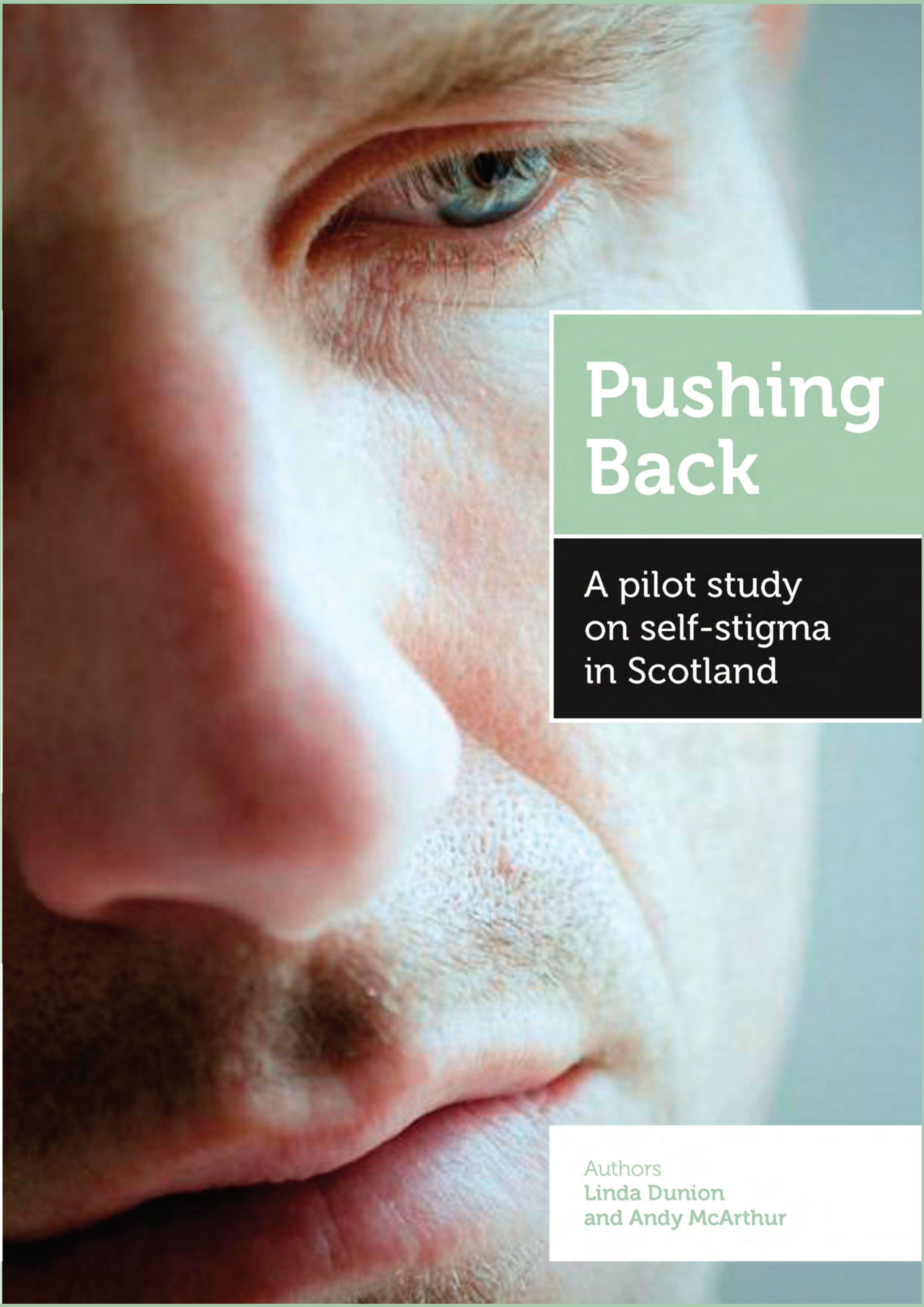

Pushing Back

A pilot study on self-stigma in Scotland

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Foreword

When the Scottish Recovery Network and 'see me' invited The Social Marketing Gateway to carry out research into self-stigma, we wanted to ensure that we developed an approach that enabled people with experience of mental ill health to be directly involved in a meaningful way.

We saw this as a crucial component of the project in terms of capturing a range of perspectives and experiences from both urban and rural Scotland. We felt that it was important, as a point of principle, for the 'voices' of people with lived experience of self-stigma to be heard, not only in the research process, but also in the development of possible ways forward.

It was for these reasons that we sought the help of two local voluntary organisations, Dundee Association for Mental Health (DAMH) and Birchwood Highland. Their contribution to the success of the project cannot be overestimated. It was through discussions with them that we devised the 'buddy conversation' research model of bringing together pairs of individuals with experience of mental ill health to discuss self-stigma, with light-touch facilitation by staff from the two support organisations.

As well as helping to shape the project, DAMH and Birchwood Highland recruited local research volunteers, hosted focus groups and research conversations and supported local stakeholder days in their areas. Their staff helped researchers from The Social Marketing Gateway reflect on what had been said. They also ensured that research volunteers had someone on hand if they needed support following the sessions. The fact that the local research activities ran so smoothly is due to their enthusiasm, commitment and willingness to do whatever it took to support both the research volunteers and our own team.

Having decided to adopt an innovative approach to gathering insight through a series of research conversations, the success of the project hinged on being able to recruit people with experience of mental ill health, who would be prepared to take on the role of research volunteers, or 'buddies'.

We are grateful to the individuals who took part in the local focus groups and the two sets of research conversations. Their openness in talking about their own experiences of self-stigma and their willingness to reflect on how it might be tackled have provided us with unique insight and helped shape suggestions in the ‘Concluding Discussion’ section of the report.

Those who took part are all at different stages on their own journeys of recovery, still living, to a greater or lesser extent, with mental health problems. It is a testament to their desire to help reduce the stigma around mental ill health and promote recovery that they gave up their time to participate in discussions that dealt with sensitive and sometimes difficult issues.

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Executive Summary

In 2011 the Scottish Recovery Network (SRN) and 'see me' (the Scottish mental health anti-stigma campaign) commissioned The Social Marketing Gateway to carry out pilot research into self-stigma in Scotland.

Self-stigma is defined as *'a process whereby a person with a mental health problem is aware of public stereotypes of mental health problems or mental illness and in an implicit manner applies these stereotypes to himself/herself resulting in low self-esteem and a lack of hope'.*

The research explored the incidence, processes and impact of self-stigma in Scotland, focusing on one urban area (Dundee) and one rural area (Invergordon).

The research gathered insight from mental health service users, third sector providers of mental health services and a range of other stakeholders. The methods involved focus groups, small group conversations, one to one in-depth discussions and a structured self-stigma questionnaire.

Two local mental health organisations - Dundee Association of Mental Health (DAMH) and Birchwood Highland - were closely involved in the research process.

A literature review showed that while the topic of stigma in relation to mental ill health has been researched over many years, internalised or self-stigma attracted little attention until the 1990s. The majority of studies focused primarily on public attitudes and the stigma in society. As a result, the body of literature on the subject of self-stigma is more limited than it is for stigma more generally. Many of the themes in the wider literature resonated with the findings of the research.

INCIDENCE OF SELF-STIGMA

A modified version of the Self-Stigma of Mental Illness (SSMI) scale was used to develop a structured, self-completion questionnaire for mental health service users. Of the 69 people responding just over two thirds of the sample (67%) reported that their mental health problem was either very or moderately serious, with some 35% stating that their problem was a serious one. Depression, anxiety and schizophrenia were the three most frequently reported diagnoses.

The results suggest that self-stigma is widespread among people with mental health problems. For example:

- Almost two-thirds felt that having a

mental health problem had spoiled their lives;

- Some 59% were disappointed in themselves because they had a mental health problem;
- Some 44% agreed that stereotypes about people with mental health problems applied to them; and
- Some 59% didn't talk much about themselves because they didn't want to burden others with their mental health problem.

PROCESSES OF SELF-STIGMA

The experiences of the research volunteers suggest that the stigma that exists in society helps generate and perpetuate self-stigma. The negative attributes associated with mental ill health, and the negative stereotypes commonly associated with different diagnoses, influence the way in which individuals with mental health problems are viewed.

These negative associations are sufficiently strong as to have become self-evident 'truths', which influence the beliefs and attitudes of individuals before they develop mental health problems. They can become embedded long before someone experiences symptoms, seeks help or receives a diagnosis. When a diagnosis of mental ill health is given, it carries with it the negative associations attributed to it by society. Consequently, the individual concerned may revise their own sense of identity and downgrade themselves.

While no two people have identical experiences of self-stigma, there are settings, relationships and circumstances which are influential in determining whether and how an individual might come to be affected by self-stigma:

Society - Stigma around mental ill health is one of the main causes of self-stigma. The research volunteers were keenly aware of the negative stereotypes associated with mental ill health. They believe these stereotypes are widely accepted in society in spite of the fact that they are not only inaccurate, but also unfair. The expectation of being 'judged' by others is a powerful disincentive to being open about having a mental health problem. It fuels a sense of being regarded as a 'lesser' person, whose mental ill health is a source of both blame and shame.

Local community - The local community has both contributed to self-stigma and mitigated it. While there were individual instances of discrimination and accounts of people being 'careful' about being open about having mental health problems, the community could also generate a sense of acceptance that enabled people to be open.

Using services - Links to local mental health organisations were highly valued. However, some research volunteers were also reluctant to have it known they were using mental health services because they felt an associated stigma. Others spoke of being shunned by friends as a result of their admission to the psychiatric hospital. A few had been pleasantly surprised that friends had been supportive and visited them in hospital.

Medical profession/diagnosis - A diagnosis of mental ill health can contribute to self-stigma, with health professionals potentially lowering expectations when giving a diagnosis (e.g. telling patients that they will never work again). GPs and psychiatrists do not usually discuss self-stigma or the social consequences of mental ill health when they give a diagnosis. Some people associated their diagnosis with a negative 'label' that is limiting and becomes part of one's identity.

The individual - A responsibility to resist internalising stigma, possibly by being more aware of how one appears to others and paying attention to personal appearance and good manners as a means of encouraging others to behave 'normally' towards them, was evident. A sense of responsibility to try and understand others' attitudes and behaviour towards them featured strongly in the conversations.

Family - Research volunteers had a great deal to say about how their families' reactions had contributed to self-stigma. There was a strong sense of disappointment and hurt at the lack of understanding and support they had received from those closest to them. Responses of family members to their mental ill health had made some people feel worthless and had reinforced negative feelings about themselves. If families got more support, they might be better able to cope and be more understanding.

The workplace - Those who were, or had been, in paid employment spoke about colleagues' attitudes having led them to doubt their capabilities. This undermined confidence and caused people to doubt their own abilities to perform their job as well as they had done in the past.

IMPACT OF SELF-STIGMA

A number of themes appeared to be closely associated with how self-stigma impacts negatively on people's lives and inhibits recovery:

Downgrading expectations and the loss of hope - A recurring theme was a lowering of expectations about what life going forward is likely to hold. People spoke of lowering their expectations following a diagnosis of mental illness, in some cases in direct response to what they had been told by GPs or psychiatrists. Some had struggled to prove a bleak outlook wrong, but their recovery process has been harder and longer because of the way that their diagnosis had been communicated. People also talked about ‘accepting the label they had been given’ – i.e. becoming the person they assumed was consistent with the diagnosis.

Low confidence and self-esteem, a sense of worthlessness and failure - People talked about doubting their self-worth and ability to do the kinds of things they had done before. Damage to people’s confidence came from many sources including medical professionals, family and people in the workplace. A sense of low self-esteem can develop into more profound negatives, such as feeling that one’s whole life has been a failure. Once it takes hold, low self-esteem and a sense of failure can be very hard to break free from, even when external encouragement is forthcoming.

Modifying and changing behaviour - Loss of confidence, growing self-doubt and a worry about how others are going to act can lead to people changing or modifying their behaviour. We uncovered many examples of people choosing not to do things that they had done previously. They spoke of difficulties when going into unknown situations, or of often avoiding them because of being unsure about how they would cope or how others would react. For some, it appears that symptoms associated with their condition are at work (e.g. people being paranoid about what others think about them), but in other cases people had lowered their expectations of themselves as a consequence of internalising stigma and feeling less worthy.

Withdrawal and social isolation - People chose not to put themselves into otherwise ‘normal’ everyday situations or had withdrawn from things that they had previously derived benefit from. Activities that people had stopped, or thought about stopping, covered a wide variety of everyday things that involve social interaction and contribute to quality of life. Some people appear to be protecting themselves from what others may think, say and do if they find out they have a mental health problem. For some, the social exclusion involved can be severe, hugely debilitating and long lasting, cutting them off from society and sources of support.

Pushing forward - countering social withdrawal - Social withdrawal was not uniform and consistent. While it can easily become a habit, it can also be confronted and overcome. A number of people recognised they had a degree of control over their recovery process and chose to ‘push themselves forward’ into situations that, while difficult, they knew would benefit them in the long run. People had pushed themselves into social activities, volunteering and charitable work as ways to rebuild their confidence and self worth.

The ‘Openness Dilemma’ - Many people felt unable or unwilling to be open about their mental health problems. When they had been open, some had felt better for it, but there were also many accounts of where being open had caused difficulties. Most had experienced external stigma in settings where it was known or suspected that they had a mental health problem.

While not surprising that people choose to keep their mental health problem to themselves, many feel a continued anxiety about not disclosing or fear the consequences if others find out. The choice of whether or not to be open is a dilemma that many research volunteers had experienced first-hand. It is a factor that seems tightly bound up with self-stigma.

Positive responses to self-stigma - Most of the research volunteers were on some form of recovery pathway and recognised that dealing with self-stigma was integral to the recovery process. For many, dealing with self-stigma was, however, not an easy or linear process; a number reported recurring episodes of self-loathing and self-doubt. People were able to point to coping strategies and things that had helped them mitigate self-stigma and move forward on a recovery path.

CONCLUDING DISCUSSION

Self-stigma is experienced widely among people with mental health problems and, for some, it continues to blight lives and hold back recovery.

The issues that surround self-stigma are complex and multifaceted. Self-stigma is closely bound up with individual responses to external stigma, anticipated stigma, the effect mental ill health has on how people feel, and with recovery. Further research is needed to better understand and identify self-stigma and its relationship to these other forms of stigma and to recovery.

While there is an immediate need to learn more about self-stigma, there is also an ongoing challenge to collectively do something about it. People with mental ill health can be supported to resist self-stigma, but it is not a battle that they should be fighting alone. Many other organisations have a role to play. This is a battle that needs to be fought on a broad front:

- Across society there are many bodies that can influence and fight against the climate of stigma around mental ill health, wherever it comes from;
- Service providers need to ensure that front line staff are aware of self-stigma and interact with people with understanding and sensitivity;
- Professionals and practitioners in the health sector need to be more aware and have a better understanding of self-stigma.

In Scotland, mental health and other organisations have developed impressive responses to tackling the stigma of mental ill health and supporting recovery. This body of policy and practice will be further strengthened by fresh insight into, and a new priority around, self-stigma.

Introduction

- Explore the incidence, processes and impact of self-stigma in Scotland.
- Identify ways in which self-stigma can be mitigated.
- Highlight practical measures to tackle self-stigma and support recovery.

In 2011 the Scottish Recovery Network (SRN) and ‘see me’ (the Scottish mental health anti-stigma campaign) commissioned The Social Marketing Gateway (The Gateway) to carry out a pilot primary research study into self-stigma in Scotland. Both SRN and ‘see me’ had been working for several years to tackle the general problems of stigma and discrimination in Scottish society towards people with mental health problems and promote recovery. Their work has raised the profile of mental health in general and of the need to tackle the damaging effects of stigma and discrimination in particular, highlighting how it undermines both quality of life and the prospects of recovery.

While both organisations have long recognised external stigma, it is only more recently that their attention has focused on the problem of self-stigma.

> “Self-stigma is a process whereby a person with a mental health problem is aware of public stereotypes of mental health problems or mental illness and in an implicit manner applies these stereotypes to himself/herself resulting in low self-esteem and a lack of hope.”
>
> SRN & ‘see me’

About one in three people with mental health problems will take the negative attitudes around mental ill health to heart.

For the purposes of this project, SRN and ‘see me’ have described self-stigma as ‘a process whereby a person with a mental health problem is aware of public stereotypes of mental health problems or mental illness and in an implicit manner applies these stereotypes to himself/herself resulting in low self-esteem and a lack of hope’.

In October 2011 The Gateway began its work on the self-stigma research project. The work was carried out by Dr Andy McArthur and Linda Dunion, with support from other members of the team, including The Gateway's Research Director Mark Cuthbert. The bulk of the work was carried out between November and December of 2011.

The Gateway worked closely with the SRN and 'see me' throughout the research process, with the clients setting up a dedicated Research Advisory Group to support the work. A key feature of the work has been the very close involvement of local mental health organisations and service users; indeed this was actively encouraged by the clients during the commissioning process.

The remit given to The Gateway was to explore the incidence, processes and impact of self-stigma in Scotland, focusing on one urban and one rural area. Dundee was selected as the urban area and Invergordon the rural.

It was the intention that the work would be solutions-focused. In addition to exploring the extent and impact of self-stigma among mental health service users in the two case study areas, the research aimed to identify ways in which the problem can be mitigated and to highlight practical steps that SRN, 'see me' and other potential partners might consider to tackle self-stigma and support the recovery process.

The close involvement of mental health organisations and service users in the research process, and the use of a 'research buddy' approach, introduced a number of innovative aspects to the research methodology. The research team hopes that this experimental approach provides valuable lessons and pointers that can be used as a basis for much needed further research work in the field.

Methodology

- Local partner organisations helping to shape the methodology.
- Mixed-method: focus groups, small group conversations and a structured self-stigma questionnaire.
- 'Research volunteers' recruited as part of an innovative 'buddy conversation' approach to gathering in-depth insight into lived experience of self-stigma.
- Research Advisory Group set up to oversee the project.

The research methodology was qualitative and focused on engaging and gathering insight from mental health service users, third sector providers of mental health services and a range of other stakeholders from the study area. The main methods involved focus groups, small group conversations, one to one in-depth discussions and a structured self-stigma questionnaire.

