. Specifically, those who agree more strongly that they

have been treated as less competent by a health professional also reported more frequently being treated as less competent by others (linear-by-linear association $\chi^2 = 50.00$, $df = 1$, $p < 0.001$). Further, using a Mann Whitney U Test to compare any differences by diagnosis, those with schizophrenia ($z=2.66$, $p<.01$) or depression ($z=2.32$, $p<.05$) were more likely than those without to report being treated as less competent by the professionals treating their mental illness.

A series of analyses was conducted comparing each single diagnosis with the remaining diagnoses, to test for significance for each individual disorder. It did not take into account that there were respondents with multiple diagnoses.

TABLE 11: DEGREE TO WHICH CONSUMERS AND CARERS REPORT THE CONSUMER IS TREATED AS LESS COMPETENT BY THE HEALTH PROFESSIONAL; AND FREQUENCY OF CONSUMER BEING TREATED AS LESS COMPETENT BY THE GENERAL POPULATION^

Health professionals	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Consumers	75 (18.3%)	154 (37.6%)	61 (14.9%)	80 (19.5%)	40 (9.8%)
Carers	19 (9.5%)	50 (25.1%)	43 (21.6%)	64 (32.2%)	23 (11.6%)

General population	Never	Seldom	Sometimes	Often	Very Often
Consumers	38 (9.4%)	76 (18.7%)	151 (37.2%)	96 (23.6%)	45 (11.1%)
Carers	82 (41.4%)	48 (24.2%)	47 (23.6%)	14 (7.1%)	7 (3.5%)

^Refers to Qs 3 and 33 Consumer survey and Qs 2 and 32 Carer survey.

TABLE 12: CONSUMER RESPONSES ABOUT HAVING BEEN TREATED AS LESS COMPETENT BY PROFESSIONALS AND OTHERS IN THE GENERAL POPULATION^

	Q3 I am treated as less competent by professionals treating my mental illness than by professionals treating other illnesses that I have had.							
			Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Total
Q33 I have been treated as less competent by others when they learned that I am a mental health consumer.	Never	n %	18 4.5%	10 2.5%	7 1.7%	3 .7%	0 .0%	38 9.4%
	Seldom	n %	19 4.7%	40 9.9%	9 2.2%	5 1.2%	3 .7%	76 18.8%
	Sometimes	n %	21 5.2%	58 14.4%	31 7.7%	29 7.2%	12 3.0%	151 37.4%
	Often	n %	13 3.2%	29 7.2%	12 3.0%	30 7.4%	10 2.5%	94 23.3%
	Very often	n %	3 .7%	14 3.5%	2 .5%	13 3.2%	13 3.2%	45 11.1%
	Total	n %	74 18.3%	151 37.4%	61 15.1%	80 19.8%	38 9.4%	404 100.0%

^Refers to Qs 3 and 33 Consumer survey and Qs 2 and 32 Carer survey.

Consumers and carers were asked whether they or the person they cared for had been advised to lower their expectations for accomplishments in life by a health professional treating the consumer’s mental illness (Table 13). Consumers were also asked the same question in relation to others in the general population (Table 14). Using Chi Square Tests, there was a significant association for respondents who had been advised more frequently to lower their expectations by both a health professional and others in the general population (linear-by-linear association $\chi^2 = 149.27$, $df = 1$, $p < 0.001$). When analyses (Chi-Square Tests) was conducted between consumer and carer responses regarding whether they had been advised to lower their expectations, 34.1% of consumers and 40.6% of carers agreed or strongly agreed that the consumer had previously been told to lower their expectations ($\chi^2 = 11.93$, $df = 4$, $p < 0.05$).

When this was explored further by diagnosis (using the Mann-Whitney U Test), consumers with borderline personality disorder ($z = -2.99$, $p < .01$), bipolar disorder ($z = -2.61$, $p < .01$) or schizophrenia ($z = -2.07$, $p < .05$) provided significantly different responses than those without these disorders regarding whether they had been advised by a professional treating their mental illness to

lower their expectations for accomplishments in life (Table 15). There was also a statistically significant difference between those with borderline personality disorder ($z = -3.59$, $p < .001$), bipolar disorder ($z = -4.39$, $p < .001$), or post-traumatic stress disorder ($z = -2.12$, $p < .05$) compared to those without these disorders in the degree to which others had advised them to lower their expectations due to being a mental health consumer (Table 16).

When examining whether consumers had been shunned or avoided by professionals treating their mental illness by diagnosis (using Mann Whitney U Tests), a significant number of those with borderline personality disorder ($z = -4.77$, $p < .001$) and post-traumatic stress disorder ($z = 3.59$, $p < .001$) agreed or strongly agreed with this statement compared to those without these disorders (Table 17). When consumers were asked whether they had been shunned or avoided by others because of their mental illness, there were significant differences in the responses depending on the diagnosis. Those with bipolar disorder ($z = 3.67$, $p < .001$), post-traumatic stress disorder ($z = 3.09$, $p < .01$), borderline personality disorder ($z = 3.67$, $p < .001$), and schizophrenia ($z = 2.32$, $p < .05$) were significantly more likely to report they had been shunned and avoided compared to those without these disorders (Table 18).

TABLE 13: CONSUMER AND CARER RESPONSES ABOUT HEALTH PROFESSIONALS ADVISING THE CONSUMER TO LOWER THEIR EXPECTATIONS FOR ACCOMPLISHMENTS IN LIFE^

	Group				
			Consumer	Carer	Total
Q5-6 I have been advised by (heard) professionals treating my mental illness (or illness of person I care for) to lower my (their) expectation for accomplishments in life.	Strongly disagree	n %	98 24.2%	24 12.2%	122 20.3%
	Disagree	n %	112 27.7%	62 31.5%	174 28.9%
	Neutral	n %	57 14.1%	31 15.7%	88 14.6%
	Agree	n %	94 23.2%	55 27.9%	149 24.8%
	Strongly agree	n %	44 10.9%	25 12.7%	69 11.5%
Total		n %	405 100.0%	197 100.0%	602 100.0%

^Refers Q6 Consumer survey and Q5 Carer survey.

TABLE 14: RELATIONSHIP BETWEEN ADVICE RECEIVED FROM HEALTH PROFESSIONALS AND OTHERS TO LOWER THE CONSUMER’S EXPECTATIONS FOR ACCOMPLISHMENTS IN LIFE^

	Q6 I have been advised by professionals treating my mental illness to lower my expectation for accomplishments in life.							
			Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Total
Q37 I have been advised to lower my expectations for accomplishments in life because I am a mental health consumer.	Never	n %	59 14.8%	40 10.1%	12 3.0%	6 1.5%	0 .0%	117 29.4%
	Seldom	n %	19 4.8%	31 7.8%	10 2.5%	15 3.8%	0 .0%	75 18.8%
	Sometimes	n %	14 3.5%	31 7.8%	27 6.8%	37 9.3%	11 2.8%	120 30.2%
	Often	n %	3 .8%	5 1.3%	6 1.5%	24 6.0%	17 4.3%	55 13.8%
	Very often	n %	1 .3%	4 1.0%	1 .3%	10 2.5%	15 3.8%	31 7.8%
Total		n %	96 24.1%	111 27.9%	56 14.1%	92 23.1%	43 10.8%	398 100.0%

^Refers Qs 6 and 37 Consumer survey.

TABLE 15: CONSUMER ADVICE FROM PROFESSIONALS TREATING THEIR MENTAL ILLNESS TO LOWER THEIR EXPECTATIONS FOR ACCOMPLISHMENTS IN LIFE, BY DIAGNOSIS^

Health Professionals	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
All Consumers (n=405)	98 (24%)	112 (28%)	57 (14%)	94 (23%)	44 (11%)
Depression (n=286)	70 (25%)	82 (29%)	37 (13%)	67 (23%)	30 (11%)
Bipolar disorder (n=115)	19 (17%)	29 (25%)	20 (17%)	32 (28%)	15 (13%)
Schizophrenia (n=48)	9 (19%)	10 (21%)	7 (15%)	12 (25%)	10 (21%)
Borderline personality disorder (n=47)	4 (9%)	13 (28%)	8 (17%)	12 (26%)	10 (21%)
Anxiety disorder (n=189)	49 (26%)	52 (28%)	26 (14%)	42 (22%)	20 (11%)
PTSD (n=46)	10 (22%)	8 (17%)	6 (13%)	13 (28%)	9 (20%)
Eating disorder (n=9)	1 (11%)	4 (44%)	0 (0%)	3 (33%)	1 (11%)
Psychosis (n=9)	2 (22%)	2 (22%)	0 (0%)	2 (22%)	3 (33%)
Dissociative Identity disorder (n=6)	1 (17%)	3 (50%)	1 (17%)	1 (17%)	0 (0%)
OCD (n=8)	1 (13%)	6 (75%)	0 (0%)	0 (0%)	1 (13%)

^Refers Qs 2 and 5 Consumer survey.

