



Age in Mind

Mental health stigma
and discrimination
in later life

A LITERATURE REVIEW



Introduction

This literature review is intended to provide a snapshot of issues relating to stigma and discrimination in Scotland of people over 50 who identify as having mental health difficulties.

Literature relevant to this specific group proved elusive and relevant findings were mainly limited to short sub-sections of more generic literature relating to either older age or mental health, stigma and discrimination, rather than all four.

Limitations of the review

Of just over 100 reports and documents reviewed, a total of 40 reports relating to older age or mental health were found to discuss issues of relevance.

Reviewed information was limited to:

- Scotland only research and documents
- UK wide research and documents inclusive of Scotland
- International research inclusive of Scotland.

Literature reviewed generally related to people either over 60 or over 65. Some reports covered all ages, including people over 50.

General and self stigma within society

Several studies established a generalised experience of discrimination by participants.

The Scottish Recovery Network (1) referred to an overarching discrimination emanating from society's general view of people with mental health difficulties, due to the predominate use of the Medical (or Charitable) Model of Disability by service providers offering mental health care and support (as well as in everyday life), as opposed to the more human rights based Social Model.

Nine out of ten people with mental health difficulties said that their lives have been affected by stigma or discrimination and that this had stopped two thirds of them doing things they would otherwise want to do – including the one in four older people who have symptoms of depression severe enough to warrant intervention. The Foresight Project, *Mental Capital and Wellbeing One-Year Review* (2) concluded that stigma surrounding mental ill health has a negative impact on all parts of a person's life, leading to a significant cost impact.

Well Scotland (3) reported that *'age discrimination is the most frequently experienced form of prejudice for people in later life and... challenging ageist public attitudes and related discrimination needs to be at the heart of mental health improvement in this area'*.

Age Concern (4) described a common experience of self stigma where older people seemed to have become used to discriminatory experiences and that this had resulted in them limiting their personal horizons or lowering their expectations of their own role and participation in society. The study described participants being denied appropriate medical support and statutory exclusion from accessing certain mental health related benefits because of their age (eg. Disability Living Allowance). This was significant because the same study described the interlinks between increased poor mental health as a result of losing their working roles at just the age they became too old to claim DLA. Many participants struggled to identify whether they had had poor experiences of services or circumstances, or whether discrimination on the grounds of age and/or mental health had taken place.

In their consultation work regarding psychological interventions for older adults, Age Scotland (5) found variation in the role stigma played in mental health in people under 75 in comparison to those aged 70-75 upwards. For those under 70, fewer stigmas were associated with mental illness as people were more freely able to discuss their mental and emotional health.

“older people who have mental health difficulties risk being seen as ‘less than’ other members of society”

Within the group, people over 70 felt that social taboos and stigma around mental health were strong. The common everyday words used around mental health such as stress or depression had negative or stigmatising associations to a generation whose measure of self-worth seemed to relate to their ability to cope. People of this age were often ‘embarrassed’ to seek help or to talk to family or friends about this for fear of loss of status and esteem, or of appearing ‘weak’.

The stigma of mental health applies to older people who have dementia for whom the difficulty of adjusting to the diagnosis is compounded by the fact that they now come under the umbrella of mental health services and are identified as having a mental health condition (6).

These attitudes of stigma and self stigma were found by the Mental Health Foundation (7) to be most commonly cited as coming from those closest to people, such as family and friends, the workplace, GPs and other health care professionals.

NHS Scotland (8) reported that older people with whom they consulted perceived that there was a strong sense of a lack of respect for older people and that ageism, in today's society, impacted on the way they were treated by health and social care professionals, as well as by employers.

Elizabeth Collier and Natalie Yates-Bolton (9) note that older people who have mental health difficulties risk being seen as ‘less than’ other members of society and that this has been identified as a global problem by the World Health Organisation.

Stigma and discrimination in the form of unpleasantness from random people in local communities was seldom mentioned in studies of older age and of mental illness. Hate crime figures released in Scotland for 2015 – 16 reported 201 incidents against disabled people, a statistic which constitutes only a very small percentage of total hate crime (10). It is not known if any of the examples provided referred to crimes specifically against people with mental illness. However, caution must be applied here, as disability related hate crime continues to be even more under reported than other forms of hate crime and reporting opportunities may sometimes be under-stated by mental health services.

Service discrimination (including employers)

Despite the fact that the Equality Act 2010 (11) made age and mental health (disability) discrimination in public sector services illegal from October 2012 in the provision of (or refusal to provide) goods, facilities or services, health and social care services were generally seen to be applying age restrictions to mental health services for older people. For example, the Faculty of the Psychiatry of Old Age of the Royal College of Psychiatrists (12) describes how services such as crisis intervention, home treatment and mental health in-patient services are often only provided through adult mental health services which people over the age of 65 do not necessarily have access to, including so called 'graduate patients'.

A roundtable discussion in Dumfries on January 24, 2008 to consider the Scottish Government's *Toward's a Mentally Flourishing Scotland* (13) raised issues about the lack of focus on older adults, specifically the lack of resources and age appropriate care and support, as well the withdrawal or reduction of a previously provided service.