A **participative and solutions-focused** approach was followed that involved:

- The direct engagement of an established mental health group in each case study area (rural Invergordon and urban Dundee);
- Drawing on each group's staff and capacity and bringing it to bear in the research process with support and capacity-building from The Gateway;
- Using the groups' existing and trusted contacts to engage with people who have lived experiences of the processes and impacts of self-stigma;
- Recruiting people with experience of self-stigma as research buddies and providing a supportive structure (drawing on the capacity of the local mental health organisations) to gather deep insight into the experience, processes and impact of self-stigma, with particular reference to recovery;
- Introducing an innovative **'buddy dialogue'** approach to gather deep insight, with the buddies participating in 3 separate sessions, plus reading and commenting on write-ups of the sessions;
- Ensuring that the voices of people who have experienced self-stigma, and the influencers who can potentially be part of the solution, were strongly heard.

It was the intention that the methodology would be relatively small scale and experimental in nature and generate learnings that could help shape further work on the topic of self-stigma.

The client was closely involved in the governance of the project, with a dedicated Research Advisory Group, with academic and service user involvement, and an additional Ethics Sub-group that oversaw the adoption of good ethical research practice.

The work programme involved the followed elements:

Active participation of local research partners - After an initial search, using the research team's existing contact networks, we engaged with Birchwood Highland (our rural partner in Invergordon) and Dundee Association of Mental Health (DAMH) (our urban partner).

The local partners actively participated in the research in a variety of ways, notably:

- Involvement in the initial research design;
- Helping to plan the delivery of the research;
- Implementing a structured self-stigma survey;
- Recruiting research volunteers – the 'research buddies' (service users) - to participate in the research;
- Participating in a focus group on self-stigma;
- Helping facilitate meetings with the research buddies;
- Distributing written accounts of the discussions with the research volunteers back to the buddies and feeding back comments to the research team.

A structured self-stigma survey - This was completed both online and in hard copy. The survey was based on an existing and verified self-stigma measurement tool that assessed service users' strength of agreement with a range of statements relating to self-stigma. 69 survey responses were received across the study areas. More detail on the sample characteristics and the survey results are presented in the following section of the report.

Focus groups with service users and staff in each area - A focus group in each area brought the research buddies together, helped scope out issues related to self-stigma, explained the purpose of the research and what would be expected of the research buddies, and enabled the research team to decide on appropriate buddy pairings and the timings of further meetings. The output from each focus group was written up and circulated to the research volunteers for comment. Some 18 service users plus 6 service staff participated.

> “The participation of the two local mental health research partners was a great help across the research process, in particular in the recruitment of service users to participate in focus groups and buddy conversations and (crucially) in being involved in the buddy conversations themselves.”
>
> The Social Marketing Gateway

Buddy conversations (two separate sessions) - Following the focus groups, two waves of buddy conversations were convened. Most of the first wave of conversations were held in pairs and lasted around 1 hour each. A total of 18 people participated (8 from Dundee and 10 from Invergordon or the nearby area). Staff from the research partners helped to facilitate the discussions, using a topic/issue guide prepared by The Gateway research team.

The sessions were (with permission from the buddies) audio taped, written up and the write-ups circulated to the research buddies for comment. The exercise was then repeated 2-3 weeks later. The great majority of the buddies participated in the second round of conversations (only 2 people dropped out). Again the sessions were audio taped, with write-ups circulated to the research buddies.

Immediately following each round of buddy sessions, The Gateway researchers held a reflection and de-briefing session with the facilitators from the local mental health partner to share thoughts on how it had worked.

Local stakeholder workshops and consultations - In parallel with the buddy research, two workshops with a mix of stakeholders were held (one in each study area) and a number of additional one to one stakeholder consultations took place. Stakeholders were recruited to represent a diverse range of society roles and responsibilities. Within the groups there were representatives from the areas of accommodation, employment, advocacy services, and general support services for people dealing with mental ill health.

The stakeholder work explored similar issues to that covered with the research buddies, and also probed aspects of each study area (urban and rural) that stakeholders felt had a bearing on self-stigma.

Analysis of data - A substantial body of material was written up during the course of the fieldwork. The bulk of this consisted of the accounts of each buddy conversation, which drew on both the hand-written notes taken by the researchers and the audio tapes of the session. The written up accounts were broadly structured around the key themes of 'processes', 'experience and impact' of self-stigma, but they also reflected the actual shape that each conversation took.

During the analysis phase, the researchers read across the written up material and drew out recurring themes that had emerged within the 'processes', 'experience and impact' framework. In this way they were able to give shape and focus to the sections of the report that deal with processes of self-stigma and impact of self-stigma.

Meetings of the Research Advisory Group (RAG) - Were held at key points in the process: i.e. early in the work to enable the client and partners' input to research design and ethics planning; and following the main fieldwork phase when tentative findings were emerging and could be discussed. A third meeting of the RAG considered the evidence presented in this report and discussed the next steps in developing practical ways forward to tackle self-stigma.

Reflections on the research method

Overall, The Gateway team feel that the methodology worked very well. There are a few points that can usefully be highlighted to inform future work of this sort.

The participation of the two local mental health research partners was a great help across the research process, in particular in the recruitment of service users to participate in focus groups and buddy conversations and (crucially) in being involved in the buddy conversations themselves.

The presence of staff from the two local mental health organisations in the engagement process, focus groups and buddy conversations helped put service users at ease. It also gave them reassurance and enabled them to engage more fully with the issues than would probably have been the case had the research team been wholly unfamiliar to them. That said, two research buddies did say that once they had 'got into the process' they might have been even more confident talking if staff from the local organisation had not been present.

Working with research buddies over three sessions and across several weeks contributed to the depth and reliability of the insight gathered. The buddies were able to add to and expand upon what they had shared at the previous session, partly because they had been reflecting on the issues in between the conversations. The circulation of written accounts of the session outputs also allowed the researchers to check and probe their interpretation of the previous session.

Over the course of the buddy sessions, a number of the research buddies voluntarily commented that they had found the experience helpful and rewarding. A number also commented that they had found the conversations tiring and draining, e.g. having to revisit some painful memories and experiences, but none of the buddies that saw the process through regretted participating.

The staff of Birchwood Highland and DAMH who actively assisted in the research also fed back positively on their experience of being involved.

From the outset the research was conceived as a pilot project. As such, we are dealing with relatively small numbers which imposes an inevitable limitation on the conclusions that can be drawn. It is not possible to make reliable statements on how self-stigma differs between different geographical areas or about the relative importance of the insights that we have been able to highlight. But the pilot research has confirmed that self-sigma is an issue for people with mental health problems in both rural and urban areas and that SRN and ‘see me’s interest in the topic is well founded.

Literature Review

- Self-stigma has been the subject of fewer research studies than the issue of discrimination in society as a whole.
- Around one third of people with mental health problems appear to be affected by self-stigma.
- The risk of experiencing self-stigma is heightened at the point of diagnosis, when external negative stereotypes dominate over knowledge and awareness of mental ill health and recovery.
- Some people become defined by their mental ill health, losing a sense of the other aspects of themselves that helped make them who they were before they became unwell.

Introduction

Historically, the topic of stigma in relation to mental ill health has been researched over many years. Internalised or self-stigma, on the other hand, attracted little attention until the 1990s. The focus of the majority of studies has been primarily on public attitudes and the stigma in society. As a result, the body of literature on the subject of self-stigma is more limited than it is for stigma more generally. Given that self-stigma is a growing area of interest, the current project for SRN and 'see me' is likely to represent an important contribution to the knowledge base, generating new and valuable insights into the processes, experiences and impact of self-stigma.

In our literature review, we have drawn on those internationally available reports, journal articles, briefings and presentations that relate most closely to the research brief for this project. Our aim has been to focus on material which helps to improve our knowledge and understanding of the processes that lead to self-stigma, the factors that mitigate it and how these relate to recovery. We have also sought examples of interventions designed to prevent or decrease self-stigma.

Definitions and characteristics of self-stigma

For the purposes of this project, SRN and 'see me' have described self-stigma as 'a process whereby a person with a mental health problem is aware of public stereotypes of mental health problems or mental illness and in an implicit manner applies these stereotypes to himself/

herself resulting in low self-esteem and a lack of hope'.

Many of those who have carried out research into self-stigma used similar descriptions of internalised or self-stigma. Watson, Corrigan et al observed that, 'When individuals face the onset of a mental illness such as schizophrenia, these stereotypes become relevant to the self' (Watson, Corrigan et al., 2007).

Boyd Ritsher wrote that, 'Internalized stigma is the psychological point of impact of society-wide stigma on the current lived experience of those labelled with mental illness. As such, it is potentially amenable to change' (Boyd Ritsher, Otilingam & Crajales, 2003).

West et al commented that, 'One consequence of society's stigmatizing attitudes is that people with mental illness often begin to internalize these stigmatizing beliefs, which in turn erodes previously-held positive beliefs about themselves'. They describe this as a loss of 'previously-held identities (e.g., as student, worker, parent) while the stigmatized illness identity becomes dominant' (West, Yanos et al., 2011).

A characteristic that features in much of the literature is that of the perceived legitimacy of discrimination on the grounds of mental ill health. As Rusch et al have pointed out, 'Some people with mental illness accept the common prejudices and lose self-esteem, resulting in self-stigmatization' (Rusch, Corrigan et al., 2009).

However, the evidence also suggests that self-stigma is not inevitable. Watson, Corrigan et al, in seeking to better understand why this should be the case, noted that 'Some people react to stigma by becoming energized and empowered, while others remain relatively indifferent and unaffected' (Watson, Corrigan et al., 2007). Using the Internalized Stigma of Mental Illness Scale (ISMI), West et al found that 36% of a sample of 144 people diagnosed with 'severe mental illness' had elevated internalized stigma scores (West, Yanos et al., 2011).

Processes and protective factors

One of the main areas of focus of the current project has been the processes that lead to self-stigma. This has been the subject of a number of studies.

Watson, Corrigan et al developed a theoretical model of self-stigma (Figure 1) which they then tested to help improve our understanding of what fosters self-stigma and what mitigates it. The model illustrates a process whereby stereotype awareness, combined with stereotype agreement leads to the internalisation (or self-concurrence) of the negative stereotypes (Watson, Corrigan et al., 2007).

Their study was carried out using the SSMI scale (or ISMI) with 71 individuals from the Chicago area who were

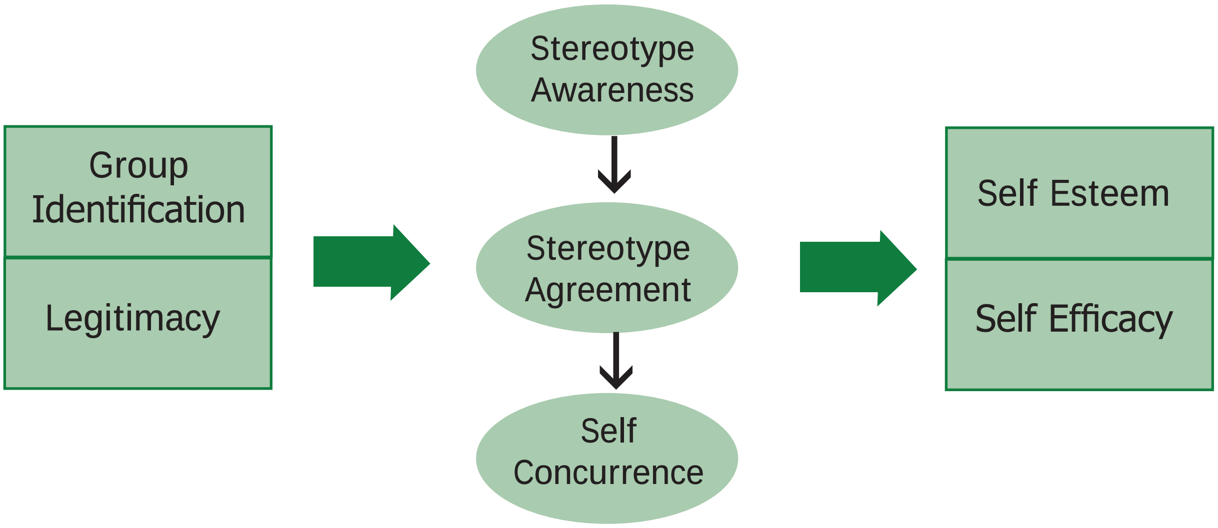


Figure 1. Source: Watson, Corrigan et al., 2007

outpatients in receipt of community support services. All the participants had been diagnosed with a serious mental illness such as schizophrenia, bipolar affective disorder or major depression and they were sufficiently disabled by their mental ill health as to be reliant on welfare benefits at the time of the study.

The researchers examined stereotype awareness, stereotype agreement, stereotype self-concurrence, and self-esteem decrement (or loss) and also explored perceived legitimacy (of negative stereotypes) and group identity (the extent to which individuals felt that they belonged to a broader group, i.e. of people with similar mental health problems).

While acknowledging that the process of self-stigma differs for each individual, they concluded that 'Identification with the group of persons with mental illness appears to play a protective role in terms of reducing stereotype agreement and self-concurrence and bolstering self-esteem and self-efficacy. In contrast, endorsing the legitimacy of mental illness stigma and discrimination makes one vulnerable to self-stigma by reducing stereotype awareness and increasing agreement and self-concurrence.' In other words, there are benefits from feeling a sense of belonging to a group in society who have a diagnosis of mental illness, whereas the more an individual agrees with widely held negative stereotypes, the more prone they are to self-stigma.

Although little work on self-stigma has been carried out on the African continent, one study carried out with members of the South African Depression and Anxiety Group (SADAG) confirmed that self-stigma was not inevitable (Sorsdahl et al., 2010). A majority of those who participated in the study reported high levels of empowerment and self-efficacy in spite of the fact that they also felt that the public held negative attitudes towards people who have mental health problems. This supports the suggestion that group identity may act as a protective factor in mitigating self-stigma.

> “Schizophrenic is the worst diagnosis because I’ve heard it in the newspapers and on TV, that they are really mad, schizophrenic people, they are very dangerous to society, they’ve got no control. So obviously I came under that category.”
>
> African-Caribbean woman (Dinos et al., 2004)

However in their study of sixty women with a diagnosis of borderline personality disorder in Germany and Switzerland, Rusch et al found no relationship between perceived legitimacy of discrimination and group identity (Rusch et al., 2009). It may be that the mitigating benefits derived from a sense of belonging to a broader group of people with mental health problems are dependent on the strength and nature of the association with different kinds of groups. So, for example, the benefits of identification with unknown others who share a diagnosis may have less impact than involvement in a mental health advocacy group or campaigning organisation. This is an area that would merit further study.

Dinos et al examined the feelings and experiences of stigma with a group of 46 people using day and community services in London (Dinos et al., 2004). This study explored feelings of stigma in the presence or absence of experiences of overt discrimination and the relationship of stigma to diagnosis and treatment.

They found that feelings of stigma were more strongly associated with some diagnoses than others. As one African-Caribbean female participant commented, ‘Schizophrenic is the worst diagnosis because I’ve heard it in the newspapers and on TV, that they are really mad, schizophrenic people, they are very dangerous to society, they’ve got no control. So obviously I came under that category’.

The point of diagnosis emerges as a potentially significant stage in the self-stigma process. Nineteen of the participants in Dinos et al’s study reported feelings of stigma following their diagnosis. Sixteen of them had been diagnosed with psychotic disorders such as schizophrenia and bipolar affective disorder.

In his book 'Shunned', Graham Thornicroft identifies one consequence of the way in which the medical profession and academics use language as being that 'some people with mental illness come to see this not as one feature of their lives but as the defining aspect of their core identity' (Thornicroft, 2006). He attributes this to the widespread use of terms such as 'schizophrenic' or 'depressive' to describe people by their diagnosis, a practice which remains commonplace in the media and daily language. Prof Thornicroft quotes one of the participants in the study, 'Leroy' to illustrate this point, 'I can't have schizophrenia because I'm not a violent person'.

Four of those with a diagnosis of schizophrenia also felt that there was stigma attached to their treatment. One female participant with a diagnosis of schizophrenia explained her feelings about this. 'Well I'm too worried about telling people I'm on medication. There are very, very few people that I talk about the Electroconvulsive Therapy (ECT) to … I hate it and it's horrible and also I feel there is a big stigma attached and if they hear about that they'd think I was really mad.'

The Impact of Self-Stigma

While individuals react differently to self-stigma, it is strongly associated with a sense of having something shameful that must be kept secret.

> "I can't have schizophrenia because I'm not a violent person."
>
> 'Leroy' (Thornicroft, 2006)

Most people affected by self-stigma experience a loss of self-esteem and self-efficacy. In his article, 'The Stigma Inside Us', featured on the SRN website, Professor Richard Warner describes this as a 'loss of mastery' (Warner, 2011).

In a study examining self-stigma as a barrier to recovery, Link et al suggested that 'people develop conceptions of mental illness early in life, from family lore, personal experience, peer relations, and the media's portrayal of people with mental illnesses (Link et al., 2001).

They identified five components that contribute to self-stigma:

- People identifying human differences and labelling them;
- The linking, in dominant cultural beliefs, of labels with negative stereotypes;
- The placing of labelled people in categories that isolate them from, and set them in opposition to, the majority;
- The experiencing by labelled people of unfair status, loss and discriminatory behaviour;

- That labelling is contingent on the power differentials existing in society.

They argued that ‘On the basis of these conceptions, people form expectations about whether most people will reject an individual who has a mental illness as a friend, an employee, a neighbour, or an intimate partner and whether most people will devalue a person who has a mental illness as being less trustworthy, less intelligent, and less competent.’ In this study, the researchers sought to establish the degree to which self-stigma affected levels of self-esteem.

The participants in this relatively early study were all members of a Clubhouse in New York, who were interviewed three times in total: once at the beginning of the study; six months later and 24 months later. All of those who took part had been diagnosed with ‘severe mental illness’.