TABLE 16: FREQUENCY OF CONSUMERS RECEIVING ADVICE FROM OTHERS TO LOWER THEIR EXPECTATIONS FOR ACCOMPLISHMENTS IN LIFE, BY DIAGNOSIS^

General population	Never	Seldom	Sometimes	Often	Very Often
All Consumers (n=405)	117 (29%)	75 (19%)	122 (30%)	60 (15%)	31 (8%)
Depression (n=289)	88 (30%)	56 (19%)	85 (29%)	40 (14%)	20 (7%)
Bipolar disorder (n=116)	16 (14%)	21 (18%)	43 (37%)	22 (19%)	14 (12%)
Schizophrenia (n=48)	15 (31%)	4 (8%)	15 (31%)	10 (21%)	4 (8%)
Borderline personality disorder (n=49)	5 (10%)	10 (20%)	13 (27%)	15 (31%)	6 (12%)
Anxiety disorder (n=190)	50 (26%)	38 (20%)	61 (32%)	29 (15%)	12 (6%)
PTSD (n=46)	6 (13%)	12 (26%)	13 (28%)	10 (22%)	5 (11%)
Eating disorder (n=9)	1 (11%)	1 (11%)	1 (11%)	3 (33%)	3 (33%)
Psychosis (n=9)	2 (22%)	0 (0%)	4 (44%)	2 (22%)	1 (11%)
Dissociative Identity disorder (n=7)	1 (14%)	2 (29%)	1 (14%)	3 (43%)	0 (0%)
OCD (n=8)	1 (13%)	4 (50%)	0 (0%)	2 (25%)	1 (13%)
Dysthymia (n=2)	0 (0%)	0 (0%)	1 (50%)	1 (50%)	0 (0%)



TABLE 17: DEGREE TO WHICH CONSUMERS HAVE BEEN SHUNNED OR AVOIDED BY HEALTH PROFESSIONALS, BY DIAGNOSIS^

Health Professionals	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
All Consumers (n=411)	75 (18.2)	168 (40.9)	49 (11.9)	73 (17.8)	46 (11.2)
Depression (n=291)	53 (18.2)	121 (41.6)	34 (11.7)	51 (17.5)	32 (11.0)
Bipolar disorder (n=117)	14 (12.0)	53 (45.3)	15 (12.8)	19 (16.2)	16 (13.7)
Schizophrenia (n=49)	8 (16.3)	17 (34.7)	7 (14.3)	7 (14.3)	10 (20.4)
Borderline personality disorder (n=49)	4 (8.2)	11 (22.4)	6 (12.2)	12 (24.5)	16 (32.7)
Anxiety disorder (n=193)	33 (17.1)	76 (39.4)	20 (10.4)	38 (19.7)	26 (13.5)
PTSD (n=46)	4 (8.7)	12 (26.1)	5 (10.9)	17 (37.0)	8 (17.4)
Eating disorder (n=9)	0 (0.0)	4 (44.4)	1 (11.1)	2 (22.2)	2 (22.2)
Psychosis (n=9)	1 (11.1)	4 (44.4)	3 (33.3)	1 (11.1)	0 (0.0)
Dissociative Identity disorder (n=7)	0 (0.0)	1 (14.3)	0 (0.0)	5 (71.4)	1 (14.3)
OCD (n=8)	0 (0.0)	5 (62.5)	0 (0.0)	1 (12.5)	2 (25.0)
Dysthymia (n=2)	0 (0.0)	0 (0.0)	0 (0.0)	1 (50.0)	1 (50.0)

^Refers Qs 2 and 5 Consumer survey.

TABLE 18: FREQUENCY OF CONSUMERS BEING SHUNNED OR AVOIDED BY THE GENERAL POPULATION, BY DIAGNOSIS^

General population	Never	Seldom	Sometimes	Often	Very Often
All Consumers (n=404)	72 (17.8)	102 (25.2)	147 (36.4)	50 (12.4)	33 (8.2)
Depression (n=289)	50 (17.3)	69 (23.9)	113 (39.1)	35 (12.1)	22 (7.6)
Bipolar disorder (n=115)	8 (7.0)	31 (27.0)	39 (33.9)	24 (20.9)	13 (11.3)
Schizophrenia (n=48)	5 (10.4)	10 (20.8)	17 (35.4)	9 (18.8)	7 (14.6)
Borderline personality disorder (n=49)	1 (2.0)	14 (28.6)	18 (36.7)	9 (18.4)	7 (14.3)
Anxiety disorder (n=190)	26 (13.7)	53 (27.9)	64 (33.7)	29 (15.3)	18 (9.5)
PTSD (n=46)	2 (4.3)	11 (23.9)	16 (34.8)	10 (21.7)	7 (15.2)
Eating disorder (n=9)	0 (0.0)	2 (22.2)	3 (33.3)	1 (11.1)	3 (33.3)
Psychosis (n=9)	2 (22.2)	1 (11.1)	2 (22.2)	4 (44.4)	0 (0.0)
Dissociative Identity disorder (n=7)	1 (14.3)	1 (14.3)	2 (28.6)	1 (14.3)	2 (28.6)
OCD (n=8)	1 (12.5)	3 (37.5)	2 (25.0)	1 (12.5)	1 (12.5)
Dysthymia (n=2)	0 (0.0)	0 (0.0)	1 (50.0)	1 (50.0)	0 (0.0)

^Refers Qs 2 and 6 Consumer survey.

When consumers and carers were asked whether the consumer had been treated fairly by professionals treating their mental illness, there was a statistically significant difference between the two groups ($\chi^2 = 15.66$, $df = 4$, $p = 0.004$), with 29.1% of carers and 21.8% of consumers disagreeing or strongly disagreeing that the consumer had been treated fairly. In contrast, 60.6% of consumers and 56.7% of carers agreed or strongly agreed

that professionals had treated them fairly (Table 19). Using the Mann-Whitney U Test, there was also a statistically significant difference between consumers with and without borderline personality disorder ($z = -2.89$, $p < .01$), schizophrenia ($z = -2.38$, $p < .05$) or post-traumatic stress disorder ($z = -2.27$, $p < .05$) with these three groups more likely to report they had not been treated fairly by professionals treating their mental illness (Table 20).

TABLE 19: COMPARISON OF CONSUMER AND CARER VIEWS ABOUT WHETHER THE CONSUMER HAS BEEN TREATED FAIRLY BY PROFESSIONALS TREATING THEIR MENTAL ILLNESS^

	n	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Consumers	409	35 (8.6)	54 (13.2)	72 (17.6)	176 (43.0)	72 (17.6)
Carers	196	15 (7.7)	42 (21.4)	28 (14.3)	95 (48.5)	16 (8.2)

Note: Denominators vary with missing data. ^Refers to Q7 Consumer survey and Q6 Carer survey.

TABLE 20: CONSUMER RESPONSES ABOUT BEING TREATED FAIRLY BY PROFESSIONALS BY DIAGNOSIS^

Health Professionals	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
All Consumers (n=409)	35 (8.6)	54 (13.2)	72 (17.6)	176 (43.0)	72 (17.6)
Depression (n=291)	20 (6.9)	34 (11.7)	51 (17.5)	136 (46.7)	50 (17.2)
Bipolar disorder (n=114)	10 (8.8)	14 (12.3)	28 (24.6)	46 (40.4)	16 (14.0)
Schizophrenia (n=49)	10 (20.4)	8 (16.3)	10 (20.4)	12 (24.5)	9 (18.4)
Borderline personality disorder (n=49)	6 (12.2)	13 (26.5)	9 (18.4)	16 (32.7)	5 (10.2)
Anxiety disorder (n=194)	17 (8.8)	26 (13.4)	31 (16.0)	89 (45.9)	31 (16.0)
PTSD (n=46)	7 (15.2)	9 (19.6)	8 (17.4)	17 (37.0)	5 (10.9)
Eating disorder (n=9)	1 (11.1)	1 (11.1)	2 (22.2)	4 (44.4)	1 (11.1)
Psychosis (n=9)	0 (0.0)	2 (22.2)	3 (33.3)	3 (33.3)	1 (11.1)
Dissociative Identity disorder (n=7)	0 (0.0)	2 (28.6)	0 (0.0)	4 (57.1)	1 (14.3)
OCD (n=8)	0 (0.0)	1 (12.5)	2 (25.0)	4 (50.0)	1 (12.5)
Dysthymia (n=2)	0 (0.0)	0 (0.0)	1 (50.0)	1 (50.0)	0 (0.0)

Consumers and carers were also asked whether they thought the professional treating the consumer was optimistic about their recovery and whether they personally felt more hopeful about the future of the consumer knowing they were seeking treatment from a professional. There was a significant association (using Chi-Square Tests) between the views of consumers about whether the professional was optimistic about their recovery, and whether seeing a professional made them feel more hopeful about their future. Those who agreed more strongly about the professional’s optimism also felt more hopeful about their own future as a result of their treatment (linear-by-linear association $\chi^2 = 139.40$, $df = 1$, $p < 0.001$) (Table 21).

Similarly, when carer responses to these items were compared, there was also a significant association. Carers who agreed more strongly that the treating health professional was optimistic about the consumer’s recovery also reported being more hopeful about the future of the person they care for due to their receiving treatment (linear-by-linear association $\chi^2 = 53.28$, $df = 1$, $p < 0.001$). Furthermore, there was a significant association

between health professional’s level of optimism about the treatment and whether or not the respondent was a consumer or a carer. More than half of consumers (55.2%) agreed or strongly agreed that health professional are optimistic compared with only 28.0% of carers ($\chi^2 = 48.64$, $df = 4$, $p < 0.001$).

When consumer data regarding whether their treating professional was optimistic about their recovery was further examined by diagnosis (using Mann-Whitney U Tests), there were statistically significant differences for those with borderline personality disorder ($z=2.79$, $p<.01$) and schizophrenia ($z=-2.78$, $p<.01$) compared to those without these diagnoses (Table 22). These two groups were less likely to report that their treating professional was optimistic about their recovery. Further there were also significant differences for those with borderline personality disorder ($z=-3.10$, $p<.01$), schizophrenia ($z=2.31$, $p<.05$) or bipolar disorder ($z=2.18$, $p<.05$) compared to those without these disorders regarding the degree to which consumers reported that seeing a professional about their mental illness made them more hopeful about their future, with these three groups being less hopeful about their future (Table 23).

TABLE 21: COMPARISON OF LEVEL OF OPTIMISM BETWEEN PROFESSIONALS, CONSUMERS AND CARERS ABOUT THE CONSUMER’S RECOVERY AND FUTURE^

Health professionals optimism regarding recovery	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Consumers (Q9)	24 (5.9%)	61 (15%)	97 (23.9%)	160 (39.4%)	64 (15.8%)
Carers (Q8)	19 (9.5%)	69 (34.5%)	56 (28%)	42 (21%)	14 (7%)

Personal optimism regarding future	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Consumers (Q10)	18 (4%)	76 (19%)	81 (20%)	150 (37%)	81 (20%)
Carers (Q9)	10 (5%)	33 (17%)	49 (25%)	76 (38%)	30 (15%)

^Refers Qs 9 and 10 Consumer survey and Qs 8 and 9 Carer survey.





TABLE 22: CONSUMER RESPONSES ABOUT THEIR HEALTH PROFESSIONAL’S LEVEL OF OPTIMISM ABOUT THEIR RECOVERY, BY DIAGNOSIS^

Health Professionals	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
All Consumers (n=406)	24 (5.9)	61 (15.0)	97 (23.9)	160 (39.4)	64 (15.8)
Depression (n=288)	12 (4.2)	45 (15.6)	70 (24.3)	121 (42.0)	40 (13.9)
Bipolar disorder (n=115)	5 (4.3)	16 (13.9)	33 (28.7)	49 (42.6)	12 (10.4)
Schizophrenia (n=49)	7 (14.3)	10 (20.4)	15 (30.6)	10 (20.4)	7 (14.3)
Borderline personality disorder (n=47)	7 (14.9)	6 (12.8)	16 (34.0)	16 (34.0)	2 (4.3)
Anxiety disorder (n=192)	9 (4.7)	31 (16.1)	42 (21.9)	83 (43.2)	27 (14.1)
PTSD (n=46)	3 (6.5)	10 (21.7)	11 (23.9)	17 (37.0)	5 (10.9)
Eating disorder (n=9)	0 (0.0)	3 (33.3)	4 (44.4)	2 (22.2)	0 (0.0)
Psychosis (n=9)	1 (11.1)	2 (22.2)	4 (44.4)	1 (11.1)	1 (11.1)
Dissociative Identity disorder (n=7)	0 (0.0)	1 (14.3)	1 (14.3)	5 (71.4)	0 (0.0)
OCD (n=8)	1 (12.5)	1 (12.5)	2 (25.0)	4 (50.0)	0 (0.0)
Dysthymia (n=2)	1 (50.0)	0 (0.0)	1 (50.0)	0 (0.0)	0 (0.0)

^Refers Qs 2 and 9 Consumer survey.

TABLE 23: CONSUMER LEVEL OF OPTIMISM ABOUT THEIR OWN RECOVERY, BY DIAGNOSIS^

General population	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
All Consumers (n=406)	18 (4.4)	76 (18.7)	81 (20.0)	150 (36.9)	81 (20.0)
Depression (n=290)	10 (3.4)	52 (17.9)	57 (19.7)	110 (37.9)	61 (21.0)
Bipolar disorder (n=115)	6 (5.2)	25 (21.7)	29 (25.2)	37 (32.2)	18 (15.7)
Schizophrenia (n=48)	6 (12.5)	11 (22.9)	10 (20.8)	14 (29.2)	7 (14.6)
Borderline personality disorder (n=47)	3 (6.4)	12 (25.5)	13 (27.7)	18 (38.3)	1 (2.1)
Anxiety disorder (n=192)	8 (4.2)	37 (19.3)	35 (18.2)	74 (38.5)	38 (19.8)
PTSD (n=44)	0 (0.0)	14 (31.8)	10 (22.7)	13 (29.5)	7 (15.9)
Eating disorder (n=9)	0 (0.0)	3 (33.3)	2 (22.2)	3 (33.3)	1 (11.1)
Psychosis (n=9)	0 (0.0)	2 (22.2)	4 (44.4)	1 (11.1)	2 (22.2)
Dissociative Identity disorder (n=7)	0 (0.0)	3 (42.9)	1 (14.3)	3 (42.9)	0 (0.0)
OCD (n=8)	0 (0.0)	1 (12.5)	3 (37.5)	4 (50.0)	0 (0.0)
Dysthymia (n=2)	0 (0.0)	0 (0.0)	1 (50.0)	1 (50.0)	0 (0.0)

^Refers Qs 2 and 10 Consumer survey.

Analysis of whether consumers and carers felt that they were an equal member of the consumer’s care team found that there was a statistically significant difference between the two groups ($\chi^2 = 32.58$, $df = 4$, $p < 0.001$). When this was further examined by diagnosis, consumers with borderline personality disorder were significantly more likely than others

to feel that they were an equal member of the treatment team (Mann Whitney U Test, $z=3.49$, $p<.001$). The majority of carers (60.5%) either disagreed or strongly disagreed that they were an equal member of the team compared with approximately one third (37.4%) of consumers (Table 24).

TABLE 24: CONSUMER AND CARER VIEWS ABOUT WHETHER THEY FEEL THEY ARE AN EQUAL MEMBER OF THE CONSUMERS CARE TEAM WHEN DECIDING ON THEIR TREATMENT PLAN^

	n	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Consumers	409	53 (13.0)	100 (24.4)	72 (17.6)	130 (31.8)	54 (13.2)
Carers	200	49 (24.5)	72 (36.0)	29 (14.5)	39 (19.5)	11 (5.5)

Note: Denominators vary with missing data. ^Refers Q17 Consumer survey and Q16 Carer survey.