This study controlled for the loss of self-esteem as a symptom of depression. The researchers found a strong and consistent association between self-stigma and low self-esteem. Study participants endorsed withdrawal as a coping mechanism and a significant number of them believed that people with a history of mental ill health would experience rejection by others and be seen as less trustworthy and less intelligent.

The link between self-stigma and self-esteem was also noted by the Highland Users Group (Highland Users Group, 2011). They commented that, ‘mental illness can cause us to lose confidence in ourselves, it can cause a myriad of negative thoughts that all add up to an unrealistic self image that is both a reflection of illness and a reflection of our assumptions about the way society views us’.

Self-stigma appears not only to influence how individuals behave in terms of secrecy or avoidance, but also the type of treatment they receive for their mental health problems. Rusch et al found that low levels of acceptance of the legitimacy of discrimination predicted the use of counselling or psychotherapy (Rusch et al., 2009). Strong group identification was associated with participation in self-help groups. A high level of self-stigma was a predictor of hospitalisation.

The researchers suggested that self-stigma may act as a barrier to help-seeking, with individuals’ negative perceptions of themselves and low self-esteem leading them to delay coming forward for help. This can result in an inability to cope, with hospitalisation becoming more likely as symptoms worsen or a crisis situation develops.

The ability or willingness to seek help is important. Receiving a diagnosis of mental ill health is helpful for many people as it opens the doors to possible treatments and provides an explanation for thoughts and behaviours that may have been a source of confusion and anxiety for some time. However, the diagnostic 'label' itself can contribute to self-stigma and the way in which a diagnosis is communicated to an individual has the potential to promote or undermine recovery.

In its 2007 report, 'A Crying Shame', the Priory Group commented that 'people who have been provided with a psychiatric label often adversely reinvent their self-images frequently leading to self-stigmatisation' (Priory Group, 2007). The same report also talks of the 'culture of silence' found in rural areas, leading individuals to 'shroud their issues and symptoms, leading to social and physical isolation, loss of employment'.

Writing in Community Care magazine in 2005, Michael Carter described how people 'will delay seeking help because they do not wish to be identified as someone with a mental health problem' (Carter, 2005). Citing a study by North West Wales NHS Trust, he noted that the fear of negative reactions is not always borne out by experience. This study found that '85 percent of responses indicated that friends who knew that a respondent had a mental health problem had been understanding, supportive and had treated the individual fairly'.

Dinos et al found that attempts by participants in their study to avoid disclosing their mental ill health 'resulted in stress, isolation and a sense of shame', confirming the findings of other studies elsewhere (Dinos et al., 2004). They also noted that such negative consequences of self-stigma can themselves exacerbate existing mental health problems, particularly depression. Self-stigma therefore leads many people to treat their mental ill health as a 'guilty secret', about which they are ashamed and fearful of exposure.

Mitigating self-stigma

The growth in interest in self-stigma over the past thirty years or so has led to a drive to find effective ways to tackle the problem. The development of the Self-Stigma of Mental Illness (SSMI) scale (also called the ISMI in the US) has helped provide a validated mechanism for measuring the extent to which an individual is affected by self-stigma. It is designed to measure the subjective experience of stigma, with subscales measuring Alienation, Stereotype Endorsement, Perceived Discrimination, Social Withdrawal, and Stigma Resistance. This is significant as it provides a means of assessing the effectiveness of interventions to combat self-stigma.

Tackling stigma in society as a whole is widely accepted as a prerequisite to reducing self-stigma. In 2011, Luckstead et al reported on an intervention that expanded on Macinnes and Lewis's earlier work to reduce self-stigma (Luckstead et al., 2011). They developed Ending Self-Stigma (ESS), a series of nine 90 minute group sessions 'combining lecture, discussion, sharing of personal experiences, teaching and practice of skills, group support and problem-solving'. They used three assessment tools at the outset: the Internalized Stigma of Mental Illness; the Mental Health Recovery Measure; and the Multidimensional Scale of Perceived Social Support, as well as ten of the 28 items on the Boston University Empowerment Scale.

Following the course they found that internalised stigma had decreased significantly, while 'recovery orientation' and social support had increased. Although conceding that the pilot was carried out with relatively small numbers in San Francisco and Baltimore, they concluded that 'ESS may help participants re-align their understanding of societal stigma and their 'selves'. They were encouraged by their findings, noting that 'ESS may be valuable as an intervention for reducing internalized stigma and improving recovery orientation and personal strengths among people with serious mental illness'.

Peter Byrne, writing in 2000, appealed to his fellow-psychiatrists to raise 'the stigma issue' with their patients, pointing out that 'Because of the nature of stigma, patients are unlikely to bring it directly to the attention of the mental health team' (Byrne 2000). He saw this as an 'essential first step' in helping patients to understand and then reject or challenge stigma rather than internalise it.

In their evaluation of the Internalized Stigma of Mental Illness (ISMI) scale in 2003, Boyd Ritsher et al saw the validation of the scale as a potential lever to bring about change in clinical practice (Boyd Ritsher et al., 2003). They observed that, 'Having a validated measure of internalized stigma may encourage clinicians to include stigma reduction as a verifiable treatment goal in addition to symptom reduction'.

In its 2008 report, 'Fighting Shadows', the Mental Health Foundation of New Zealand investigated the causes and impacts of self-stigma, with the aim of identifying effective ways to mitigate it (Paterson et al., 2008).

Drawing on the findings of their research, which included a series of focus groups with people from different cultural backgrounds with experience of mental ill health, Paterson et al developed a new model of self-stigma which includes the identification of 'circuit-breakers'; measures that can help mitigate the different components of self-stigma.

The 'circuit-breakers' model developed by Paterson et al. is shown in the following Figures 2 and 3.

Circuit breakers (actions) that can interrupt the cycle of self-stigma

Element	Circuit breaker	Explanation
Difference	Celebrating and accepting difference	If society celebrates and accepts difference, rather than rejecting it, people with experience of mental illness will feel more 'normal'.
	Disclosure	Disclosure helps normalise mental illness.
Inevitability or unchangeability	Recovery-oriented practices	If mental health services instilled hope and if people with experience of mental illness knew they could recover, then self-stigma would be reduced.
Comparison	Positive role models	If people compare themselves with successful people with experience of mental illness, then self-stigma will be reduced. People can also learn from each other how to combat self-stigma.
	Leadership	Having visible consumer leaders is vital.
Devaluation	Empowerment Affirmation of human rights	If people with experience of mental illness are encouraged to empower themselves, their self efficacy and self-esteem will increase thus combatting self-stigma.
	Recognition of the contribution of people with experience of mental illness	Recognising the human rights and valuing the contribution to society of people with experience of mental illness will also combat self-stigma.
Discrimination	Challenging attitudes and behaviour	If people are encouraged to challenge discrimination when it occurs, anti-stigma and discrimination programmes are implemented, and people with experience of mental illness challenge their own attitudes and behaviour, self-stigma will be reduced. Emphasis must continue to be on eliminating the societal and public discrimination associated with mental illness.

Figure 2. Source: Paterson et al., 2008

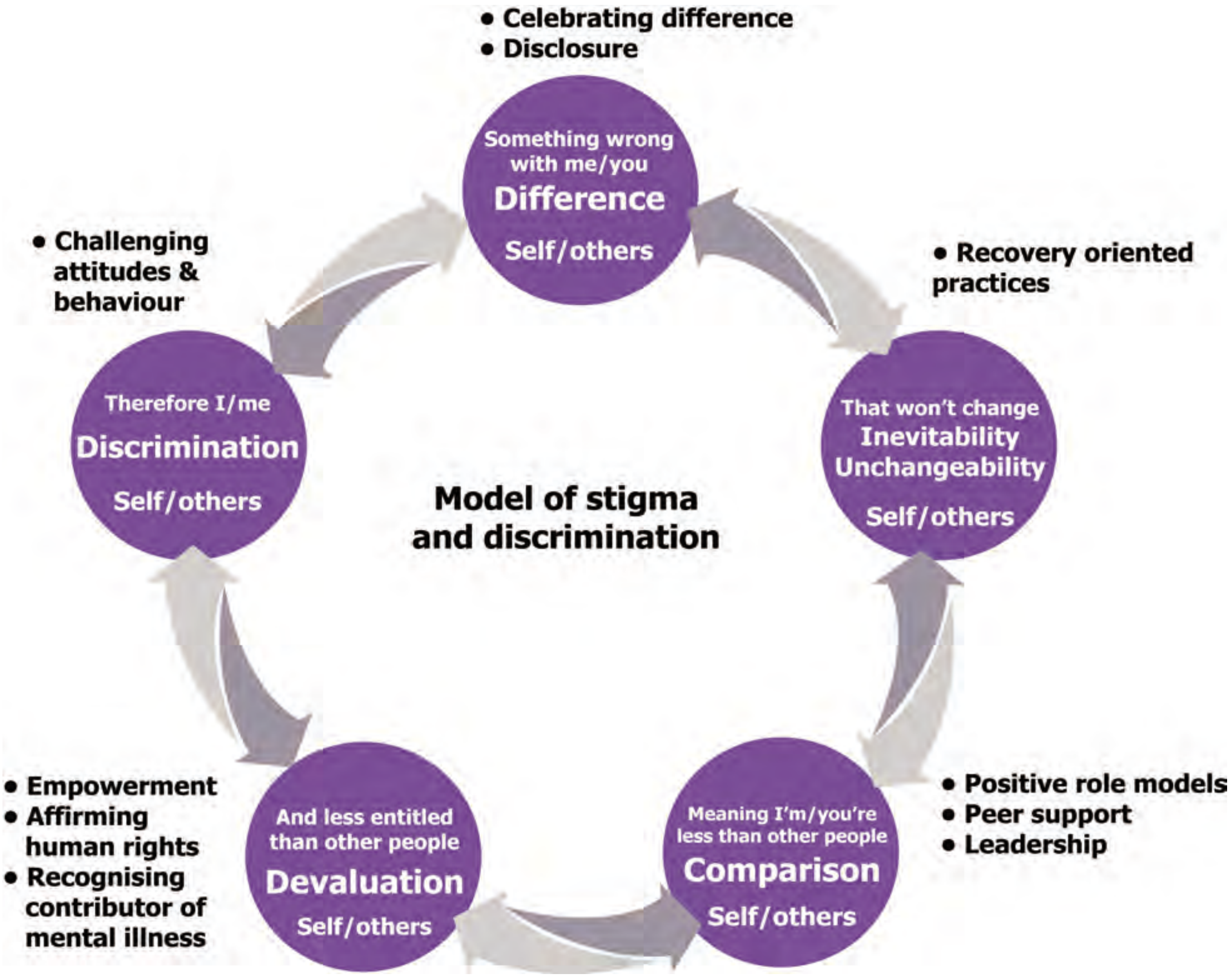


Figure 3. Source: Paterson et al., 2008

The literature suggests that the concept of self-stigma is strongly associated with the stigma that exists in society at large and with actual or anticipated discrimination experienced by people who have mental health problems. The degree to which individuals have already internalised the negative stereotypes associated with different diagnoses, and the extent to which they concur with those stereotypes, seem likely to influence the development of self-stigma.

A number of factors emerge as being potentially significant components of any strategy to mitigate self-stigma:

- Reducing stigma and improving attitudes and behaviour in society as a whole;
- Improving understanding and acceptance of mental ill health and the people who experience it;
- Wider awareness, acceptance and support for recovery-oriented approaches to mental ill health.

Incidence of Self-stigma

- The Internalised Stigma of Mental Illness Inventory (ISMI) tool was used to measure the incidence of stigma in the two case study areas.
- The survey was completed by 69 individuals in the two study areas.
- Self-stigma appeared to be higher among the urban-based Dundee respondents than among those from the more rural setting of Invergordon.

In this section we report on the findings of the self-stigma survey. This presents the feedback from respondents to a range of statements adapted from the Internalised Stigma of Mental Illness Inventory (ISMI) tool (Boyd Ritsher et al., 2003). We used four of the ISMI's five subscales, dropping the 'Perceived Discrimination' subscale because the questions were felt by the RAG to be over-negative and also to make the self-report survey more manageable for respondents.

These questions were organised into 4 subscales or clusters, each with between 5 and 7 items or statements:

1. **Alienation** - 6 statements sought to measure the subjective experience of being less than a full member of society, or having a 'spoiled identity'.
2. **Stigma Resistance** - 5 statements portrayed the experience of resisting or being unaffected by internalized stigma.
3. **Stereotype Endorsement** - 7 statements measured the degree to which respondents agreed with common stereotypes about people with mental illness.
4. **Social Withdrawal** - 6 statements sought to measure the extent to which people withdraw socially as a result of experiencing self-stigma.

The statements are designed to assess the extent of self-stigma across a range of indicators. Survey respondents were asked to rate each statement on the following 4-point anchored Likert scale: 1=strongly disagree, 2=disagree, 3=agree, 4=strongly agree.

In one cluster only (Stigma Resistance) the statements are reverse coded – in this case high agreement is associated with lower self-stigma, whereas in the other 3 clusters the stronger the agreement, the greater the measure of self-stigma.

As we will see, the most striking finding from the results is that self-stigma appears to be consistently higher among the urban-based Dundee respondents than among those from the more rural setting of Invergordon.

Before looking in more detail at the responses to these statements, some basic information on the sample is presented.

Sample characteristics

A total of 69 people responded to the self completion survey. Of these, 43 (62%) were from Dundee and 26 (38%) from Invergordon. The sample also included all of the 18 initial research buddies (8 from Dundee and 10 from Invergordon). who were given the questionnaire to complete by staff working in the local mental health organisations that assisted in the research.

The overall sample size was, therefore, relatively small and lacks representativeness across all demographic groups and, as such, our interpretation of the results needs to be tempered by this realisation.

In addition, there are some other limitations to the process by which the sample was recruited that should be noted. All respondents were recruited from within or through local organisations that focus on mental health issues. As such, it is likely that the most isolated of people who are dealing with mental ill health, those who do not engage with these organisations, were not included in this sample.

In addition, with some of the respondents to the questionnaire already being engaged with the project through the buddy research, it is likely that the issue of self-stigma could be amplified in their minds.

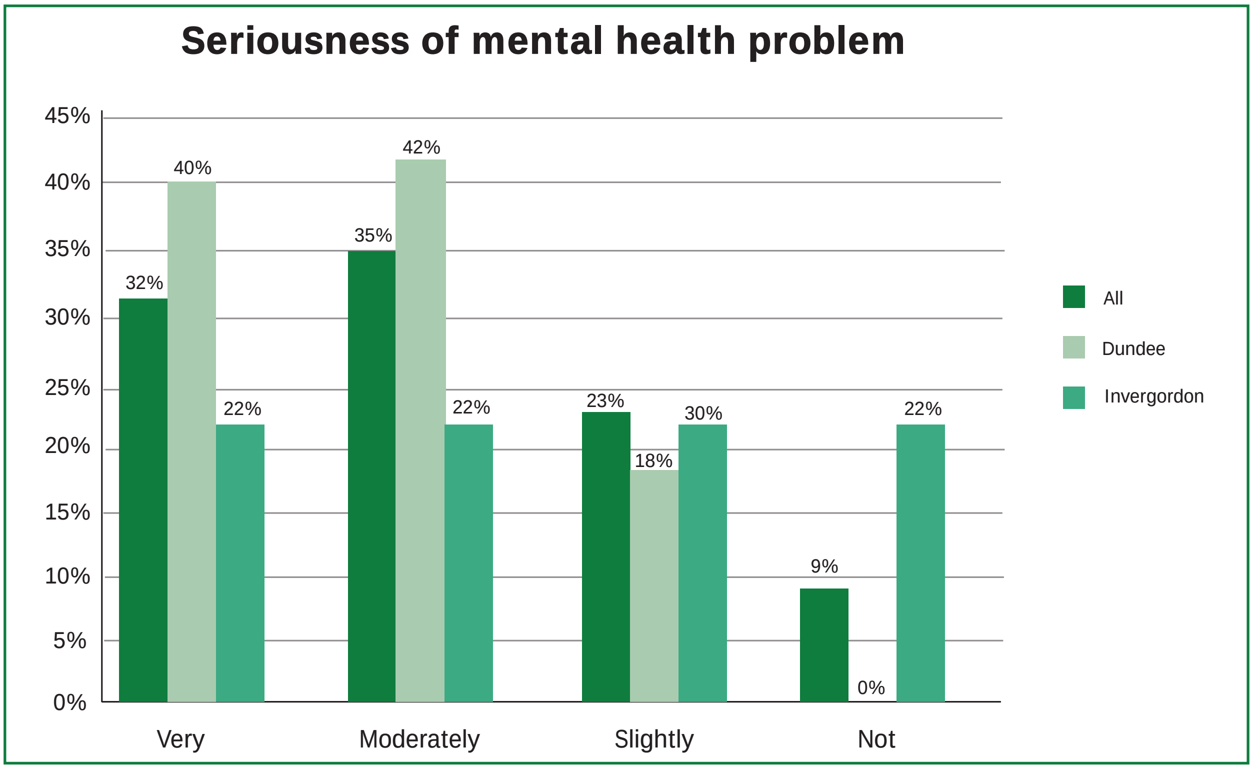
For these reasons it is important to view the findings of the quantitative research as indicative only.

Seriousness of mental health problem

Just over two thirds of the sample (67%) reported that their mental health problem was either very or moderately serious, with 32% describing their problem as a very serious one.

A higher proportion of the Dundee respondents reported that their mental health problem was very or moderately serious compared to those from Invergordon: 82% compared to 44% respectively.

These findings are, however, somewhat at odds with what the researchers observed when carrying out the buddy research. Although only a minority of the survey respondents were also research buddies, in Invergordon it was observed that more of these buddies appeared to be currently dealing with the serious effects of their mental health diagnosis than was the case in Dundee.