DISCUSSION

The scope of this study was broad, with the aim of identifying the extent and nature of stigma that exists among mental health and other health professionals providing mental health services. This meant looking across the broad spectrum of workers and practitioners providing services to those experiencing mental health issues, not just being limited to practitioners specialising in mental health.

This study explored the degree to which mental health consumers and carers experience stigmatising attitudes and beliefs from treating health professionals, referencing this against their experiences within the general population.

The literature review demonstrated that research in this area is limited, consisting of mainly qualitative evidence that paints a picture of consumers and carers feeling stigmatised, disconnected and isolated within their own community (Link, Morotznik & Cullen 1991; Link, Streuning, Reese-Todd, Aomussen and Phelan 2002). Not surprisingly, it also revealed that stigma is a major barrier to recovery for people with a mental illness, to the point of being more disabling than the mental illness itself (Boyd 2003; Rethink/Institute of Psychiatry, 2003).

The challenge for this study is to digest the results in their entirety, considering the positives and negatives and to decide what changes need to be made to improve the experiences and outcomes for consumers and carers. This brings to the fore the issue of improving knowledge and understanding about mental illness for both the professionals providing mental health services and the community more generally.

What emerged from this study is that mental health consumers do experience stigma, often, and from health professionals, mental health professionals as well as the general community. It also found that consumers and carers have very different experiences, at different times, and this can vary according to diagnosis.

From here, the report will move into a more detailed discussion of the earlier presented results, with the addition of qualitative comments provided by consumers and carers who completed the survey.

When consumers were asked whether they avoided telling others that they had a mental illness, the overwhelming majority (91.4%) (Table 4) responded that they did so at least sometimes, with only one in five (18.6%) indicating that this was seldom or never the case. Fewer respondents reported being shunned or avoided often or very often (20.6%) than those reporting that this was seldom or never (47%) the case. Although if the first figure is combined with those consumers who indicated that they are sometimes shunned and avoided (36.4%), it suggests that more than half of all consumers are having negative experiences, with varying frequency. This is an example comment provided by a carer:

My daughter lost her job after a psychotic episode which needed a few restorative days. She now never tells her employers her health status as she feels this gets used against her (she is right about this!) Physical illnesses eg diabetes do not attract the same sort of stigma. She has managed to hold down this job for many years very successfully! (Carer, #0130)

The majority of consumers (54.6%) worried (often or very often) that people would view them unfavourably, with a further one-third of respondents (32%) holding this concern at least some of the time. Very few consumers (13.5%) had never worried about this as an issue. When further analysis was conducted by diagnosis, those with eating disorders or anxiety disorders responded differently to those without them. Consumers are often shunned and have concerns about how others view them (Table 4).

I think personal stigma is a far greater problem than societal attitudes towards consumers. I think most people are pretty accepting however sometimes knowing that isn't enough to defeat the shame you carry. (Consumer, #0131)

It was not something that came out in the quantitative part of the survey, but some consumers and carers provided references to the public stigma they felt as well as the negative portrayal of mental illness in the media.

I think people's understanding and support for people with depression has improved over the years. However, I think the media still portrays people with a psychotic illness (like schizophrenia) in movies particularly, very badly. Movies also portray psychiatric hospitals very badly and with only about 20% of truth to them, very sensationalised, which induce[s] fear and misunderstanding. (Carer, #132)

I feel that there is very little support for consumers in the small town I live in and am very nervous about sitting in a hall way with MENTAL HEALTH plastered against the wall in a public area. Everyone knows that is where the Mental Health people go and there is no discretion when waiting for your appointments which is in a hallway used for people wanting blood tests and to see the GP. Mental Health patients are asked to sit directly outside the room and not the general waiting room. (Consumer, #133)

I have seen media showing a man walking through his town naked with only his private parts blurred [and] another of a man on his roof obviously mentally unwell where the camera zoomed in to close-up mode clearly showing his face, recording what he was saying. I have heard media make statements such a "schizophrenic did..." when schizophrenia is an illness not a species! (Carer, #134)

The results of this study suggest that many people hold stigmatising attitudes and beliefs about what it means to have a mental illness. It also indicates that consumers concerns about being perceived negatively are reinforced by the high number of consumers being shunned or avoided.

On the other hand, most consumers reported positive experiences such as receiving understanding and support from their friends and family, and being treated fairly by others. Almost half (48%) of consumers felt that friends and family were understanding and supportive of them with less than one in six (15.8%) reporting that this was seldom or never the case. Similarly, the majority of respondents indicated that they have been treated fairly often or very often (52.9%), with very few consumers indicating that this was not the case (12.6%). However, the interpretation of these latter results is limited by the lack of the information about who this fair treatment is being received from, or not. It could be that some groups are fairer than others although this level of detail was not captured in the responses. It was clear that carers were much less likely to be shunned and more likely to be treated fairly by others than consumers were. It is not surprising, although positive to note, that carers are less likely to be stigmatised than consumers (Table 5).

When analysing the results in relation to consumer and carer experiences of stigma from health professionals, carers consistently reported that consumers were not treated as well as consumers reported their treatment to be. It should be noted that the consumers taking part in the survey were not necessarily the same people referred to by the carer participants who spoke about the person they care for. Further, given that carers are more likely to be providing care to a person at the more severe end of the spectrum of mental disorders, it should be noted that this may have affected the results.

While 20.6% of consumers reported that others in the general community had shunned or avoided them (Table 4), almost one-third (29%) of consumers reported that health professional/s treating their mental illness had shunned them (Table 6), which was lower than the numbers reported when carers were asked the same questions.

I think the [sic] stigma is ingrained in the health profession. I have been in the emergency area of the hospital when I have overheard a treating doctor asking if it was full moon to another doctor - and they both responded by laughing. When I asked this doctor if it was a full moon, because I was there due to a back problem (nothing to do with my ill son), the comment was that they had had quite a few patients with mental illness in, in a row.
(Consumer, #135)

Over half of the consumers (50.8%) worried that health professionals would treat them unfavourably once they found out they had a mental illness, which was similar to the reported response to this question in relation to the general community. In contrast, just over one-third of carers (38.9%) were concerned that health professionals would treat the consumer unfavourably (Table 7). The majority of consumers felt that the professionals treating their mental illness were understanding and supportive (64.7%), which was substantially higher than the number of carers (46.2%) providing the same response. Comparatively speaking, a similar number of consumers (60.6%) and even more carers (56.7%) agreed that the health professional had treated the consumer fairly (Table 20). Although consumers diagnosed with bipolar disorder, schizophrenia or an eating disorder were significantly less likely to report this as being the case. It is possible that the treatment provided in relation to these disorders is different, or is at least provided by specific service providers, which should be considered regarding the difference between those with or without these diagnoses.

This is consistent with earlier survey findings by SANE Australia (2004), which indicated that health professionals regularly treat consumers unfairly and with disrespect. Of the 300 consumers and carers surveyed by SANE, 80% reported experiencing

stigma during the previous two years, with 57% reporting that they had experienced this stigma from health professionals, and to the same or worse degree than more than two years ago. The following comment depicts the variability in experiences that can exist, even for one individual in the present study:

It was difficult for me to answer the initial questions in the survey because of the difference in treatment between psychologists and psychiatrists. My treatment by psychologists on the whole has been very good, whereas my treatment by ambulance staff, Department of emergency medicine staff, and many psychiatrists has been very poor and heavily stigmatised.
(Consumer, #136)

When consumers and carers were asked about their most recent visit to a health professional for a physical or mental illness, there were six professional groups reported including: GPs, counsellors, psychiatrists, psychologists, social workers and mental health nurses (Table 10). Respondents were asked a variety of questions in relation to particularly good and/or poor care received by the consumer, as well as whether the care provided varied according to professional grouping and/or whether they were mental health specific. The results showed that there were significant differences between health professions and the level of care provided. The following quotes reflect consumers and carers varied experiences:

My daughter does not like anyone to know there is anything wrong with her. She would not set foot on the grounds of a public MH facility which makes coordination of services much more difficult and in a way I have to be case manager if she is unwell. There is a HUGE difference in the respect offered to both her and myself in a Private Hospital setting. She is greeted[sic] very respectfully at the clinic where she has been on many occasions. When she left the public facility about 8 years ago, we

were both in shock. I had been told she most likely would not live to 25 due to her self-harming attempts.
(Carer, #137)