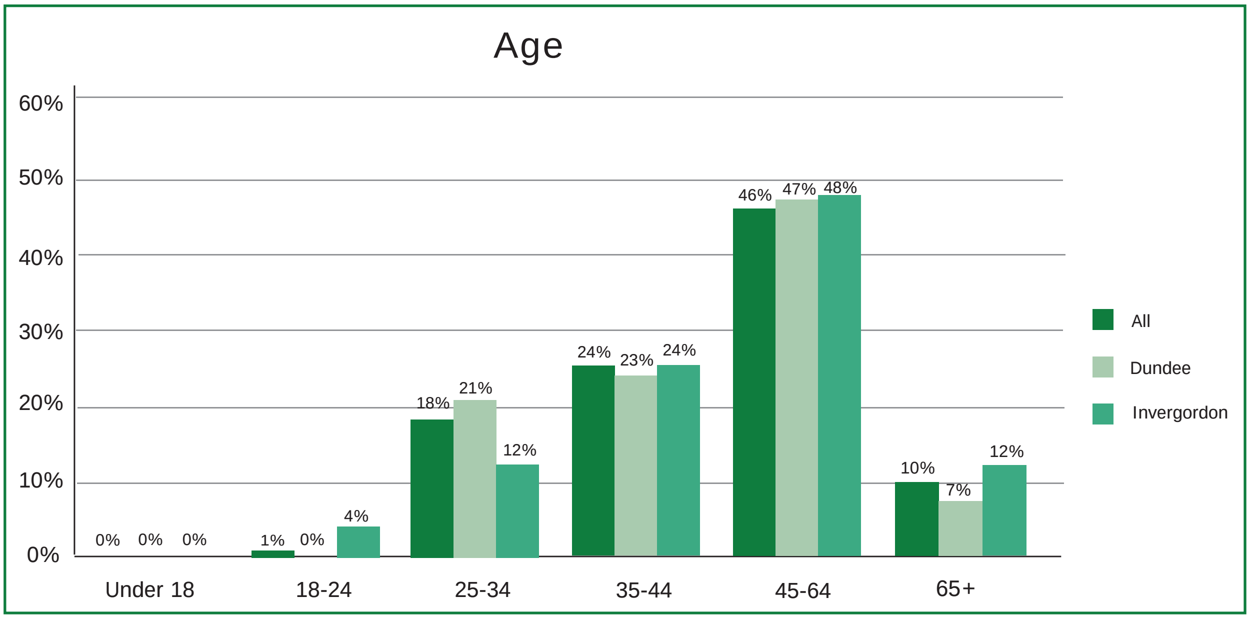

Seriousness of mental health problem

(Sample size: 69)

Age of respondents

The majority of the respondents were middle aged or older: with some 56% being aged 45 years or above.

The Dundee sample was slightly younger, but the differences between the two areas were not great. Less than 20% of the sample was under 25 years.


Age

(Sample size: 69)

Current situation of respondents

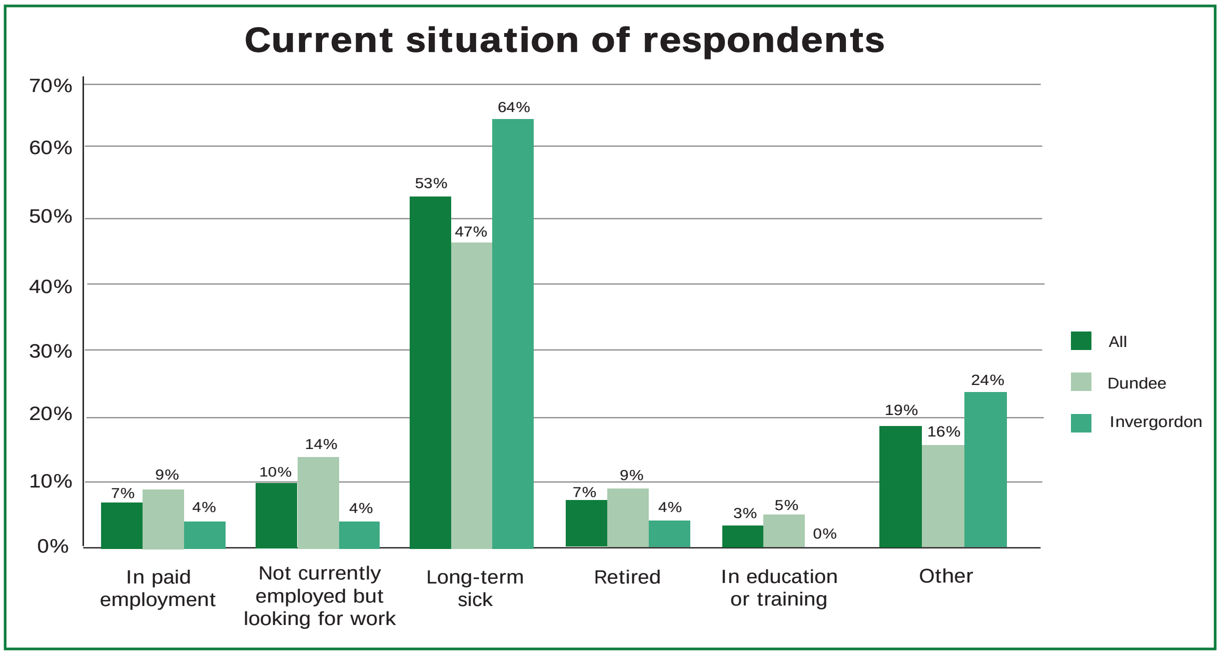
The majority of sample respondents were, on the whole, not currently active in the labour market. 7% reported that they were in paid employment and a further 3% were in education or training, but over half (53%) were long term sick and a further 10% were not working but were looking for a job.

Comparing the two areas, in Dundee higher proportions were in work, looking for work, or in education and training, and fewer were long term sick. This is consistent with the impression that the researchers formed on the basis of the characteristics of the buddy groups in the two areas.

Nature of the mental health problem experienced

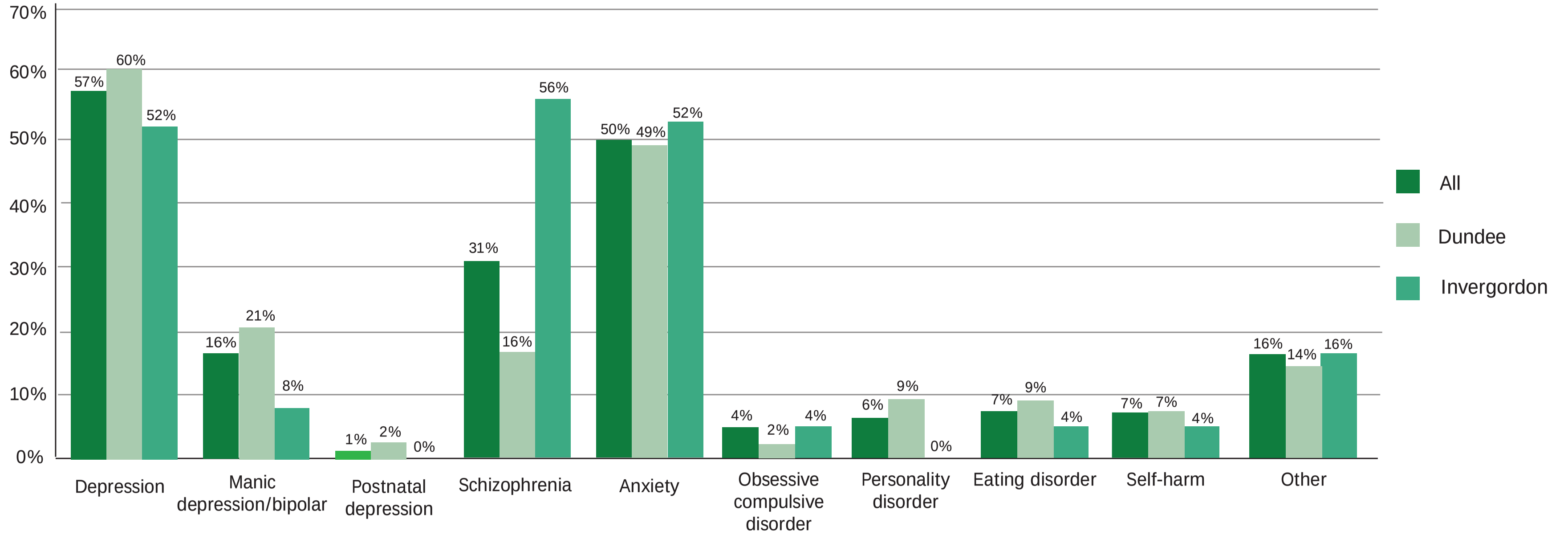
A number of respondents reported more than one mental health problem. Of the individual diagnoses cited, depression, anxiety and schizophrenia were the three most frequently reported, accounting for 57%, 50% and 31% of diagnoses respectively.

In Dundee, depression was the most frequently mentioned mental health problem whereas in Invergordon it was schizophrenia. Indeed, in Invergordon, schizophrenia was mentioned more than 3 times as often as it was in Dundee. Again this is consistent with the impression gained by the research team who observed that the research buddies in Invergordon were dealing with more severe symptoms than were their counterparts in Dundee.


Current situation of respondents

(Sample size: 69)

Nature of the mental health problem



(Sample size: 69)

Note - Respondents could choose more than one answer

Self-stigma Cluster - Alienation

The statements used within this cluster were:

- I feel out of place in the world because I have a mental health problem
- Having a mental health problem has spoiled my life
- People without a mental health problem could not possibly understand me
- I am embarrassed or ashamed that I have a mental health problem
- I am disappointed in myself for having a mental health problem
- I feel inferior to others who don't have a mental health problem

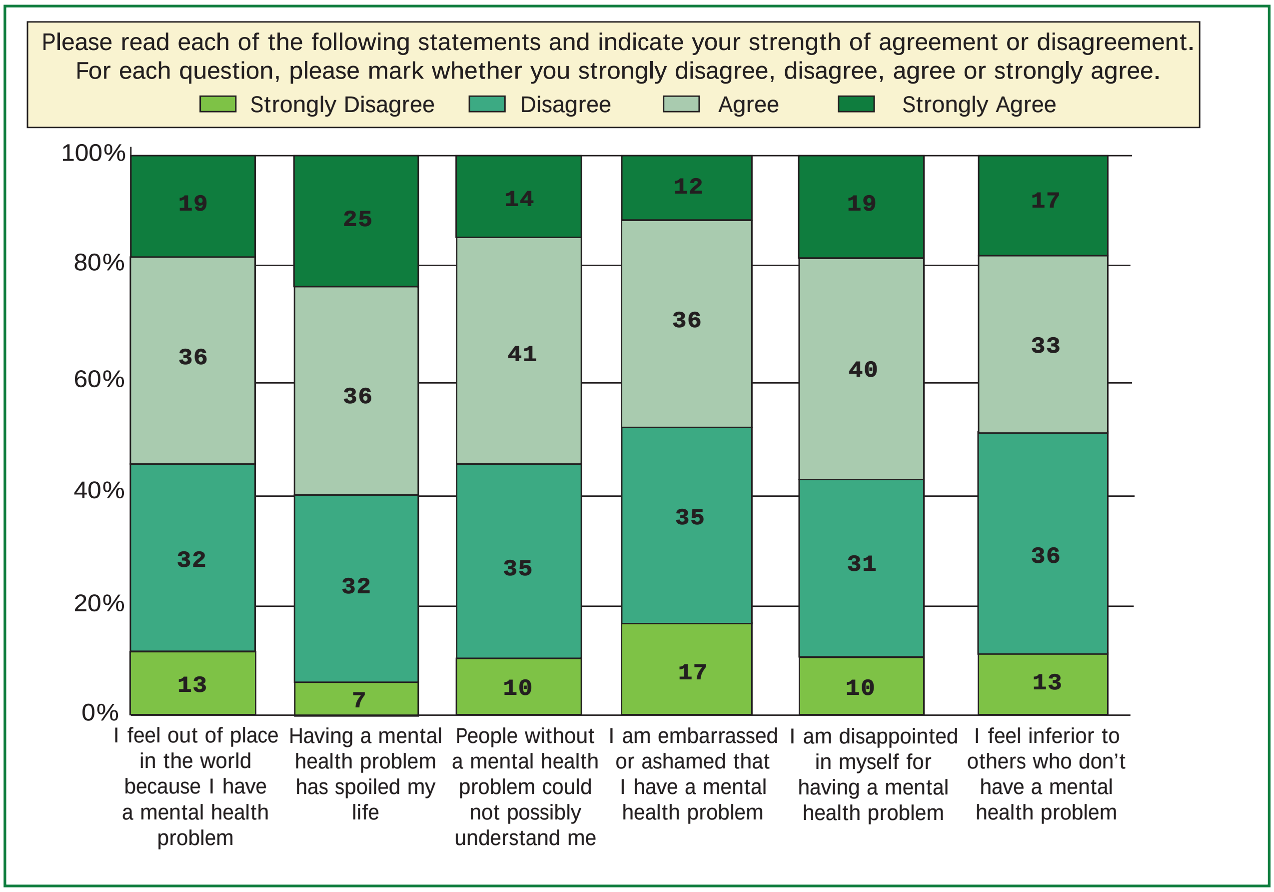
The statement that the largest proportion (61%) of respondents agreed with was 'Having a mental health problem has spoiled my life'. This was closely followed (59%) by 'I am disappointed with myself for having a mental health problem'.

On both indicators, respondents in Dundee were more likely to agree than those in Invergordon.

The statement that attracted least agreement (48%) was 'I am embarrassed or ashamed that I have a mental health problem'. A much smaller proportion from Invergordon agreed (35%) compared to 56% in Dundee.

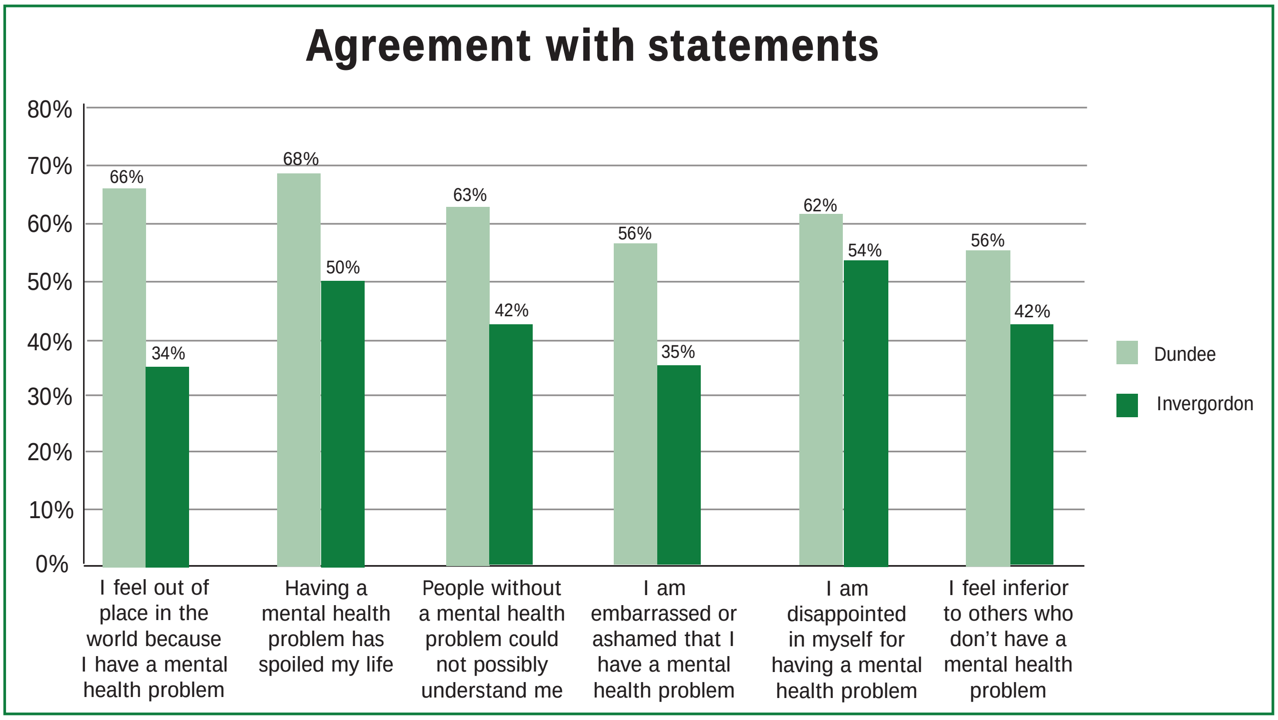
Across all of the individual statements in this cluster we can see higher levels of agreement among the Dundee sample. Please note, however, that due to the limited size of the samples in each location these findings should only be regarded as indicative.

Alienation (All)



(Sample size: 69)

Alienation (Dundee / Invergordon split)



(Dundee sample size: 43, Invergordon sample size: 26)

Self-stigma Cluster - Stigma Resistance

The statements used within this cluster were:

- I feel comfortable being seen in public with an obviously mentally ill person
- In general, I am able to live life the way I want to
- I can have a good, fulfilling life despite my mental health problem
- People with a mental health problem make important contributions to society
- Living with a mental health problem has made me a tough survivor

Please note that in this cluster only, people's strength of agreement with the statements is negatively associated with self-stigma – in other words where people agreed they were associating with positive characteristics that mitigate against self-stigma.

The statement that most people agreed with was that 'People with a mental health problem make important contributions to society', with some 87% of respondents agreeing. Comparing the two areas we see a divergence of 9% points, with 83% in Dundee agreeing compared to 92% in Invergordon.