*I would like to say that I have come across some very nice, genuinely caring professionals in my 11 years as a mental health consumer. My current psychiatrist, psychologist and GP are excellent and I feel that the care they provide is very good. I have had more negative experiences in public hospitals than in private practice. I understand that public psych wards can be very unrewarding workplaces, but I sometimes feel that the staff can get a little *too* disillusioned. The poor communication between the public system and my private doctor can lead to more stigmatising and assumptions as when my descriptions differ from the official record, I am assumed to be lying. To be honest, the psych registrars in the public wards are often more understanding and polite than the nursing staff. Most of my negative experiences have been at the hands of nursing staff. I'm not sure whether more comprehensive education of nursing staff would be enough to shift the attitude problem I have encountered.*
(Consumer, #138)

When comparing mental health professions, consumers generally rated mental health professionals higher than carers in terms of providing respect and good care, with both groups rating psychologists highest and social workers lowest, although the extremely small number of social workers cited makes validation of these findings difficult. Interestingly, consumers rated GPs treating a mental illness and mental health professionals similarly whereas carers rated GPs substantially higher than mental

health professionals. Carers also rated GPs the same regardless of whether they were treating a physical or mental illness, whereas consumers rated GPs treating their physical illness slightly higher than GPs treating their mental illness (Table 8). Also, further analysis of consumer responses revealed no significance difference according to their diagnosis.

This was typical of the qualitative responses that consumers and carers provided in relation to the treatment received from health professionals:

I have found that most doctors, be they GPs or Psychiatrists, don't really listen to someone who is mentally ill. Every so often a good one comes along who listens, seems to have a real understanding and a genuine interest in bringing out the best in a patient. For the most part however, the majority 'go through the motions', writing out scripts when necessary and putting in a token ten minutes or so to justify their fee/time. In places like A&E and mainstream hospitals, there is no priority given to a patient with a mental illness, no consideration given to how difficult it is for them to wait lengthy times or even be surrounded by lots of other people/noises. Any reaction by these patients is perceived as 'bad behaviour' and [they] are made to wait longer or be treated with less compassion than they deserve.
(Consumer, #139)

The results were quite different when consumers were asked about any experiences of particularly poor care they had received from a health professional. Consumers most often reported that GPs delivered particularly poor care, with a similar number reported for psychiatrists (Table 10). The professional groups least likely to provide the consumer with poor care were counsellors, social workers and psychologists. The survey results indicate that consumer and carer views about treatment being provided by health professional can vary considerably, for both their positive and

negative experiences. These results suggest that there is great variance between most professions and also between individual service providers. Psychologists were the only professional group to receive consistently positive comments, with only very few negative ones.

When considering why certain professional groups tend to receive more positive or negative feedback than others, it should be recognised that certain professionals may be more likely to provide treatment to people with certain disorders. For example, psychiatrists may be more likely to be treating the more severe end of the spectrum of disorders such as schizophrenia, borderline personality disorder and bipolar disorder, while psychologists may be more likely to see consumers with less severe disorders such as mood and anxiety disorders. Another possibility is that certain disorders may have certain behaviours or characteristics associated with them that trigger negative responses from the treating professionals. This research does not purport to have examined these issues, but they certainly warrant further investigation.

Any time I go to the hospital for treatment for a physical illness I am treated first for my mental illness regardless of whether it is relevant or not. I can be perfectly well in terms of my mental illness but am not believed and am forced to be reviewed by mental health staff first, [and] then my physical symptoms are treated. The staff attitude also changes toward me once they realise I have a mental health history – it's as if they think they can catch it off me! (Consumer, #140)

The attitudes of professionals towards people who experience Mental Illness has changed positively in the last decade. My experiences over the last decade have been primarily positive from a range of health professionals including psychiatrists;

psychologists; nurses; social workers; and professionals employed in the community services field. As a professional actively employed in the Mental Health Field for 13 years, [it] has given me the opportunity to educate professionals to break down stigma. (Carer, #141)

When the survey looked at levels of optimism about consumer recovery, it did so from the perspective of the consumer, as well as their perception of the health professional's level of optimism. The majority of consumers felt that seeking treatment from a professional for their mental illness made them hopeful about their future, and similarly believed that their treating health professional was optimistic about their recovery. Consumers with a diagnosis of bipolar disorder and schizophrenia were less likely than consumers without these disorders to report that their treating health professional was optimistic about their recovery. Those with schizophrenia and bipolar disorder were also the least hopeful about their own future.

When carers were asked the same questions, but in relation to the person they care for, the results were quite different. Only one-quarter of carers believed that the health professional treating the consumer was optimistic about their recovery, yet the majority of carers themselves were hopeful about the person's future as a result of them seeing a health professional.

It is interesting that carers are optimistic about the outcome of the consumer's future due to them seeing a professional, even though so few of them believe that the health professional is optimistic about their recovery. This is particularly true given that the majority of carers felt that the health professional did not understand what it means to have a mental illness. Below are few of the typical comments made by a consumers and carers:

It is often difficult to discuss matters with people or professionals who have not experienced similar environments or cultures or social status. For example, how does someone 60 years old, who grew up in poverty & hunger in another country, explain their

upbringing to a 30yo professional who grew up in Australia with much given to them – even water & electricity – and no war or violence on home soil? The professionals need to have much more social interaction in their training before they are awarded their certification. Only a certain amount of training for working in the mental health sector can be achieved via books & the classroom. (Consumer, #142)

Some staff at the same mental health unit are wonderful and some treat mentally ill people and me, as a carer, with no respect at all. There is no concrete example I can give. It is just the way we are spoken to, as if we are nuisances disturbing their busy life, and of having no intelligence. My daughter also has many physical illnesses and the doctors treating her for these are generally much more respectful. (Carer, #143)

Personally I think most-not all professionals don't have an understanding of what it's like to live day to day with these disorders. The majority don't have them & can't fathom how unnerving, let alone frustrating it is to ask questions about what is happening with you only to be told nothing or given answers in large chunks you're not equipped to deal with. (Consumer, #144)

Almost half of carers indicated that they have heard a health professional caution the consumer to lower their expectations of life accomplishments, although only one-third of consumers reported this same advice. Consumers with borderline personality disorder, bipolar and schizophrenia provided significantly different responses to those without these disorders, more often responding that they had been advised to lower their expectations by health professionals. The reasons for these findings cannot be established from this data, although one explanation for the difference between consumers and carers could be that both groups interpret what health professionals say. It could also be that the carers in the survey are caring for someone that is not able to live completely independently and/or has a more severe and persistent mental illness. This comment was made by one carer in relation to this issue:

Question 5 was the most difficult to answer because we have sat in a room with [a] psychiatrist telling our extremely intelligent, ambitious, well-educated and capable daughter (at 18) that she should stop expecting anything from life because she has a mental illness, even leaving her bedroom to join the family for meals was apparently far too ambitious. She was told in my presence by the psychiatrist to accept it (not being able to leave the bedroom) & stop complaining. (Carer, #145)

This reinforces research that indicates that doctors and psychologists sometimes discourage consumers from setting high goals (Wahl 2004).

It would appear that despite predominantly negative comments made by carers about health professionals, they still believe that the treatment provided to the consumer is of benefit. The evidence suggests that the attitudes of health care professionals are related to the care they provide (Lauber & Rossler, 2007). Therefore if many health professionals have low expectations for their patients, it is unlikely that they will be enthusiastic or proactive about the care that they are providing.

LIMITATIONS

This study had a number of limitations, the major one being the characteristics of the participants. Given that the majority of consumer and carer respondents in this study were female, Caucasian, well-educated and employed full-time, they are unlikely to be representative views of all Australians with a mental illness. In general, it could be assumed that the majority of respondents were high-functioning, at least in comparison to many people experiencing a mental illness, and particularly for those with severe and persistent disorders. It did not include people with limited education, non-English speaking people, the homeless or those without internet access. In all likelihood it probably did not include people with severe and persistent mental illness or those who are hospitalised. It also had limited representation from Aboriginal and Torres Strait Islander people and young people. These factors should be considered when interpreting the results, as well as noting that the carer respondents were probably not related to the consumer respondents and both groups are likely to be mutually exclusive.

During the data collection phase many requests were received from hopeful respondents or service providers regarding the possibility of completing the survey in hard-copy. Unfortunately resources were not available to facilitate these requests. The study was also reliant on consumers and carers that were connected to relevant networks and services affiliated either directly or indirectly with the Mental Health Council of Australia, as this was the means for distributing the survey. Those who are not engaged in services, and arguably most in need, have not had their voices heard, nor have the many people who have not accepted or recognised that they have a mental illness, and therefore would not have taken part in the study.

It should also be noted that the respondents were self-selecting and consumers and carers who have had particularly good or bad experiences may have been more likely to take part. This is not quantifiable, however it should be recognised that those who were particularly sensitive to stigma or particularly motivated for the reasons already stated could have skewed the results toward greater levels of stigma.

Also, carers are less likely to be caring for consumers with mild symptoms, therefore their responses could be affected by the fact that consumers they care for are at the more severe end of the spectrum. It should also be noted that the consumer and carer groups are almost certainly mutually exclusive, however it is unknown what number of matched consumer and carer respondent pairs took part in the survey. There is no way of tracing or tracking this, due to the anonymous nature of the survey.

The representation of respondents according to their disorder was also an anomaly, with over-representation of some disorders, such as depression and schizophrenia, compared to the prevalence of mental disorders in the Australian population. It is also unknown whether respondent's self-classification of their mental illness accurately reflected their diagnosis.

CONCLUSION

In addition to the quantitative findings, there were a few key issues that arose from the qualitative comments (last question on the survey) that highlighted consistent themes raised by consumers and carers. The first related to the positivity or not of comments in relation to the setting of their treatment. It was clear that many of the negative comments received about various professionals occurred in a hospital setting. The second was that many people had mixed experiences and that these could be within or between professional groups. The third theme that emerged from the comments was that many people qualified their statements about having negative experiences by saying that they were much improved from those received several years ago.

What this study has found is that many people with a mental illness have experienced or observed the person they care for being subjected to stigmatising attitudes and beliefs. This has consistently been the case for both groups, with stigma being received from health professionals and also from members of the community. These results suggest that the training of health professionals regarding mental health issues may be lacking and their views are not too dissimilar to those of the wider community. Certainly, there was evidence that consumers and carers view different professional groups differently, although it is unknown whether this is related to the mental disorders and the severity of them, or whether there are some inherent issues with particular professional groups.

The findings of this research have identified a number of deficits and scope for further work, including examination of each of the health professions providing mental health services, to establish what is happening currently in relation to training and any ongoing professional development courses. Once any deficits have been identified, it is possible that both curricula and cultural changes will be required. Certainly, this will not occur without considerable investment of resources and ongoing training and policy development to tackle the problem of stigma within mental health services.

Further studies such as this should be repeated to compare results over time, but with the inclusion of a representative sample, rather than the convenience sample used for this study. Such a study would require a broader scope to include severe and persistent disordered consumers, inpatient consumers and carers, those with limited education, homeless, Aboriginal and Torres Strait Islander people and Culturally and Linguistically Diverse people.

As there is no previous research in Australia that has looked at the specific questions asked in this study, it is impossible to determine whether the situation is improving or becoming worse. What is clear is that stigma is a profoundly negative experience for mental health consumers and the impact will seriously interfere with their recovery, particularly when that stigma experience is received from a treating health professional.

APPENDIX 1. ETHICS APPLICATION

DEAKIN UNIVERSITY
Human Ethics Research
Office of Research Integrity
Research Services Division
70 Elgar Road Burwood Victoria
Postal: 221 Burwood Highway
Burwood Victoria 3125 Australia
Telephone 03 9251 7123 Facsimile 03 9244 6581
research-ethics@deakin.edu.au



Memorandum

To: Prof Ann Taket
School of Health & Social Development
B cc: Ms Rachelle Irving
From: Deakin University Human Research Ethics Committee (DUHREC)
Date: 29 October, 2010
Subject: 2010-193
Consumer views about stigma experienced within mental health services

Please quote this project number in all future communications

The application for this project was considered at the DU-HREC meeting held on 27/09/2010.

Approval has been given for Ms Rachelle Irving, under the supervision of Prof Ann Taket, School of Health & Social Development, to undertake this project from 29/10/2010 to 29/10/2014.

The approval given by the Deakin University Human Research Ethics Committee is given only for the project and for the period as stated in the approval. It is your responsibility to contact the Human Research Ethics Unit immediately should any of the following occur:

- Serious or unexpected adverse effects on the participants
- Any proposed changes in the protocol, including extensions of time.
- Any events which might affect the continuing ethical acceptability of the project.
- The project is discontinued before the expected date of completion.
- Modifications are requested by other HRECs.

In addition you will be required to report on the progress of your project at least once every year and at the conclusion of the project. Failure to report as required will result in suspension of your approval to proceed with the project.

DUHREC may need to audit this project as part of the requirements for monitoring set out in the National Statement on Ethical Conduct in Human Research (2007).

Human Research Ethics Unit
research-ethics@deakin.edu.au
Telephone: 03 9251 7123

APPENDIX 2. CONSUMER SURVEY

CONSUMER EXPERIENCES OF STIGMA FROM MENTAL HEALTH AND OTHER SERVICE PROFESSIONALS

The next 31 questions will ask you about your experiences as a mental health consumer when seeking treatment for mental illness/es. This might included treatment from a number of professionals including but not limited to counsellors, general practitioners, nurses, psychiatrists, psychologists, social workers or any other qualified person who may have provided care to you during the past two years.

1. Please indicate which of the following applies to you:

- ☐ I have/have had a mental illness
(A person who is currently using, or has previously used a mental health service.)
- ☐ I am/have been the carer of a person with a mental illness *(A person whose life is affected by virtue of his or her close relationship with a consumer, or who has a chosen caring role with a consumer. A carer may also refer to the consumer's identified family, including children and parents, as well as other legal guardians and people significant to the consumer.)*
- ☐ I am neither a mental health consumer or carer
- ☐ I am both a mental health consumer and carer
- ☐ Other (please specify)

2. If relevant, which of the following mental illnesses have you been diagnosed with (please select all that apply)?

- ☐ Depression
- ☐ Bipolar disorder
- ☐ Schizophrenia
- ☐ Borderline personality disorder
- ☐ Anxiety disorder
- ☐ Other mental illness (please specify)

3. I am treated as less competent by professionals treating my mental illness than by professionals treating other illnesses that I have had.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

4. Professionals who have treated my mental illness have been understanding and supportive.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

5. I have been shunned or avoided by professionals when it was revealed that I had a mental illness.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

6. I have been advised by professionals treating my mental illness to lower my expectation for accomplishments in life.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

7. I have been treated fairly by professionals treating my mental illness.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

8. I have worried that professionals will view me unfavourably once they find out they will be treating me for a mental illness.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

9. I think that the professional/s treating my mental illness are optimistic about my recovery.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

10. Seeing a professional about my mental illness makes me feel more hopeful about my future.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

11. I find that the professionals treating my mental illness encourage me to make plans about my future.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

12. Health professionals treating my physical illnesses behave differently when they find out I have a mental illness.

☐ Strongly disagree ☐ Disagree ☐ Neutral
☐ Agree ☐ Strongly agree

13. I sometimes feel that the professionals treating my mental illness don't really understand what it means to have a mental illness.

☐ Strongly disagree ☐ Disagree ☐ Neutral
☐ Agree ☐ Strongly agree

14. The professionals treating my mental illness afford me the same dignity and respect that I see given to people with physical illnesses.

☐ Strongly disagree ☐ Disagree ☐ Neutral
☐ Agree ☐ Strongly agree

15. Sometimes I get the feeling that the professionals treating my mental illness don't feel comfortable talking to me.

☐ Strongly disagree ☐ Disagree ☐ Neutral
☐ Agree ☐ Strongly agree

16. I feel more listened to by professionals treating my mental illness than by professionals treating other illnesses that I have had.

☐ Strongly disagree ☐ Disagree ☐ Neutral
☐ Agree ☐ Strongly agree

17. When talking to professional/s about my mental illness, I feel that I am an equal member of the team deciding on my treatment plan.

☐ Strongly disagree ☐ Disagree ☐ Neutral
☐ Agree ☐ Strongly agree

18. When was the last time you visited a general practitioner (doctor, GP)?

☐ Less than one week ago
☐ Less than one month ago
☐ 1-6 months ago
☐ 7-12 months ago
☐ More than a year ago
☐ More than two years ago

19. What was your reason for visiting the doctor (tick one or both options)?

☐ Mental illness (please provide details)
☐ Physical illness (please provide details)

20. Thinking about this visit to the doctor, I feel that the doctor treated me with respect and provided me with good care.