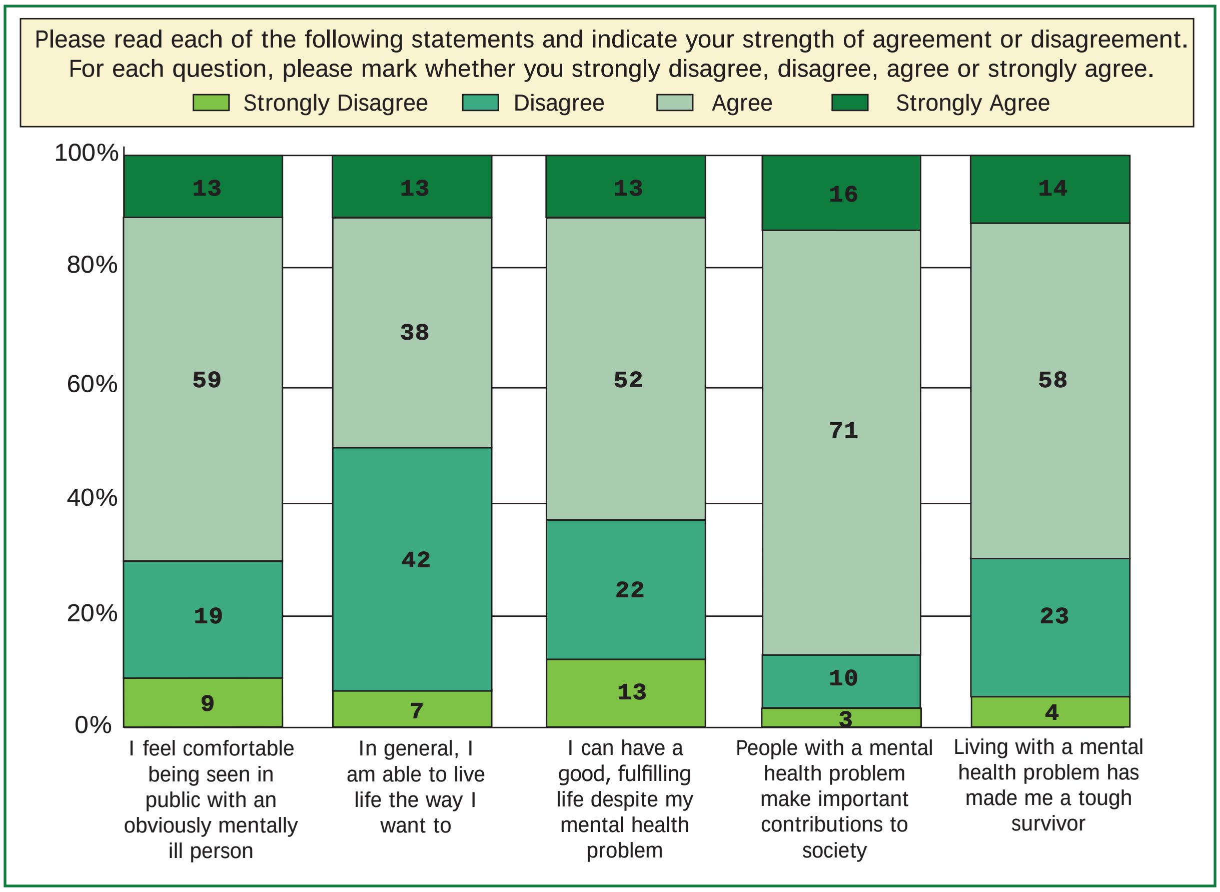
The statement that fewest respondents agreed with was that 'I am able to live life the way I want', with only 51% agreeing. Again, we see a difference between the two areas, with 40% agreeing in Dundee compared to 69% in Invergordon.

Hence, in Dundee, where the researchers observed that fewer of the buddies appeared to be dealing with the more severe symptoms of their condition and were more likely to have got their lives stabilised and back on track, they were less likely to feel that they were able to live their lives they way they want. This could be because the process of recovery is a difficult and challenging one, something that (as we will see below) the buddy research tended to bear out.

Other observations that are consistent with the above comment is that a larger proportion of the Dundee respondents (79%) felt that living with a mental health problem had made them a tough survivor, compared to 61% in Invergordon. Also, in Dundee the proportion that felt they could have a good and fulfilling life despite their mental health problem was lower (60% compared to 73%) indicating the greater realisation of the struggle that is recovery.

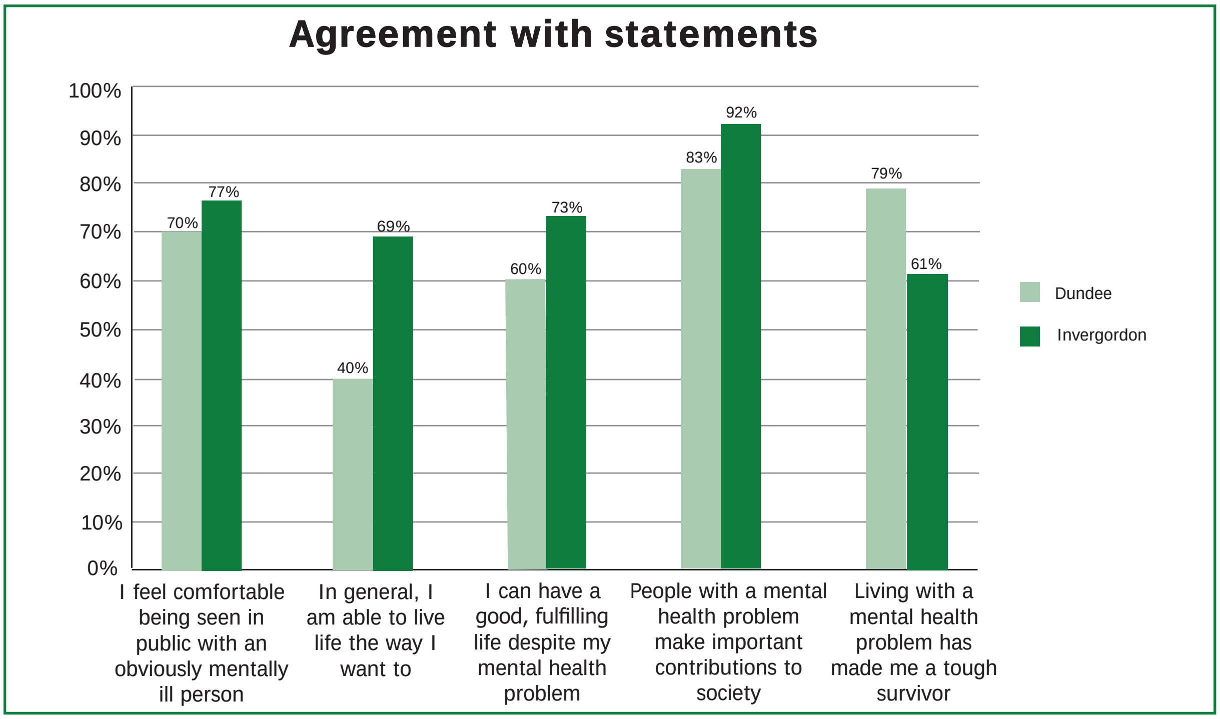
Across all of the individual statements in this cluster we can see lower levels of agreement among the Dundee sample.

Stigma Resistance (All)



(Sample size: 69)

Stigma Resistance (Dundee / Invergordon split)



(Dundee sample size: 43, Invergordon sample size: 26)

Self-stigma Cluster - Stereotype Endorsement

The statements used within the third cluster were:

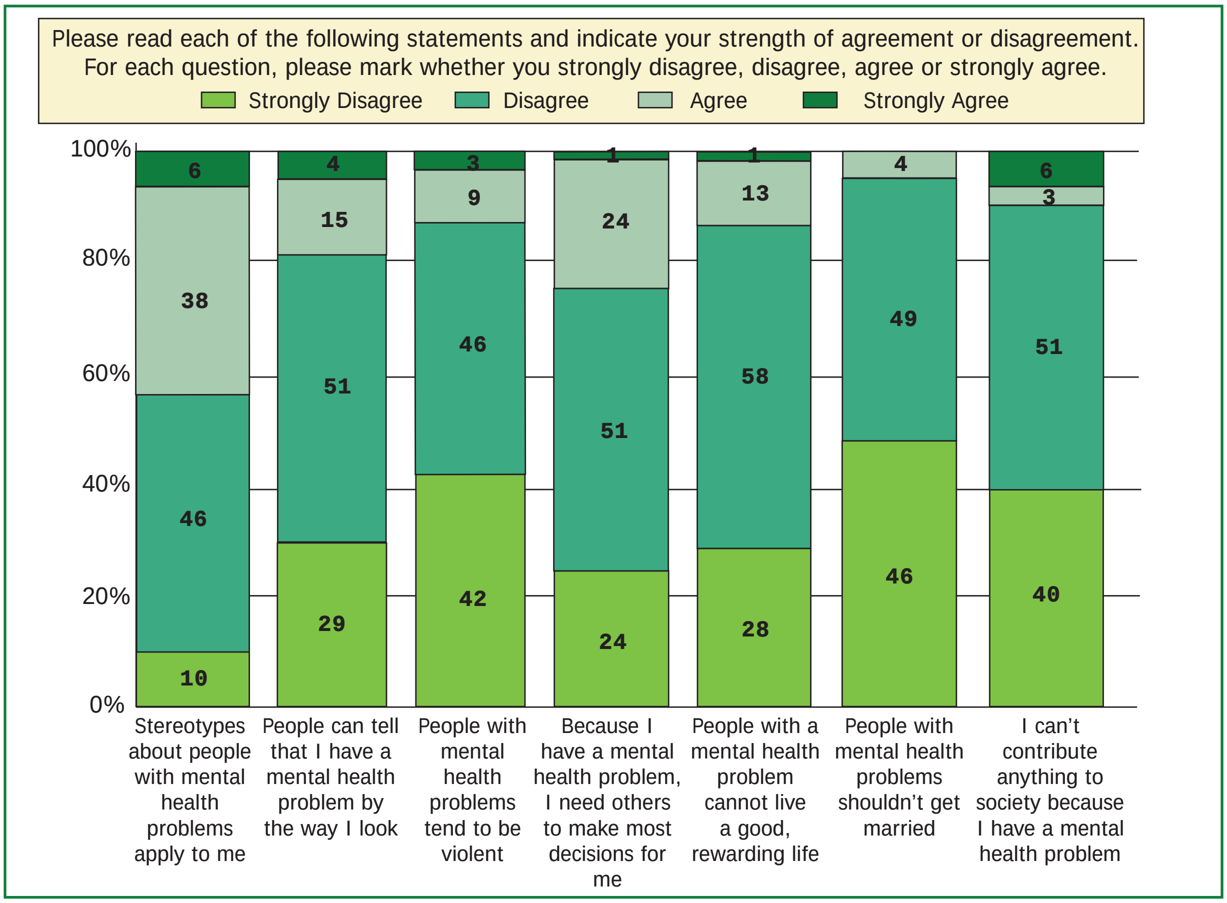
- Stereotypes about people with mental health problems apply to me
- People can tell that I have a mental health problem by the way I look
- People with mental health problems tend to be violent
- Because I have a mental health problem, I need others to make most decisions for me
- People with a mental health problem cannot live a good, rewarding life
- People with mental health problems shouldn't get married
- I can't contribute anything to society because I have a mental health problem

The proportions agreeing with the statements around 'stereotype endorsement' were much lower than in the first two clusters. Here the largest proportion agreeing focused on the statement 'Stereotypes about people with mental health problems apply to me', with 44% of respondents agreeing. In Dundee a greater proportion agreed (47%) than in Invergordon (39%).

The statement attracting the lowest agreement was 'People with mental health problems shouldn't get married', with only 4% agreeing. In Dundee, however, 7% agreed (though none 'strongly' in agreement) compared to 0% in Invergordon.

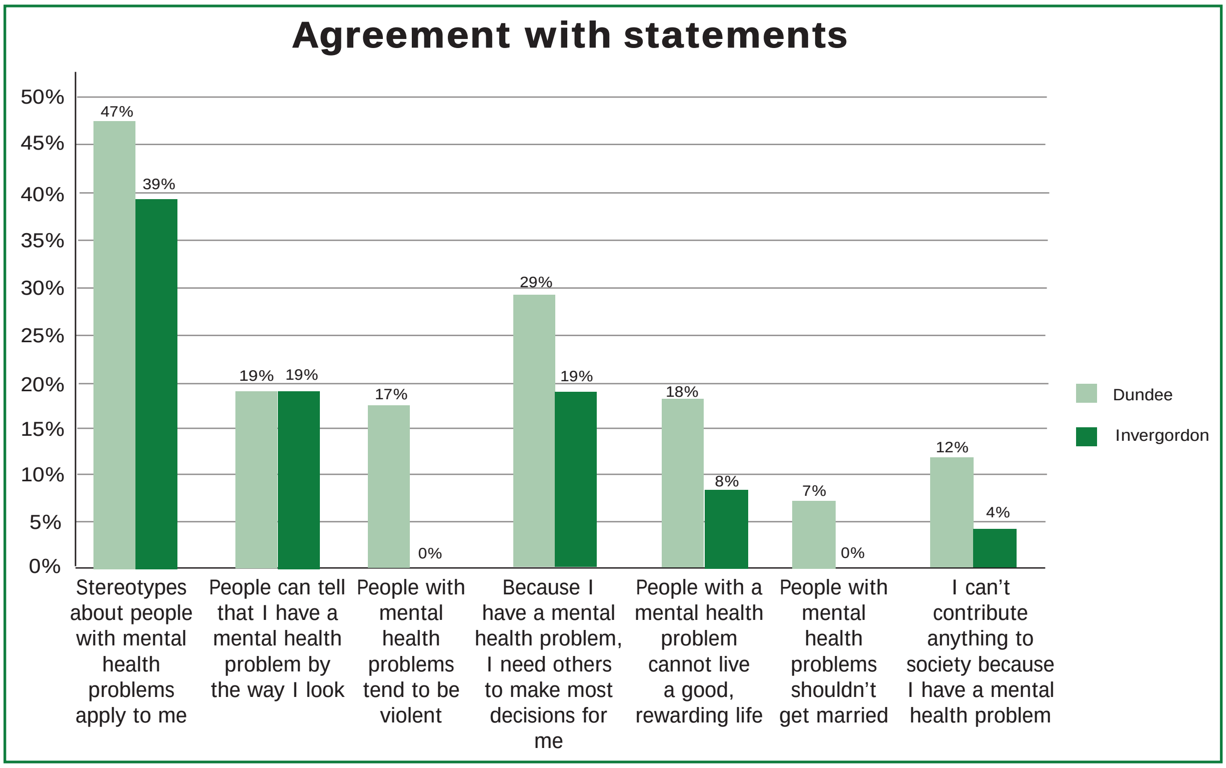
Across all of the individual statements in this cluster we can see higher levels of agreement among the Dundee sample.

Stereotype Endorsement (All)



(Sample size: 69)

Stereotype Endorsement (Dundee / Invergordon split)



(Dundee sample size: 43, Invergordon sample size: 26)

Self-stigma Cluster - Social Withdrawal

The statements used within the fourth cluster were:

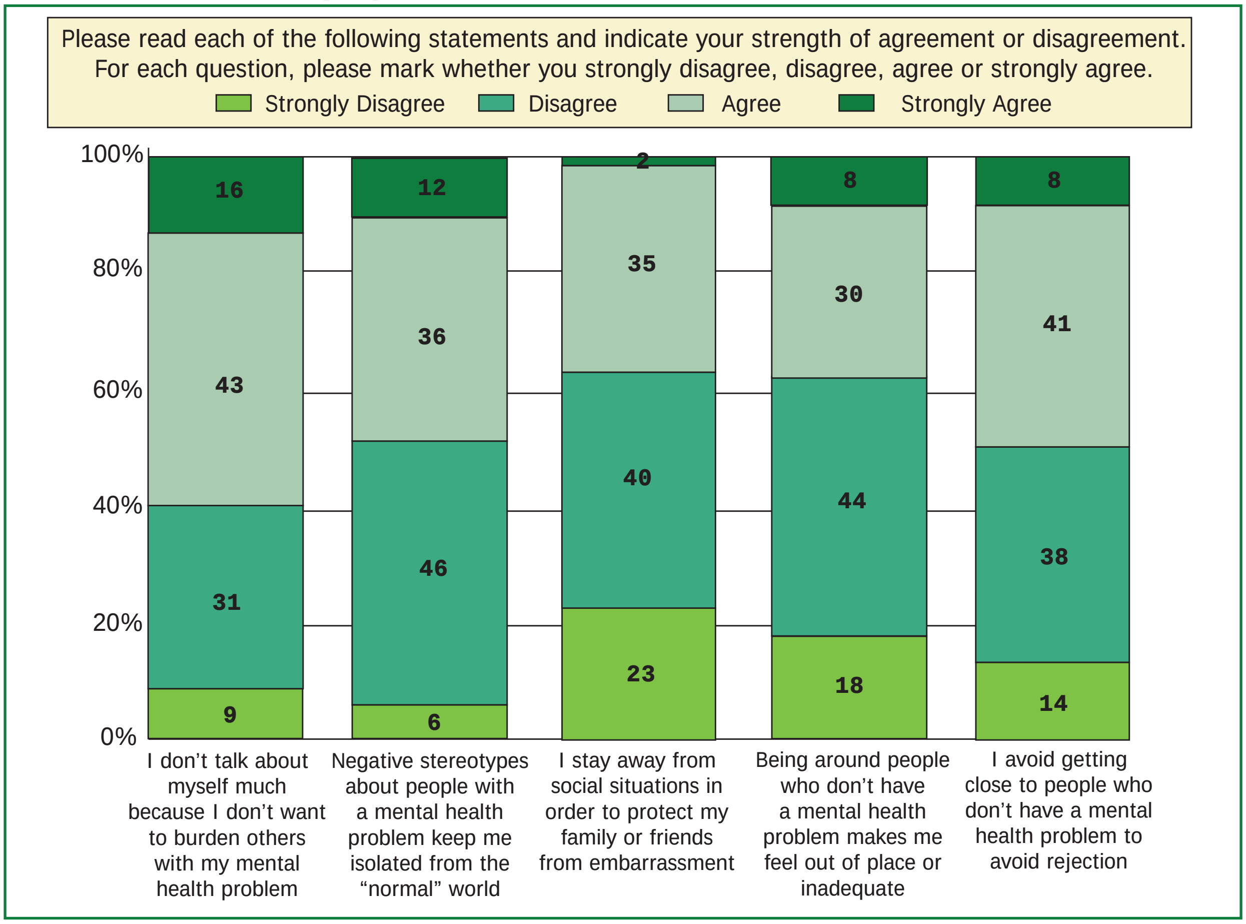
- I don’t talk about myself much because I don’t want to burden others with my mental health problem
- Negative stereotypes about people with a mental health problem keep me isolated from the “normal” world
- I stay away from social situations in order to protect my family or friends from embarrassment
- Being around people who don’t have a mental health problem makes me feel out of place or inadequate
- I avoid getting close to people who don’t have a mental health problem to avoid rejection

The statement attracting the largest level of agreement was ‘I don’t talk about myself much because I don’t want to burden others with my mental health problem.’ Yet again we see a much higher proportion from Dundee (70%) agreeing with this statement compared to only 40% of Invergordon respondents.