☐ Strongly disagree ☐ Disagree ☐ Neutral
☐ Agree ☐ Strongly agree

21. When was the last time you visited a mental health professional (e.g. psychologist, psychiatrist, counsellor, nurse, social worker)?

☐ Less than one week ago
☐ Less than one month ago
☐ 1-6 months ago
☐ 7-12 months ago
☐ More than a year ago
☐ More than two years ago

22. What type of mental health professional was this visit with?

☐ Counsellor
☐ Psychiatrist
☐ Psychologist
☐ Social worker
☐ Other (please provide details)

23. What was your reason for visiting a mental health professional (tick one or both options)?

☐ Mental illness (please provide details)
☐ Other (please provide details)

24. Thinking about this visit to a mental health professional, I feel that they treated me with respect and provided me with good care.

☐ Strongly disagree ☐ Disagree ☐ Neutral
☐ Agree ☐ Strongly agree

25. If you can, please outline an occasion during the past two years where you received care from a professional for a mental illness that you thought was particularly good. We are interested in what happened and any details you can give about why you thought the care was particularly good (without mentioning specific names of providers or services).

26. Who provided you with this experience of good care (please tick all that apply)?

☐ Counsellor
☐ Psychiatrist
☐ Psychologist
☐ Social worker
☐ Other (please provide details)

27. Which of the following settings did this experience of good care occur in?

☐ Private clinician/mental health professional's room
☐ Doctor's surgery or medical centre
☐ Public hospital accident & emergency
☐ Private hospital accident & emergency
☐ Public hospital general ward
☐ Private hospital general ward
☐ Psychiatric hospital/inpatient facility
☐ Community service/setting (please provide details)
☐ Other (please provide details)

28. If you can, please outline an occasion during the past two years where you received care from a professional for a mental illness that you thought was particularly poor. We are interested in what happened and any details you can give about why you thought the care was particularly unsatisfactory (without mentioning specific names of providers or services).

29. Who provided you with this experience of poor or unsatisfactory care?

☐ Counsellor
☐ Psychiatrist
☐ Psychologist
☐ Social worker
☐ Other (please provide details)

30. Which of the following settings did this experience of poor or unsatisfactory care occur in?

☐ Private clinician/mental health professional's room
☐ Doctor's surgery or medical centre
☐ Public hospital accident & emergency
☐ Private hospital accident & emergency
☐ Public hospital general ward
☐ Private hospital general ward
☐ Psychiatric hospital/inpatient facility
☐ Community service/setting (please provide details)
☐ Other (please provide details)

31. Thinking about the last two years, are there any examples of stigmatising behaviour that you experienced from health professionals who knew you had a mental illness?

The next 9 questions will ask you about your experiences of stigma within the general community once individuals and groups learn that you have a mental illness.

32. I have avoided telling others outside my immediate family (or intimate circle of friends) that I am a mental health consumer.

☐ Never ☐ Seldom ☐ Sometimes
☐ Often ☐ Very often

33. I have been treated as less competent by others when they learned that I am a mental health consumer.

☐ Never ☐ Seldom ☐ Sometimes
☐ Often ☐ Very often

34. Family and friends who learned I am a mental health consumer have been understanding and supportive.

☐ Never ☐ Seldom ☐ Sometimes
☐ Often ☐ Very often

35. I have been shunned or avoided by others when it was revealed that I am a mental health consumer.

☐ Never ☐ Seldom ☐ Sometimes
☐ Often ☐ Very often

36. I have been in situations where I have heard others say unfavourable or offensive things about mental health consumers and their illnesses.

☐ Never ☐ Seldom ☐ Sometimes
☐ Often ☐ Very often

37. I have been advised to lower my expectations for accomplishments in life because I am a mental health consumer.

☐ Never ☐ Seldom ☐ Sometimes
☐ Often ☐ Very often

38. I have been treated fairly by others who know I am a mental health consumer.

- ☐ Never ☐ Seldom ☐ Sometimes
☐ Often ☐ Very often

39. I have seen or read things in the mass media (e.g., television, movies, books) about mental health consumers and mental illnesses which I find hurtful or offensive.

- ☐ Never ☐ Seldom ☐ Sometimes
☐ Often ☐ Very often

40. I have worried that others will view me unfavourably because I am a mental health consumer.

- ☐ Never ☐ Seldom ☐ Sometimes
☐ Often ☐ Very often

The last 10 questions will ask you some details about who you are so we can understand whether certain groups experience more or less stigma both within the community and/or from their health professionals. These questions are really important so that we can gain a better picture about the nature and extent of stigma being directed towards people with a mental illness.

41. Please indicate your year of birth below:

42. Please indicate your gender below:

- ☐ Male ☐ Female

43. Please indicate your current marital status below:

- ☐ Single
☐ De facto
☐ Married
☐ Divorced
☐ Separated
☐ Widowed
☐ Civil union

44. What race or ethnic group/s do you identify with (please indicate all that apply)?

- ☐ African-American
☐ Asian
☐ Caucasian Australian
☐ European
☐ Hispanic
☐ Indian
☐ Indigenous Australian
☐ Maori
☐ Middle-Eastern
☐ Torres Strait Islander
☐ Other (please provide details)

45. How many children do you have?

46. What is the highest level of education that you have achieved to date?

- ☐ Primary school
☐ High school
☐ TAFE/CIT course completion
☐ Professional course
☐ Undergraduate degree
☐ Postgraduate degree
☐ Other (please provide details)

47. Are you currently employed (please select all that apply)?

- ☐ I am employed full-time
☐ I am employed part-time or casually
☐ I am not currently employed
☐ I am in receipt of a pension
☐ I am currently employed but on leave due to a health condition (please specify)
☐ I am unable to work due to a health condition (please specify)
☐ I am retired
☐ I cannot work due to my role as a carer
☐ I am a voluntary worker
☐ Other (please provide details)

48. What state/territory do you live in?

49. Please provide your four-digit residential postcode in the space provided below:

50. What is your current living situation?

- ☐ Living alone in a house or apartment
☐ Living with parents/other family members
☐ Living with friends/acquaintances
☐ Semi-independent living in supervised home/apartment
☐ Currently under hospital care
☐ No current residence
☐ Other (please provide details)

51. After answering the above questions you may feel that there was something else that you really wanted to say but haven't yet been able to. Please feel free to talk here about any other matters relating to stigma that you have experienced from professionals because of having a mental illness.

We would like to thank you for taking the time to share your thoughts and experiences with us by completing this very important survey. The results from the survey will be published on the MHCA website www.mhca.org.au from July 2011.

Thank You!

APPENDIX 3. CARER SURVEY

CARER EXPERIENCES OF STIGMA FROM MENTAL HEALTH AND OTHER SERVICE PROFESSIONALS

The next 30 questions will ask you about your experience as a mental health carer when assisting/ accompanying the person you care for (mental health consumer) in seeking treatment or services for their mental illness. This may have included treatment from a number of professionals including but not limited to counsellors, general practitioners, nurses, psychiatrists, psychologists, social workers or any other qualified person who may have provided care to the person you care for during the past two years.