‘I stay away from social situations in order to protect my family or friends from embarrassment’ attracted the lowest level of agreement of the cluster statements (37%), though it was very closely followed by ‘Being around people who don’t have a mental health problem makes me feel out of place or inadequate’ (38% agreeing).

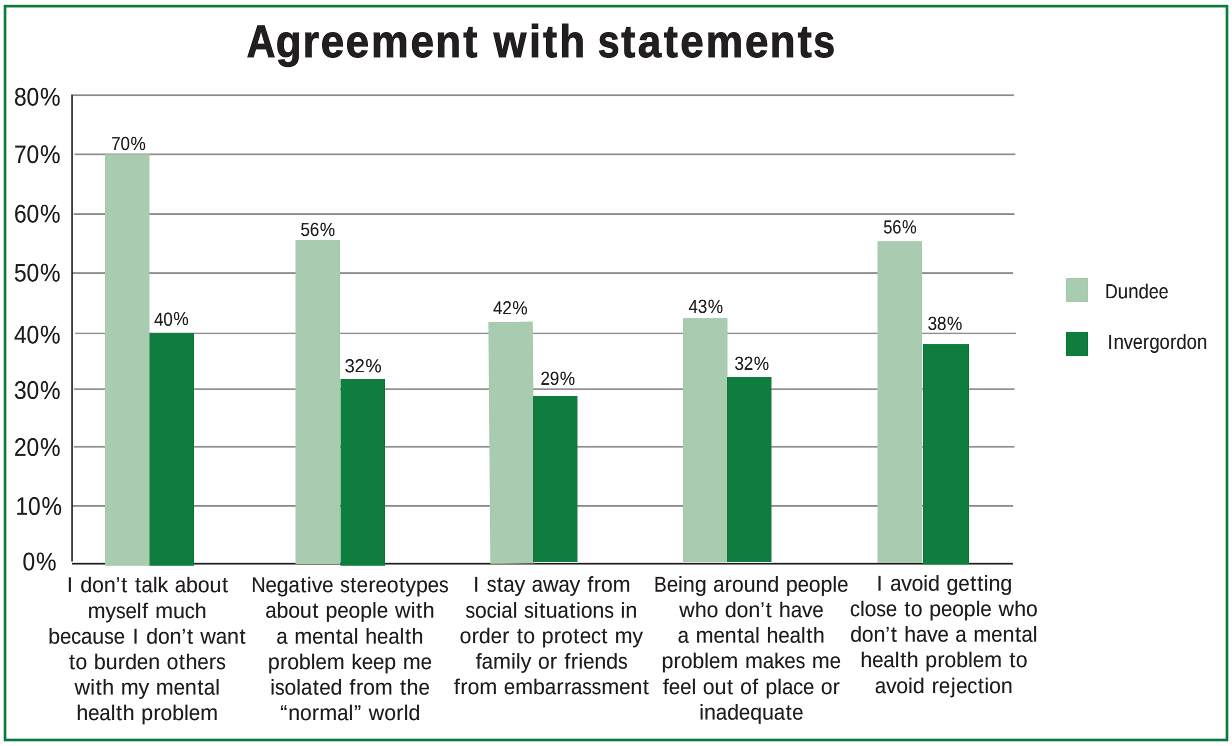
Again, it should be noted that the Dundee respondents were more likely to agree with statements associated with social withdrawal: i.e. in the case of all 5 of the social withdrawal statements, we find higher proportions of respondents from Dundee agreeing.

Social Withdrawal (All)



(Sample size: 69)

Social Withdrawal (Dundee / Invergordon split)



(Dundee sample size: 43, Invergordon sample size: 26)

Summing up

The self-stigma survey generated a number of very interesting, albeit indicative, findings. For example:

- Across the 3 clusters that are directly associated with self-stigma (i.e. Alienation, Stereotype Endorsement and Social Withdrawal) we can see that the stronger associations with self-stigma were in the Alienation cluster. It was here that the highest levels of agreement with the cluster statements could be found.
- Comparing the Stereotype Endorsement and the Social Withdrawal clusters, the levels of agreement with the cluster statements were higher among Social Withdrawal. As will be seen in the next sections that report on the processes and impact of self-stigma as uncovered in the buddy research, social withdrawal emerges as a very strong theme.
- The Stigma Resistance cluster, the only cluster of the four where higher agreement is a positive sign, generated the highest levels of agreement of all of the clusters.
- The differences between Dundee and Invergordon were striking and consistent across the data. In Dundee the survey respondents consistently responded in a way that points to a higher level of self-stigma than is the case among the Invergordon respondents.

> “In Dundee the proportion that felt they could have a good and fulfilling life despite their mental health problem was lower (60% compared to 73% in Invergordon) indicating the greater realisation of the struggle that is recovery.”
>
> The Social Marketing Gateway

- Although, at face value, the evidence may appear to suggest that self-stigma is higher in urban Dundee than in more rural Invergordon and its surrounding area, we would caution against this conclusion.
- Certainly the Dundee sample reported a higher level of self-stigma than the Invergordon sample. But we must be mindful of the small numbers covered, and differences in part of the sample make-up that the researchers observed when carrying out the buddy research.

Processes of Self-stigma

- The stigma that exists in society helps generate and perpetuate self-stigma.
- Self-stigma is more prevalent in people who are aware of society's negative attitudes towards them and feel they are justified.
- GPs, psychiatrists and other health workers can contribute to self-stigma because of low awareness and poor communication at the point of diagnosis.
- When families react negatively to a loved one's diagnosis of mental ill health this can contribute to self-stigma.

One aim of the study has been to gather insight into the processes of self-stigma. Recognising that there are different factors that contribute to the stigma around mental ill health in society, we set out to find out more about the circumstances, settings and relationships that prompt some people with mental health problems to take stigma to heart to such an extent that it fundamentally affects, not only their behaviour, but goes to the core of their sense of themselves.

It is clear from the evidence, and from the experiences of those who participated in this study, that the stigma that exists in society helps generate and perpetuate self-stigma, but it is not the whole story.

The negative attributes associated with mental ill health, and the negative stereotypes commonly associated with different diagnoses, influence the way in which individuals with mental health problems are viewed. These negative associations are sufficiently strong as to have become self-evident 'truths', which are likely to have influenced the beliefs and attitudes of individuals before they develop mental health problems. They may have become embedded long before someone experiences symptoms, seeks help or receives a diagnosis.

When a diagnosis of mental ill health is given, it carries with it the negative associations attributed to it by society, often leading the individual concerned to revise their own sense of identity as a result. As one research volunteer said, *"You downgrade yourself"*.

The extent to which someone is likely to experience self-stigma is difficult to predict. However, self-stigma appears to be more prevalent in people who are both aware of society's negative attitudes towards those who have mental health problems, and who also feel that the prevailing stereotypes and the discrimination that flows from society's stigmatising attitudes are valid or justified. Around one third of people with a diagnosis of mental ill health experience a greater or lesser degree of self-stigma, with a third being unaffected by it and the remainder being galvanised to challenge the stigma and discrimination associated with mental health problems.

> "Feeling judged by other people because of their negative attitudes towards people with mental health problems leads to self-stigma. Self-stigma dents your self-esteem and you hold yourself back as a result."

One stakeholder from the Highland Users Group, interviewed in the course of this research, meets people who say: *"there's no such thing as stigma – by which they really mean that it's not justified and they won't take it on. It's other people's problem, and they shouldn't be damaged by it".* He feels that they arrive at this position, at least in part *"by going back to an old-fashioned concept like acceptance. Some feel that they've got an illness so why feel guilty any more than you'd feel guilty about any other illness?"*.

In this project, the processes of self-stigma were explored through the 'buddy conversation' format in Dundee and Invergordon. In these facilitated conversations, research volunteers were invited to share their views on self-stigma, based on their own experiences. In addition to these conversations, a number of interviews were carried out with individuals whose work makes them well placed to comment on self-stigma. While many of the research volunteers were unfamiliar with the term 'self-stigma' and had not previously discussed it, most were quick to grasp the concept and relate it to their own experiences.

While no two people have identical experiences of self-stigma, there are clearly settings, relationships and circumstances which are influential in determining whether and how an individual might come to be affected by self-stigma. These are described below.

Society

As noted above, stigma around mental ill health in society is seen as one of the main causes of self-stigma. In keeping with what has been found in other studies, the research buddies in Dundee and Invergordon were keenly aware of the negative stereotypes associated with mental ill health. They thought that these stereotypes are widely accepted in society in spite of the fact that they are not only inaccurate but also unfair. One research volunteer said: “*Feeling judged by other people because of their negative attitudes towards people with mental health problems leads to self-stigma. Self-stigma dents your self-esteem and you hold yourself back as a result.*”

The expectation of being ‘judged’ by others is a powerful disincentive to being open about having a mental health problem. It fuels a sense of being regarded as a ‘lesser’ person, whose mental ill health is a source of both blame and shame.

As one research volunteer said: *“Before you become unwell, you are exposed to stigma in society and the negative attitudes that people hold towards those who have mental health problems. When you do become unwell yourself, you know that these views exist and expect that they will be attached to you. This fuels self-stigma.”*

One stakeholder who was interviewed, observed that self-stigma is sometimes fuelled by an unhelpful ‘victim’ mentality. *“Some people rely on victimhood to ‘have a voice’, so it becomes the psychiatrists, media, policy-makers all acting against our interests. Each thing that contributes to that drives us further into victimhood and away from feeling that we can live positive lives, acceptable lives without having ‘enemies’ that confirm that negative identity.”*

> “Before you become unwell, you are exposed to stigma in society and the negative attitudes that people hold towards those who have mental health problems. When you do become unwell yourself, you know that these views exist and expect that they will be attached to you. This fuels self-stigma.”

Unlike the majority of physical health problems, mental ill health is often seen in society as ‘self-inflicted’, ‘self-indulgent’ and something that individuals could overcome if they wanted to. These can be particularly damaging perceptions when they are held by those best placed to offer support and understanding, such as family members.

The strong perceived link between schizophrenia and uncontrollable and unpredictable violent behaviour is deeply rooted in the public psyche, fuelling particularly negative reactions and fear towards those with this diagnosis. One Invergordon research volunteer spoke of being *'terrified'* when she was diagnosed with schizophrenia.

One stakeholder felt that self-stigma is related to the wider problem of the way in which society frowns on the negative aspects of life, with the media in particular promoting the notion that it is only positive emotions that are valid and valued. He observed that: *"The root of stigma is maybe that there are a lot of emotions that society doesn't accept as positive – sadness, loneliness, anger, despair, confusion. We shun people with those emotions. They are associated with mental ill health and a sense of weakness and lack of worth."*

The same stakeholder also spoke of the challenge faced by people with mental health problems in a society that has unrealistic expectations of individuals' capacity to be permanently up-beat. He commented that: *"There is huge pressure to always be positive and happy – it's seen as a measure of someone's worth… It's hard for lots of people to live up to. One of the consequences is that if you're not seen to be this confident, well-adjusted and rational person who can be irrational in a capable way, you're part of the detritus."*

Local community

The local community can both contribute and mitigate to self-stigma. Invergordon research volunteers in particular felt that, while there were some individual instances of discrimination, the community did not contribute significantly to feelings of self-stigma.

One male research volunteer in Invergordon had been called names in the street by local teens, which he felt demonstrated the importance of improving young people's awareness and attitudes. However, other research volunteers more often cited examples of local people and shopkeepers being encouraging and understanding.

While there was felt to be a sense of acceptance in the community in Invergordon, research volunteers were nonetheless 'careful' about being open about having mental health problems. One married couple who participated in the research said that they would not speak to strangers or to their neighbours about their mental ill health as they could not be certain of how they would react. However, there was a sense that this was no different from any other health problem, where you would not share private information with anyone other than those closest to you.

There was some discussion of faith groups both in Dundee and in Invergordon. One Invergordon research volunteer had been persuaded by her minister not to give up playing the organ in church, a role that she enjoyed. She had felt discouraged by the attitude of some of the congregation, whom she felt did not want her around due to her mental ill health.

One Dundee research volunteer deflected questions from fellow worshippers who had asked him what he was going to do after lunchtime prayers at his local mosque on one of the research days. Rather than tell them that he would be re-joining his fellow research volunteers at Kandahar House for the afternoon session, he simply said that he had things to do in town. Both he and the other research volunteer involved in this session agreed that evasiveness of this kind is a tactic that they both use but they did not see it as self-stigma. It was more about not exposing yourself to other people's prejudice or in a positive way choosing to retain some degree of privacy in their lives.

Within the stakeholders' sessions there was also reference to the connections that people with mental health problems have with other touch-points in society. Examples included the police, fire service, local cafes and shops and also with neighbours. These touch-points can be negative as a result of the relative ignorance of people in society.

For example, we heard of one mental health service user who had been asked to get off a bus because the driver did not feel they qualified to use their free bus pass. That said, it was noted by research volunteers in both Dundee and Invergordon that they were also very aware of many extremely positive touch-points in their communities, where local service users are made to feel welcome and supported.

Using services

The research volunteers in Invergordon all received support from Birchwood Highland. This was highly valued and Birchwood was regarded as a 'safe' community within which people could speak about their mental health problems. However, one male volunteer was not comfortable carrying on conversations about personal mental health outwith Birchwood. He commented that he was unhappy when a fellow service user began speaking about their mental ill health at the bus stop where they could be overheard.

The Chief Executive of Birchwood, who was instrumental in developing the research volunteer element of this project, commented that her own organisation had itself in the past not been immune to self-stigma. When she first joined Birchwood several years earlier, staff had been concerned at the suggestion that they raise the profile of their services and put clear signage outside their premises. Now, Birchwood Highland and their services are well publicised, accepted and respected in the area.

The way in which one can be exposed through being known to use particular services was mentioned by another research volunteer, who said: *"I wouldn't tell people that I was going to TAG (a project for people with mental health* *problems) because they would know I have mental health problems."*

> "I wouldn't tell people that I was going to TAG (a project for people with mental health problems) because they would know I have mental health problems."

There were similar issues in Dundee. Here research volunteers acknowledged that they preferred not to be seen going into the DAMH's premises at Kandahar House. As one participant quipped, *"nobody will know I'm going to DAMH. I might be going to Alcoholics Anonymous (in the same building)."* The implication is that there was less stigma attached to having an alcohol dependency problem than mental ill health.

One young female research volunteer commented that she: "*still finds that friends think she works at Kandahar House rather than going there to use its services".* She sees this as itself a kind of stigma, which she interprets as her friends thinking that she's one of their friends – not someone with mental health problems.

Being treated in a hospital setting was also believed to contribute to self-stigma. One research volunteer in Dundee spoke about this. He said: *"Being put in hospital really hit me. There was a stigma associated with being put in a hospital outside of the town. The stigma goes with the hospital. It reinforced taking on all the hang-ups of being mentally ill. It's better to keep people out of hospital whenever possible."*

He felt that the change of emphasis from being treated in hospital to living in the community had helped break down stigma. This participant, a man in his 50s, had a long history of mental ill health and felt more positive about himself now that he was living in the community, taking part in mainstream activities as well as receiving on-going support from a range of services, including DAMH.

> "Being put in hospital really hit me. There was a stigma associated with being put in a hospital outside of the town."

Invergordon research volunteers spoke of their expectation of being shunned by friends as a result of their admission to the psychiatric hospital in Inverness. Some had lost contact with friends in these circumstances, but one man spoke of being pleasantly surprised that friends had visited him just as they would have done if he had been hospitalised with a physical health problem. He said: *"It made me feel still part of the group."*

Medical profession / diagnosis

Getting the right diagnosis and treatment were regarded as important because of the connections that research volunteers made between feelings of self-stigma and the symptoms of their mental health problems; such as low self-esteem, anxiety about other people's opinions of them, lack of confidence and low expectations for the future. However, most of the research buddies felt that the diagnosis itself could contribute to self-stigma.

> “You carry your diagnosis about you like a very negative label. This makes you feel negative about yourself.”

There was some discussion of labelling. The 'label' (i.e. the diagnosis) can become part of an individual's identity, making people feel restricted because of the limitations and negative factors associated with the diagnosis in society generally. One research volunteer commented, *“You carry your diagnosis about you like a very negative label. This makes you feel negative about yourself.”*

One stakeholder pointed out that there needs to be more public debate about the role of diagnosis. He too recognised that diagnosis can be helpful, but that it can also lead people to define themselves according to the label, with all the negative assumptions that go with that.

He commented: *“even if you have the label, you don't need to define yourself with it. For example, when you meet someone new you don't think about how to tell them you've got diabetes. If mental ill health just became an inconvenient part of life it would be better.”*

One female research volunteer in Invergordon talked about how when she was unwell, she thought that people felt negatively towards her when in reality they did not. However, she also believes that she did behave differently when she wasn't well and that this made it harder for others to relate to her. Getting the right diagnosis and the right medication was, therefore, very important to enable her to stay as well as possible.

The medical profession, including GPs and psychiatrists, was discussed in some depth during the 'buddy' conversations. Many of the research volunteers felt that doctors contributed to self-stigma and that they ought to be more aware of self-stigma, better informed and trained to communicate more sensitively and effectively with patients at the point of diagnosis.

What GPs and psychiatrists do at the point of diagnosis can be a very important trigger for self-stigma. One male participant in Dundee talked about a young man who attends Kandahar

House: *"At the point of diagnosis (schizophrenia) this young lad was told there is no hope. 'This is you for the rest of your life.' But if he hadn't been told this, at a time when he was pretty ill, he would not have been put into such a negative state of mind."*

> "Self-stigma should be recognised in the treatment you receive. It should be right up there and there should be appropriate therapies to help. GPs should be more informed."