1. Please indicate which of the following applies to you:

- ☐ I am/have been the carer of a person with a mental illness.
(A person whose life is affected by virtue of his or her close relationship with a consumer, or who has a chosen caring role with a consumer. A carer may also refer to the consumer's identified family, including children and parents, as well as other legal guardians and people significant to the consumer.)
- ☐ I have/have had a mental illness
(A person who is currently using, or has previously used a mental health service.)
- ☐ I am neither a mental health consumer or carer
- ☐ I am both a mental health consumer and carer
- ☐ Other (please specify)

2. The person I care for is treated as less competent by professionals treating his/her mental illness than by professionals treating other illnesses that he/she has had.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

3. Professionals who have treated the mental illness of the person I care for have been understanding and supportive.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

4. I have seen the person I care for shunned or avoided by professionals when it was revealed they had a mental illness.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

5. I have heard professionals treating the mental illness of the person I care for tell them that they should lower their expectation of accomplishments in life.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

6. I have seen the person I care for treated fairly by professionals when treating their mental illness.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

7. I have worried that professionals will view the person I care for unfavourably once they find out they will be treating them for a mental illness.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

8. I think that the professional/s treating the mental illness of the person I care for are optimistic about his/her recovery.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

9. Knowing the person I care for is seeing a professional about his/her mental illness makes me feel more hopeful about their future.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

10. I find that the professionals treating the mental illness of the person I care for encourage him/her to make plans about their future.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

11. Health professionals treating the physical illnesses of the person I care for behave differently when they find out he/she has a mental illness.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

12. I sometimes feel that the professionals treating the mental illness of the person I care for don't really understand what it means to have a mental illness.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

13. The professionals treating the mental illness of the person I care for afford him/her the same dignity and respect that I see given to people with physical illnesses.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

14. Sometimes I get the feeling that the professionals treating the mental illness of the person I care for don't feel comfortable talking to him/her.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

15. I feel more listened to by professionals treating the mental illness of the person I care for than by professionals treating other illnesses that he/she has had.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

16. When talking to professional/s about the mental illness of the person I care for, I feel that I am an equal member of the team deciding on his/her treatment plan.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

17. When was the last time you visited a general practitioner (doctor, GP) with the person you care?

- ☐ Less than one week ago
- ☐ Less than one month ago
- ☐ 1-6 months ago
- ☐ 7-12 months ago
- ☐ More than a year ago
- ☐ More than two years ago

18. What was your reason for visiting the doctor (tick one or both options)?

- ☐ Mental illness (please provide details)
- ☐ Physical illness (please provide details)

19. Thinking about this visit to the doctor, I feel that the doctor treated the person I care for with respect and provided him/her with good care.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

20. When was the last time you visited a mental health professional (e.g. psychologist, psychiatrist, counsellor, nurse, social worker) with the person you care for?

- ☐ Less than one week ago
- ☐ Less than one month ago
- ☐ 1-6 months ago
- ☐ 7-12 months ago
- ☐ More than a year ago
- ☐ More than two years ago

21. What type of mental health professional was this visit with?

- ☐ Counsellor
- ☐ Psychiatrist
- ☐ Psychologist
- ☐ Social worker
- ☐ Other (please provide details)

22. What was your reason for visiting a mental health professional (tick one or both options)?

- ☐ Mental illness (please provide details)
- ☐ Other (please provide details)

23. Thinking about this visit to a mental health professional, I feel that they treated the person I care for with respect and provided him/her with good care.

- ☐ Strongly disagree ☐ Disagree ☐ Neutral
- ☐ Agree ☐ Strongly agree

24. If you can, please outline an occasion during the past two years where you have observed the person you care for receive care from a professional for a mental illness that you thought was particularly good. We are interested in what happened and any details you can give about why you thought the care was particularly good (without mentioning specific names of providers or services).

25. Who provided the person you care for with this experience of good care (please tick all that apply)?

- ☐ Counsellor
- ☐ General practitioner (GP, doctor)
- ☐ Nurse
- ☐ Psychiatrist
- ☐ Psychologist
- ☐ Social worker
- ☐ Other (please provide details)

26. Which of the following settings did this experience of good care occur in?

- ☐ Private clinician/mental health professional's room
- ☐ Doctor's surgery or medical centre
- ☐ Public hospital accident & emergency
- ☐ Private hospital accident & emergency
- ☐ Public hospital general ward
- ☐ Private hospital general ward
- ☐ Psychiatric hospital/inpatient facility
- ☐ Community service/setting (please provide details)
- ☐ Other (please provide details)

27. If you can, please outline an occasion during the past two years where you have observed the person you care for receive care from a professional for a mental illness that you thought was particularly poor. We are interested in what happened and any details you can give about why you thought the care was particularly unsatisfactory (without mentioning specific names of providers or services).

28. Who provided the person you care for with this experience of poor or unsatisfactory care?

- ☐ Counsellor
- ☐ Medical practitioner (GP, doctor)
- ☐ Nurse
- ☐ Psychiatrist
- ☐ Psychologist
- ☐ Social worker
- ☐ Other (please provide details)

29. Which of the following settings did this experience of poor or unsatisfactory care occur in?

- ☐ Private clinician/mental health professional's room
- ☐ Doctor's surgery or medical centre
- ☐ Public hospital accident & emergency
- ☐ Private hospital accident & emergency
- ☐ Public hospital general ward
- ☐ Private hospital general ward
- ☐ Psychiatric hospital/inpatient facility
- ☐ Community service/setting (please provide details)
- ☐ Other (please provide details)

30. Thinking about the last two years, are there any examples of stigmatising behaviour that you have experienced from health professionals who knew you were a mental health carer?

The next 8 questions will ask you about your experiences of stigma within the general community once individuals and groups have become aware that you are a mental health carer.

31. I have avoided telling others outside my immediate family (or intimate circle of friends) that I am a mental health carer.

- ☐ Never ☐ Seldom ☐ Sometimes
- ☐ Often ☐ Very often

32. I have been treated as less competent by others when they learned that I am a mental health carer.

- ☐ Never ☐ Seldom ☐ Sometimes
- ☐ Often ☐ Very often

33. Family and friends who learned I am a mental health carer have been understanding and supportive.

- ☐ Never ☐ Seldom ☐ Sometimes
- ☐ Often ☐ Very often

34. I have been shunned or avoided by others when it was revealed that I am a mental health carer.

- ☐ Never ☐ Seldom ☐ Sometimes
- ☐ Often ☐ Very often

35. I have been in situations where I have heard others say unfavourable or offensive things about mental health consumers and their illnesses.

- ☐ Never ☐ Seldom ☐ Sometimes
- ☐ Often ☐ Very often

36. I have been treated fairly by others who know I am a mental health carer.

- ☐ Never ☐ Seldom ☐ Sometimes
- ☐ Often ☐ Very often

37. I have seen or read things in the mass media (e.g., television, movies, books) about mental health consumers and mental illnesses which I find hurtful or offensive.

- ☐ Never ☐ Seldom ☐ Sometimes
- ☐ Often ☐ Very often

38. I have worried that others will view me unfavourably because I am a mental health carer.

- ☐ Never ☐ Seldom ☐ Sometimes
- ☐ Often ☐ Very often

The last 10 questions will ask you some details about who you are so we can understand whether certain groups experience more or less stigma both within the community and/or from their health professionals. These questions are really important so that we can gain a better picture about the nature and extent of stigma being directed towards people with a mental illness as well as towards the people who care for them.

39. Please indicate your year of birth below:

40. Please indicate your gender below:

- ☐ Male ☐ Female

41. Please indicate your current marital status below:

- ☐ Single
- ☐ De facto
- ☐ Married
- ☐ Divorced
- ☐ Separated
- ☐ Widowed
- ☐ Civil union

42. What race or ethnic group/s do you identify with (please indicate all that apply)?

- ☐ African-American
- ☐ Asian
- ☐ Caucasian Australian
- ☐ European
- ☐ Hispanic
- ☐ Indian
- ☐ Indigenous Australian
- ☐ Maori
- ☐ Middle-Eastern
- ☐ Torres Strait Islander
- ☐ Other (please provide details)

43. How many children do you have?

44. What is the highest level of education that you have achieved to date?

- ☐ Primary school
- ☐ High school
- ☐ TAFE/CIT course
- ☐ Professional course
- ☐ Undergraduate degree
- ☐ Postgraduate degree
- ☐ Other (please provide details)

45. Are you currently employed (please select all that apply)?

- ☐ I am employed full-time
- ☐ I am employed part-time or casually
- ☐ I am not currently employed
- ☐ I am in receipt of a pension
- ☐ I am currently employed but on leave due to a health condition (please specify)
- ☐ I am unable to work due to a health condition (please specify)
- ☐ I am retired
- ☐ I cannot work due to my role as a carer
- ☐ I am a voluntary worker
- ☐ Other (please provide details)

46. What state/territory do you live in?

47. Please provide your four-digit residential postcode in the space provided below:

48. What is your current living situation?

- ☐ Living alone in a house or apartment
- ☐ Living with parents/other family members
- ☐ Living with friends/acquaintances
- ☐ Semi-independent living in supervised home/apartment
- ☐ Currently under hospital care
- ☐ No current residence
- ☐ Other (please provide details)

49. After answering the above questions you may feel that there was something else that you really wanted to say but haven't yet been able to. Please feel free to talk here about any other matters relating to stigma that you have experienced from professionals because of having a mental illness.

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Thank You!

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