During the conversations with the research buddies and the focus groups, there was discussion of how and when doctors and psychiatrists informed people of a mental health diagnosis, particularly of a serious condition such as schizophrenia. Given that there is so much stigma and public misunderstanding about this kind of diagnosis, medical practitioners have a role in explaining properly what the diagnosis may mean, but to do so in a way that does not rob people of hope for the future.

GPs' attitudes were seen as contributing to self-stigma. Two of the Dundee research volunteers felt that GPs, by their own admission, do not know enough about mental health problems and that they are *"not very understanding"*. Both said that they had been advised by their GPs to go the internet to find out more about their diagnoses.

Research volunteers spoke of the way in which one's expectations can be lowered when they receive a diagnosis, such as being told they will never work again. Doctors and psychiatrists do not discuss self-stigma or other issues about the social consequences of mental ill health when they give a diagnosis.

> "At the point of diagnosis (schizophrenia) this young lad was told there is no hope. 'This is you for the rest of your life.' But if he hadn't been told this, at a time when he was pretty ill, he would not have been put into such a negative state of mind."

Research volunteers identified the need to get advice on stigma and self-stigma at the point of diagnosis. They stressed that people with mental health problems should be made aware that they may experience stigma and discrimination from others and that they might themselves experience self-stigma as a consequence of taking on other people's negative attitudes. They felt that such a discussion with their health practitioners might help reduce the chance of developing self-stigma.

One research volunteer described feeling relieved to have a name put to his problems – schizophrenia – as it paved the way for treatment. However, while there had been some discussion about what schizophrenia might mean to him on a daily basis, there had been no mention of stigma. He said: *"Self-stigma should be recognised in the treatment you receive. It should be right up there and there should be appropriate therapies to help. GPs should be more informed."*

One female research volunteer had been told by her GP that she could never have children because of the drugs that she would need to take to help control the symptoms of schizophrenia. There appears to have been no discussion of her options. She said: *"I was devastated. I know that it wouldn't be safe to get pregnant when you're on this , but I feel that this could have been communicated better."*

Beyond the specific area of diagnosis, there was mention in the stakeholder session in Invergordon about the perception that many GPs have a 'general fear' about dealing with people with mental ill health issues and the negative impact this can have on GP patient relationships. An example of this was when a service provider was required to assist a GP in carrying out a readiness to work assessment of a service user. The service provider felt that the GP was doing everything they could do to avoid talking openly about the issue of mental health and how it would affect the service user's ability to work. The view of the service provider was that this perceived 'fear' led to the assessment being very poorly carried out.

The individual

Many of the research volunteers recognised that they had to take some personal responsibility to resist internalising stigma. A Dundee research buddy commented: *"See the person not the label – applies to yourself as well as other people. It's important not to label yourself. The 'see me' campaign was very good at getting across the point that people with mental health problems are many more things than just their mental health diagnosis. It's still an important message."*

Two male research buddies in Invergordon spoke of feeling out of place, particularly with strangers. However, they both thought that this was partly due to the symptoms of their mental ill health, which meant that they have a tendency to focus on what people might be *thinking about them* rather than what they are actually saying to them.

The need to try to distinguish between symptoms and stigma was raised by buddies both in Invergordon and Dundee. Being aware of your symptoms, or changes in frame of mind, was seen to really matter.

> “See the person not the label – applies to yourself as well as other people.”

One Dundee research volunteer raised a question about whether self-stigma existed before getting a diagnosis of mental ill health because *“you already feel that you are different from other people”.* Self-stigma was strongly associated by many research volunteers with the sense of ‘feeling different’ and knowing that there was ‘something wrong’ with you. The process of isolation, stemming from suspicions about what other people may be thinking and perceptions that it will be difficult to open up to others, were mentioned as factors that fed self-stigma.

A female buddy spoke of finding ways to resist self-stigma. She said: *“Self-awareness can help give you some control. You can do things to help pull yourself back.”* The same research volunteer felt it was important to recognise when you were beginning to self-stigmatise, which she described as *“a mindset that can lead you to almost ‘attack’ yourself, running the risk of even pushing away people who are trying to help you”.*

She believes that it is possible to help herself by recognising that there are areas of her life which she can control. She said: *“When you put yourself in the ‘illness/can’t recover’ box, that can stop you recovering if you don’t realise that you’re doing it.”*

In both Dundee and Invergordon, research volunteers discussed what they could do themselves to resist the process of self-stigma. One said: *“Trying to feel less self-stigma could be a solution itself because it may be that self-stigma sends out a signal to others that you expect to be treated differently or are less capable than other people.”*

Making an effort to be aware of how they appear to other people was seen by some research buddies as an important way of combating potentially stigmatising attitudes held by other people, which could fuel self-stigma. As one research volunteer put it: *“Some people could be helped to cope a lot better, and sooner. But the person still has to put effort in.”*

A number of the research volunteers spoke of the need to pay attention to personal appearance and good manners as a means of encouraging others to behave ‘normally’ towards them. As one Invergordon participant put it: *“You need to make sure that you dress nicely and speak politely. Then people will not have any reason to be negative towards you*

> “Trying to feel less self-stigma could be a solution itself because it may be that self-stigma sends out a signal to others that you expect to be treated differently or are less capable than other people.”

and you’ll feel better yourself because of it.”

A sense of responsibility to understand others’ attitudes and behaviour towards them featured in the conversations in both Dundee and Invergordon. For some research volunteers, this was an issue of self-awareness and understanding how their own behaviour might be interpreted, for others it was an issue of being empathetic with others. One research volunteer said: *“It’s important to recognise that other people have their own problems and that this affects how they behave towards you. You need to recognise that it’s not necessarily personal to you.”*

Several people spoke of the need to try to prevent self-stigma feeding on itself. One Dundee participant talked about having realised that *“my attitude to myself affects the way that I behave and this in turn affects how other people react. It can be a self-fulfilling situation, where the more someone stigmatises oneself, the more other people will stigmatise you.”*

This view suggests that self-stigma can be a cause as well as an effect of stigma.

> “It can be a self-fulfilling situation, where the more someone stigmatises oneself, the more other people will stigmatise you.”

Age and youth

In Dundee and Invergordon there was discussion of the need to improve awareness and understanding among young people, both to help them recognise and deal with mental health problems that they might experience themselves and also to encourage them not to stigmatise mental ill health.

One conversation in Dundee spent some time considering the differences between older and younger people. The two research volunteers involved in this discussion represented different ends of the age spectrum: one a young woman in her twenties, the other a man in his fifties.

Both agreed that older people generally are less bothered about other people's attitudes, whereas most young people want to fit in with their peers. Peer pressure was a much stronger influence on young people, making it essential to try to promote positive attitudes and behaviours as the norm for young people.

One of the two research volunteers involved in this discussion reflected their shared view that: *"Younger people can be less negative but also have less experience and confidence, which can mean that they are likely to leave you to isolate yourself and do nothing to stop you, whereas older people might not."*

While both research volunteers acknowledged that older people's attitudes could also be negative, the young female participant had found older people to be more willing to 'accept you at face value'. She thought this was because younger people were less sure of themselves and didn't know how to respond. The male participant also recognised this and thought that *"when you're older you're more likely to have known people with mental health problems or experienced them yourself".*

Family

Research volunteers had a great deal to say about how their families' reactions had contributed to self-stigma. There was a strong sense of disappointment and hurt among many research volunteers at the lack of understanding and support they had received from those who were closest to them. One research buddy in Dundee said: *"With the exception of an aunt, I had no support from my family. They just shut the door."*

People talked about the family as ideally being a source of love and support, particularly when facing problems. To some research volunteers, where this fails to materialise, it suggests that even the people who are supposed to love you most do not think that you are worth supporting. That makes people feel worthless. It then follows that other people, who are not as close as family members, will have even less reason to think that you are worthy of their support.

"Looking back the whole experience was so awful. I thought others would agree that I was a bad person - I felt they had a right to think that."

A Dundee research volunteer spoke of her sense of worthlessness when she was diagnosed with mental health problems. In spite of other family members having had diagnoses of bipolar affective disorder and depression in the past, the family reaction was one of 'denial of mental health problems'. She went through a period when her anxiety was such that she feels she prevented her children from leading ordinary lives. *"Looking back, the whole experience was so awful. I thought others would agree that I was a bad person – I felt that they had the right to think that."*

Differing reactions to different diagnoses within families was raised in another Dundee conversation, where one research volunteer spoke of feeling that her family's reaction to her seeking help for her mental health problem was one of resentment. This contrasted to their reaction to her stepfather being off work with work-related stress. Then family members were, in her opinion, much more understanding. This young woman commented that: *"If you're earning and in a job, you're expected to have stress – you're not just seen as a worthless ragamuffin".*

The same research volunteer felt that stigma from other people can make you think that you're not worthy of getting better. She stressed that if you're constantly referred to as *'the black sheep'*, you do internalise an expectation of failure.

A male research volunteer in Invergordon spoke of having turned his back on his family because he felt they *"didn't care"* and were *"not wanting to listen". "Getting caught up"* in his *"own problems"* probably reinforced his negative feelings about himself and the sense that he could not expect help and support from his family. This situation has got better since he started on new medication and is now better able to recognise that his family *"has had their own problems to go through".*

The workplace

There is a wealth of solid evidence to show that work is generally good for us. It gives a sense of worth from making a contribution to society, provides social contact and enables us to generate an income. Having a mental health problem is not in itself a barrier to employment. Many people with mental health problems continue to work through periods of mental ill health, with or without the support of their employers.

The workplace can, however, be a source of stress for any employee. Being in work can exacerbate mental ill health and for some people, particularly those whose daily lives are more negatively affected by their mental health problems on a long-term basis, full-time paid employment may not be an option.

One stakeholder expressed the view that society needs to consider why employment is seen as the only measure of success and worth. He noted that *"people feel no sense of worth because they're on benefits or coming to a HUG meeting. We need to re-examine what contribution actually means".*

One stakeholder, who manages the Working Towards Health Team in Dundee, works with people whose health problems present a barrier to employment. Around 80 per cent of her client group cite mental health problems as the main barrier to employment. She argued that the benefits system itself leads to some people being effectively ‘written off’.

“Health professionals were under pressure to get people to claim health instead of work benefits. People were told they couldn’t work. From a health point of view, if you are told that by professionals, how then do we change behaviour?”

She observed that in the last recession Job Centres were encouraged to get people to claim health benefits rather than unemployment benefits. *“Health professionals were under pressure to get people to claim health instead of work benefits. People were told they couldn’t work. From a health point of view, if you are told that by professionals, how then do we change behaviour?”*

Since then, the emphasis has shifted to focus on what people can do in an effort to encourage more people to get into work. Self-stigma now presents a real barrier. Having been told that they cannot work, and having been living on benefits for a number of years, it is no surprise that individuals do not ‘believe’ that they are capable of getting and keeping a paid job. This stakeholder had carried out training with social work, criminal justice and other services to try to get the professionals to change their mindset from one that reinforced self-stigma to one that enabled them to help clients aspire to work.

With two exceptions the research volunteers who participated in this project did not have either full or part-time employment, due to their mental health problems. However, some had worked in the past. People’s workplace experiences had, in some instances, contributed to self-stigma.

One female research volunteer in Dundee, who currently works part-time, had been open about her mental health problems when she took up her job, but she now questions if this was the right decision. She said: *“My colleagues tend to be over-protective of me because they know I’ve got mental health problems. However, rather than being good for me, it is quite undermining, because it leads me to doubt my own abilities.”*

Other research volunteers who had been in paid employment also spoke of the way that colleagues’ attitudes suggested that they doubted their capabilities, even to carry out duties which they had previously delivered competently. This not only added to self-stigma, but it could become self-fulfilling as loss of confidence undermines the individuals' ability to perform the job.

> "My colleagues tend to be over-protective of me because they know I've got mental health problems. However, rather than being good for me, it is quite undermining, because it leads me to doubt my own abilities."

Impact of Self-stigma

- Self-stigma leads people to lose hope and lower their expectations of what the future holds for them.
- Self-stigma is associated with a sense of worthlessness and failure, low self-esteem and loss of confidence.
- One consequence of self-stigma is social withdrawal from friends, families or places where they had once enjoyed mixing with others.
- Speaking about mental ill health is made more difficult as a result of self-stigma, making it an obstacle to the openness that can help others provide support.
- People can and do fight back, but it is a hard and ongoing battle.

In this section we are concerned with the impact that self-stigma has on people's quality of life and prospects of recovery. We are able to identify a number of themes that appear to be closely associated with how self-stigma impacts negatively on both of these fronts.

A challenge that we need to be mindful of when analysing the information gathered is that the research volunteers, when talking about the impact of self-stigma (i.e. how it made them feel and behave), at times also talked about other bad things associated with their diagnosis. It was natural for them to make this connection: for example people talked about self-stigma making the mental health problem worse and self-stigma reinforcing the negative beliefs they already held about themselves.

The need to factor out low self-esteem as a symptom of mental ill health, when carrying out research into self-stigma, is reflected in the research literature (Link et al., 2001). In reporting on the impact of self-stigma we too have tried to distinguish the impact of self-stigma from the impact of mental health diagnoses.

However, the issues are complex. Self-stigma remains closely bound up with the anticipation of stigma from others, how external stigma makes people feel, how people are affected by their illness itself, and how resilient they are to these multiple negatives.

Downgrading expectations and the loss of hope

A recurring theme, and one that underpins other negative consequences, is the loss of hope and the lowering of expectations about what life going forward is likely to hold. A number of people spoke of how they had lowered their expectations following receipt of a diagnosis of mental illness. In some cases this was in direct response to what they had been told by doctors or psychiatrists. Some had been told that they would never work again, or that they would have the problem for life.

In cases like these, such a negative prognosis (with little or no advice from a trusted professional source about what to expect and do), had proved to be a 'drag' on individuals' recovery. Some people had clearly struggled to prove a bleak and negative outlook wrong, but their recovery process had been harder and longer because of the way that their diagnosis had been communicated in the first place.

> "It has a negative effect on the thoughts that you carry around about yourself. It reinforces your negative thoughts and your ability to do things."

For many of the research volunteers, the diagnosis of mental illness was a significant, negative turning point in their lives. Although some people had 'suspected' that something had been wrong with them, or that they were in some way different from others, it was not until they had received a diagnosis that things really sank in and newer, more negative perceptions of themselves took hold.

People talked about *'accepting the label they had been given'* – i.e. becoming the person they assumed was consistent with the diagnosis. In this respect they were bringing both their own and other people's stereotypes and prejudices together. Some of the older research volunteers stressed that they, not just other people, had carried stigmatising attitudes about mental ill health with them from an early stage in their lives and had simply applied them to themselves following diagnosis.

During the sessions people talked about how the 'label' (i.e. the diagnosis) can easily become part of one's identity. The person then felt restricted because of the limitations and negative factors associated with the diagnosis in society generally. In this way the research volunteers recognised that, while people with mental health problems might not be ill every day, there is a tendency to embrace wider social prejudices and that they were allowing themselves to be defined by their mental health problem.

People talked about the effect that having a diagnosis or label has in terms of *"leading you to question what kind of person you really are".* As one female research volunteer put it: *"It has a negative effect on the thoughts that you carry around about yourself. It reinforces your negative thoughts and your ability to do things."*

Low confidence and self-esteem, a sense of worthlessness and failure

Closely linked to the above is the individual's loss of confidence and a resulting questioning of their ability to do things that would have been normal before the diagnosis of a mental illness. For several of the research volunteers, the negative feelings that had developed had led them to doubt their self-worth and their ability to do things that they had previously been capable of.

> "It totally knocked my confidence. I felt useless. I felt that I couldn't contribute to society at all."

One woman recounted her experience when she was in the process of arranging to become a foster parent through Barnardo's. She had brought up two daughters who were doing well and she was well into the fostering process when her mental health problem was disclosed. She had then been subjected to a lengthy and probing enquiry resulting in her fostering application being rejected.

The impact on her confidence was profound. As she said: *"It totally knocked my confidence. I felt useless. I felt that I couldn't contribute to society at all. Until then I thought that I had been a good mum, but they obviously didn't. I couldn't take the dog for a walk. I felt like I was tattooed across the forehead and that people were saying, 'look at her, she can't even foster'."*

The sense of acute personal failure in the above account was echoed by other research volunteers. Another woman talked about how when she compares herself to the parents of her kids' friends she feels inferior: *"For some reason I feel ashamed of myself."*

Damage to people's confidence can come from many sources, including medical professionals, family and people in the workplace. In the workplace, for example, individuals may feel they are being treated differently or unfairly because it is known that they have a mental health problem. For one female research volunteer who went back to work in a nursery under a 'return to work programme', having been a nurse with over 15 years' experience, the resulting loss of confidence contributed to her leaving the job.

> "For some reason I feel ashamed of myself."

In the above case, the employer's HR staff were aware of her anxiety problems and this filtered through to other work colleagues who started to treat her differently. For example, she was told by colleagues that sometimes she did certain things (like getting up too quickly to deal with something) and that colleagues would attribute this behaviour to her having a bad day with her mental health problem.

Although she did not feel that she was behaving out of the ordinary, this treatment by others gradually made her start to doubt herself and her professionalism: *"It made me feel like I was not as good a nurse as I thought I was. It started to chip away at my confidence to do the job. I stopped doing things that I'd normally do in case people thought I was hyper today. I knew I was a competent nurse, but by the time I left the Unit I felt 'why did I bother getting back into nursing?' I felt undermined. My self-worth was down. You become hesitant and need more reassurance."*

> "It made me feel like I was not as good a nurse as I thought I was. It started to chip away at my confidence to do the job. I stopped doing things that I'd normally do..."

This individual also suffers from chronic pain. She believes that because her physical pain is understandable to others, it is easier for people to relate to her depression. This helps her manage how she feels about herself (i.e. less apart and less misunderstood): *"Because I've got an illness attached to it, I don't feel so bad. Others can see they would be the same and get depressed as well. It's like having a physical illness makes the mental illness more genuine."*

It seems that a low self-esteem (which in itself does not necessarily constitute self-stigma) can develop into more profound internalised negatives, such as the person feeling that their whole life has been a failure. A number of research buddies talked about a sense of being a failure within the context of their close family. Indeed, sadly in some cases, it appears to have been provoked and reinforced by the actions of family members themselves.

One older man with a grown-up family, who has managed after many years to get his life back on track, still sometimes feels a failure when he thinks about his children: *"I still sometimes see myself as the weak link. I say to myself 'I couldn't have done that'."*

Another research volunteer attributed much of her negative self-perception to how her mother treated her. She felt her mother didn't trust her and that she was not worthy to be her daughter: *"You just* *see total rejection. You feel that you are a failure. My Mum was saying 'I've had ten kids and everyone is in a job except you'."*

> "...it's hard to give yourself credit because of the poor self-image you carry about."

Once it takes hold, low self-esteem and a sense a failure can be very hard to break free from, even where external encouragement is forthcoming. Research volunteers commented that even when encouragement and praise exist, the way that you see yourself can make it very difficult to accept it. For example, one woman's consultant has repeatedly told her that she should see it as an achievement that she manages to get up, get dressed and do the dishes when she is not feeling well. But this does not stop her frequently telling herself: *"No, everyone does this."* In other words *"it's hard to give yourself credit because of the poor self-image you carry about".*

Certainly feelings around inadequacy and worthlessness seem to be common. One woman talked about how she is often withdrawn even when people are reaching out to her: *"I don't want people asking me how I'm doing because I don't think I'd be of interest to people. They have jobs and interesting lives. I think 'why would they be interested in me?'"*

Modifying and changing behaviour

A loss of confidence, growing self-doubt and a worry about how others are going to act can often lead to people changing or modifying their behaviour. During the research conversations we uncovered many examples of people choosing not to do things that they did before, and perhaps could and should continue to do.

> "It's like you know that there is more to yourself, but you are frightened to show it. Even when I try to be more assertive I still feel that people don't hear me. I go back inside my shell because that's where I feel safe."

One woman gave the example of despite realising that she can push herself forward and speak up at work, she often holds back from communicating and saying the things that are on her mind. She recalled an occasion when she had felt that she could not cope during a trade union meeting: *"I felt I couldn't say this or that because people would feel I'm stupid. It's like you know that there is more to yourself, but you are frightened to show it. Even when I try to be more assertive I still feel that people don't hear me. I go back inside my shell because that's where I feel safe."*

Several research volunteers spoke of difficulties when going into unknown situations or of avoiding them because of being unsure or anxious about how they would cope, or of how others would react. This could reflect symptoms associated with their condition (e.g. people being irrational or paranoid about what others might think). Anticipated stigma could also be at work, with people holding back because they expect to be on the receiving end of external stigma and discrimination. However, in other cases people seem to have lowered their expectations of themselves as a consequence of internalising stigma and feeling less worthy because they have a mental health problem. They were altering their behaviour because of this.

Withdrawal and social isolation

A fairly strong feature of people's lives, certainly at points in their past when their self-esteem and confidence has been particularly low, is social withdrawal. People decide not to put themselves into otherwise 'normal' everyday situations and/or withdraw from things that they would otherwise do and derive benefit and reward from.

> "It's often easier to walk away so you can protect yourself and potentially them from being worried."

A wide range of examples of activities that people had stopped or thought about stopping were highlighted, such as: socialising with friends; taking the kids out to play; doing the shopping; playing the organ in church. They were withdrawing from and avoiding everyday activities that call for social interaction and that contribute to the quality of people's lives.

For some research volunteers who reported that they had withdrawn socially as a result of how they felt about themselves, it appears that at least two defence mechanism drivers might be at work: self-protection and protecting others.

The first defence mechanism is where people feel they are 'protecting themselves' from what others may think, say and do if they find out they have a mental health problem. In other words they are anticipating and protecting themselves from external stigma and discrimination. But, in some instances, this 'external stigma' can be relatively soft or benign, such as where others are over-protective, and do not let a person with a mental health problem take on what might be seen as more stressful roles for fear of exacerbating their mental health problems.

The second defence mechanism is feeling that, by withdrawing, they are in some way 'protecting others' from being worried or uncomfortable about how to respond to a person with a mental health problem. They are, therefore, avoiding a problem that they feel other people would have to deal with before it happens. In this case they are still perceiving themselves to be the cause of the potential problem.

These two defence mechanisms are possibly closely linked and may frequently coexist. For example, they are certainly evident in the following statement: *“It’s often easier to walk away so you can protect yourself and potentially them from being worried.”*

On balance, it seems that the first of these two drivers (i.e. ‘protecting yourself) is the dominant one of the two. One research volunteer talked about being “*terrified*” of his friends finding out about his past and how his fear of being rejected by them has caused him to pre-empt the possibility by social withdrawal: *“You ask yourself, should I tell them? I might as well push them away now so I will get hurt less in future.”*

Another research volunteer frequently decides not to participate in social activities when he is experiencing particularly negative feelings. He cited one recent occasion of a neighbour’s wedding that he and his wife had been invited to: *“I said no instantly without even thinking about it. Actually I was saying that I didn’t want to socialise with people. It is as if you are choosing to be different.’”* He explained this in the following words: *“Thinking negative scenarios can make you feel distant at times. You think people don’t like you so you cut yourself off.”*

> “Thinking negative scenarios can make you feel distant at times. You think people don’t like you so you cut yourself off.”

Again, in the above example, we are seeing the erosion of self-confidence and self-belief underpinning a process of social withdrawal that will probably be compounding the individual’s low opinion of themselves.

In some cases, as illustrated by the next example, the social exclusion involved can be severe, hugely debilitating and long lasting, all but cutting people off from society and possible sources of support.

One woman’s story covered a period of close to a year when she hardly ever went out: *“I was frightened to let the kids out even though they were driving me up the wall. I thought unimaginable things might happen (to them). They even had to play skateboarding in the hall. It would have helped to have had some family and friends to provide* *support. Even someone to go round the shops with would have made a big difference."*

Her illness meant that she did not feel able to take her daughters out and do the normal things that mums do. This struck at the heart of her perception of herself as a good mother. At the time she had found herself thinking: *"You are so bad to those kids."* Although this woman has managed, with some help from others, to get her life back on track she sometimes thinks back to that period and, even now, often still holds very critical and negative perceptions about herself.

Pushing forward – countering social withdrawal

While social withdrawal was certainly a widespread pattern, a number of the research volunteers made the point that social withdrawal was neither uniform nor consistent. It can easily become a habit – the default position – but it can also be confronted and overcome. It was clear that a number of people, being aware that they have a degree of control of their recovery process, consciously choose to 'push themselves forward' into situations that, while they may still find them difficult, they know will benefit them in the long run.

One research volunteer, who had frequently cut himself off from social activities, has made a real effort to push himself to confront his fears. He has become active in a local band, playing guitar and singing. He also signed up to be Santa Claus, although did not realise exactly what it would involve, with long hours meeting and greeting local children. But he saw it through, and the experience of making children happy was very rewarding. He plans to do it again even though he realises that he will have to make another big effort to force himself and push back against the self-stigma that drives social withdrawal.

> "You cut yourself off and it's a struggle to fight against it. You need to push yourself and there should be more of an understanding of this from others. I want acceptance, but to get it you've got to ask for help and push yourself out there."

Other research volunteers echoed this message and talked about the benefits of *"doing things for other people"*, whether it be helping local charities sell raffle tickets, befriending someone going through a hard time, or a range of other examples. It was important for a number of the research buddies to have found voluntary activities that they could do to help others. It was rewarding work, helped rebuild confidence and self-worth and appeared to be a critical ingredient in the recovery process.

Breaking free from the ‘default position’ and pushing oneself forward was, for many people, a hard task. As one woman commented: *“You cut yourself off and it’s a struggle to fight against it. You need to push yourself and there should be more of an understanding of this from others. I want acceptance, but to get it you’ve got to ask for help and push yourself out there.”*

A few other research volunteers talked about how they felt they had to excel – how they had to push back and be better than others around them at work, in college or among peers – in order to justify to themselves that they deserved to be ‘part of the group’ or to ‘blend in’. But there also seemed to be another reason for this extra effort: i.e. to stop people looking at them too closely and possibly spotting that they were ‘different’; that they had a mental health problem.

For instance, one of the younger research volunteers spoke of her fears that her new group of friends would reject her if they found out that she has a mental health problem. Many agreed with her when she went on to describe how she felt that she has to out-perform colleagues in the workplace to overcome low expectations of her own abilities.

The Openness Dilemma

Many of those who took part as research volunteers felt unable or unwilling to be open about their mental health problems. In some instances, when they had been open they had felt the better for it, but there were also accounts of where being open had caused people difficulties. Indeed, most had experienced external stigma and discrimination in a variety of settings, such as the bank, at university, the job centre and on city buses where it was probably known or suspected that they had a mental health problem.

One woman, for example, talked about her bad experience at the local Benefits Office where an aggressive Disability Officer asked for far too much information and reduced her to tears. She says: *“I dread to go near these places now.”* In response to this account, several people in the same focus group said that they expected the new ESA interviews would be *“a nightmare”*.

While it is not surprising that some people choose to keep their mental health problem to themselves, many also fe a continued anxiety about not disclosing and/or fear the consequences if people find out. The choice of whether or not to be open was a dilemma that many of the research buddies had experienced first-hand. It is one factor that seems tightly bound up with self-stigma.

An individual’s anxiety over exposing themselves and being open about

> “I’m not prepared to show them the book, so how can they read it? But if you’re not prepared to open up and tell, then you just reinforce the self-stigma.”

their mental ill health was often based on negative experiences in the past. Several of the research buddies had personal stories to tell about how being open about their mental health had caused them problems and difficulties, and in some cases had made it difficult for them to continue with their normal life.

One young woman recounted an experience when she was at University. She was encouraged to tell the University services that she had a mental health problem. A lecturer then put in an official complaint that this could be dangerous for other students which led to a risk assessment of her being carried out. She believes that the simple step of being open and honest: *“threw all this stuff into motion that meant everyone found out about me”.* Consequently she felt really uncomfortable and exposed with a negative knock-on impact on her studies.

Largely because of bad previous experiences, another male participant explained that when he was in a social situation where he did not know anyone else, he often felt *“very uncomfortable to the point of being openly nervous. I have been virtually shaking with fear at the prospect of people finding out. You feel that you do not know how people will react and you assume their reaction will be negative. You feel this way because of how people have reacted in the past”* (i.e. negatively).

> “People would talk about you, but not to you, they wouldn’t involve you in things. They’d make you feel like an outsider.”

Not surprisingly a number of research volunteers were somewhat ambivalent about the question of whether or not to be open about their mental health problem. They found it appropriate to characterise this as a kind of ‘Catch 22’ situation. As one individual said: *“I’m not prepared to show them the book, so how can they read it? But if you’re not prepared to open up and tell, then you just reinforce the self-stigma.”*

The down side of not being open was fairly widely appreciated. People recognised self-stigma as something that makes it hard for them to speak to family members, friends or others they socialise with. There was a clear distinction here between a mental health and a physical health problem. Research volunteers admitted that they would be more likely to speak to people about a physical health problem, so that others would be able to understand and be supportive.

People talked about work, educational or service settings all as places where one tends to protect oneself because having a mental health problem can give other people an excuse to criticise or bully you, or simply just to treat you differently. One participant commented about his experience in the workplace: *"People would talk about you, but not to you, they wouldn't involve you in things. They'd make you feel like an outsider."*

Others cited examples of attending projects or activities specifically for people with mental health problems, but not telling their friends where they were going because they would then know they had a mental health problem. In this respect they were participating furtively while keeping their mental health problem to themselves. While most research volunteers could identify with this behaviour, some did question whether this form of non-disclosure is really an example of self-stigma.

A number of people recognised that they engaged, at least on occasion, in furtive participation or evasiveness of some kind about having a mental health problem. Most saw this as merely a tactic that they used. It was not really considered to be self-stigma, which people regarded as being much more serious and limiting. People tended to see evasiveness, or keeping things to themselves, as mainly a response to anticipated discrimination and not wanting to expose themselves to other people's prejudice.

Nevertheless, in many respects, it was the fear of negative reactions from others that made it harder for people with mental health problems to be open and disclose that they have a mental health problem. This, in turn, makes it difficult for them to have discussions with people who can potentially help and who know about what living with a mental health problem means and what makes things better or worse.

However, several research volunteers resisted the suggestion that they 'should' be open, or the presumption that it is their responsibility to tell people about their mental health. They backed this up by making the point that it is not common to tell people about physical health problems unless there is good reason to do so (such as being unable to participate in a game because of injury). So, why should people have to be open about their mental health, particularly given the history of stigma and discrimination that they have experienced?

Positive responses to self-stigma

Many of the research volunteers were

on some form of recovery pathway, although for some it had taken several years to move in this direction. People agreed that self-stigma made the mental health problems that they were living with worse, and recognised that dealing with self-stigma was integral to the more general recovery process.

For many, dealing with self-stigma was, however, not an easy or linear process. People reported having recurring episodes of self-loathing and self-doubt. As one of the older men in the group put it: *"People fail to realise that just trying to get well is hard work in itself."* To this, a female research volunteer added: *"And it's hard to give yourself credit for trying because of the poor self image you carry about."*

That said, many of the research volunteers were able to point to coping strategies or other factors that had helped them mitigate self-stigma and move forward on a recovery path. Even so, they stressed that the recovery process was a hard battle and one that has to be continually fought.

> "And it's hard to give yourself credit for trying because of the poor self image you carry about."

Concluding Discussion

Self-stigma is widespread among people with mental health problems.

The self-stigma survey of mental health service users in Dundee and Invergordon provides a range of evidence for this:

- Almost two-thirds felt that having a mental health problem had spoiled their lives;
- Some 59% were disappointed in themselves because they had a mental health problem;
- Some 44% agreed that stereotypes about people with mental health problems applied to them; and
- Some 59% didn't talk much about themselves because they didn't want to burden others with their mental health problem.

The research volunteers we engaged with could understand the idea of self-stigma. It was a problem that continues to blight many of their lives and holds back or disrupts recovery.

Building the evidence
The findings from the research echo a number of themes in the wider literature, such as:

- Stigmatised *'illness identity'* can become dominant, with people accepting the labels that others impose and *'defining'* their core identity by their diagnosis;
- People often accept discrimination by others because, with a lowered view of themselves, they *'perceive the discrimination to be legitimate'*;
- Service users can experience a sense of shame and a feeling that their mental ill health should be kept secret;
- There is widespread loss of self-confidence and self-esteem as a result of self-stigma (our research links social withdrawal closely with this);
- Self-stigma is not inevitable – people can become empowered, push back and develop their self-efficacy; and
- The protective role of the peer group (of other mental health service users) in reducing stereotype agreement is important in creating a social environment conducive to recovery.

In addition, our research uncovered other insights not drawn out from the literature, e.g.:

- People modify their behaviour to avoid disclosing their mental health problem and behave in ways that would not project outward signs of their illness;
- People feel strongly that they themselves have a responsibility

to battle self-stigma and make a real effort to improve their self-esteem and build a more positive sense of themselves; and

- People acknowledge that self-stigma can be a *cause* of external stigma through the signals that self-stigma can send out to others.

Complexities of self-stigma

The issues that surround self-stigma are complex and multifaceted. People with mental health problems are well aware, and probably have been on the receiving end, of society's stigma. Many shrug it off and get on with their lives. Others are negatively affected in a range of potentially interconnecting ways.

People may anticipate stigma, because they have been socialised to expect it or, as is very likely, because they have had first hand experience of it. Others may be experiencing stigma from a number of possible fronts: e.g. family, the workplace, the community or the media. Whether the stigma is anticipated or real, both can make people feel bad about themselves and may lead to them altering their behaviour as a result. Added to this is the fact that feeling bad about themselves can be a direct consequence of people's mental ill health.

These scenarios are not necessarily evidence of self-stigma, but they can all contribute to it. The wider dynamics of stigma and mental ill health increase the risk that people will start to blame themselves for how they feel or how they are perceived by others. They may see themselves as different, apart or defined by the labels that society attaches to their mental illness. And, they may perceive themselves as being less worthy and diminished as human beings as a result.

It is important to bear in mind that this research project was a pilot study. There is a risk in drawing too many conclusions and firm recommendations from a limited research exercise. Further research is needed to better understand and identify self-stigma and its relationship to other forms of stigma (e.g. anticipated stigma) and to recovery.

Further research

There are a number of areas that could usefully be researched including:

- A study that examines the processes whereby information is communicated to people about a diagnosis, especially in relation to the roles of GPs and psychiatrists;
- A qualitative study of those people who 'resist' self-stigma processes to try and identify factors that support resilience and recovery;
- An action research project that pilots and evaluates the impact of an Ending of Self-Stigma (ESS) group programme;
- A literature review of multi-cultural factors that influence the process of

self-stigma;

- A qualitative study in Scotland of people's experience of self-stigma in the context of minority communities.

Moving forward

While there is an immediate need to learn more about self-stigma, there is an ongoing challenge to collectively do something about it. During the research, we heard from many people with mental health problems that self-stigma can be tackled, and that they themselves can take responsibility and push back against it. We were also told that it's a hard and ongoing battle.

People with mental ill health feel that they can do things to resist self-stigma, but it is not a battle that they should be fighting alone. They need support and many other organisations have a role to play. This is a battle that needs to be fought on a broad front:

- Across society there are many bodies that can influence the climate of stigma around mental ill health and have a key role in fighting misconceptions, discrimination and stigma in society, wherever it comes from;
- Organisations that provide services, in both public and private sectors, need to ensure that front line staff are aware of self-stigma so they can interact with people with understanding and sensitivity;
- Service providers that deal directly with mental health service users – crucially professionals and practitioners in the health sector – need to be more aware and have a better understanding of self-stigma;

In Scotland we have a good platform to build from. In recent years, mental health and other organisations have developed an impressive set of responses to tackling the stigma of mental ill health and supporting recovery. This body of policy and practice will be further strengthened by fresh insight into, and a new priority around, self-stigma.

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Pushing Back

A pilot study on self-stigma in Scotland

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