Although Scotland's Mental Health Strategy (2012–2015:43) recognised that 'more older people experience illnesses such as depression and anxiety than experience dementia, and that there is a need to better respond to their needs', this has not been recognised equitably in funding regimes (14). The Strategy promised to address inequalities of psychological service provision for older people experiencing mental illness. However, despite acknowledging achievements in recent years, the report, *Improving Access to Psychological Therapies* (15) recognised that there are still particular challenges and gaps between mental health services for older people compared to those under the age of 65 despite the expectation being that NHS services should be provided on the basis of clinical need alone, regardless of age. Updated figures published in June 2016 indicate that people over 65 remain less than half as likely to be referred for psychological therapies as the general population (16).

Older people themselves raised concerns that where resources are finite and services differentiated by age, it is more likely that services for older people will receive reduced levels of funding and care, including mental health services (17).

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The Department of Health (18) in its review of ageism and age discrimination in mental health care in the United Kingdom recognises the issues of discrimination and inequity faced by older people with mental health difficulties stating that neither depression or any other mental health problem is a natural or normal part of ageing, but that there is evidence that older people can experience discrimination and inequity in access to and availability of mental health services and therefore experience poorer quality of care.

The Scottish Perspective on NICE public health guidance (19) noted that 40% of older people attending GP surgeries and 60% of those living in residential institutions reporting to have 'poor mental health', discrimination, relating to age or culture was highlighted as a reason for the low expectations of professionals towards them.

Audit Scotland (20) found for every half time psychologist post for over 65's, there were 6.7 full time equivalent psychologists for adults aged up to 64, and that the Royal College of Psychiatrists (21) had called on the government to urgently address inequalities in mental health services generally, and in particular, in older people's services.

Sometimes what is excluded from literature can be as relevant as what is included. This can be seen in the key framework (which most mental health nurses currently practising in Scotland would have been trained under) as there is no mention of stigma or discrimination despite data from the last two decades showing high percentages of people with mental health difficulties as having experienced stigma.

Discrimination by services was not seen as being confined to the NHS and many people found their support services withdrawn when they reached 65 (22). Quoting participants in a survey by Crown (2007, Review) people described being 'kicked out' of drop-in centres because of age.

However, this literature review also found that provision of differentiated age based services could not automatically be viewed as discrimination. The Equality Act (2010) (23) allows for the provision of services being differentiated on the ground of age if an objective justification can be evidenced. Although no clear objective justification was raised in any of the literature reviewed for differentiating services, some researchers did question whether replicating service design for younger adults is the best solution for people over 65.

In a UK wide survey of 371 (45%) trainee clinical psychologists (24), whilst acknowledging that discrimination did exist in access to services, they felt that clinical psychology had less to offer older people.

Elizabeth Collier and Natalie Yates-Bolton (2011) took this a stage further raising concerns that specialist mental health services for older people, a relatively new development, still used classification of mental illness as it had been categorised for people in younger age groups. However, the understanding of the symptoms of eg. clinical depression were not developed in the context of older people with the accompanying complexities and implications of ageing processes and physical illness, or both. They identified continuing discriminatory and dismissed attitudes from service providers for older people which focussed on providing care, rather than meeting aspirations, as being the problem.

Participants in a roundtable discussion in Dumfries in 2008 on the Scottish Government's *Towards a Mentally Flourishing Scotland Policy and Action Plan* (25) recognised the need for differentiation in services, feeling that the focus on services for older people needed to be on preventative work to address the reasons which were causing them to become depressed.

The Scottish Government's Mental Health Strategy (2012–2015) promised to address inequalities in access to employability for people experiencing mental illness (26). However, no literature could be found which described ways of addressing the discriminatory barriers to employment for older adults with mental health difficulties.

It is anticipated that the Scottish Government will publish its new mental health strategy towards the end of 2016.

Multiple discrimination

Multiple discrimination is a cross-cutting issue affecting many people as groups which are stigmatised in other ways also tend to have higher levels of mental health difficulties.

The notion of 'double disadvantage' was expressed where older people with mental health difficulties subject to additional discriminations eg. both ageism and racism, were actually more than doubly to be affected by their experience of multiple discriminations. This broad principle was recognised by participants in the previously referenced Help the Aged/Open University report who reflected that discrimination was usually felt more by 'people who have a lifetime of discrimination' but it has also been recognised in studies regarding a number of other groups, including:

- People who have additional physical health needs or disabilities (27)
 - People from older Lesbian, Gay, Bisexual, Transgender groups also faced mental health related stigma, particularly for gay men for whom practice of their sexual identity was illegal before the Sexual Offences Act 1967 and whose sexuality led to them being deemed to be mentally ill by mental health services (28)
 - People from Black and Minority Ethnic and Refugee communities, where older people from Black and Minority Ethnic communities may be even less able to access services, partly because of language, but also because of discriminatory barriers such as professionals assuming that people from Black and Minority Ethnic communities are always able to look after their own (29).
- or**
- where general racial discrimination was recognised to take place (30) (31) and (32).
- or**
- where service design or gender based violence posed barriers to inclusion of minority groups (33)
- Gender issues, where barriers can lead to failure to recognise the different risk factors and mental health problems (34 especially for women, for whom discriminatory assumptions and stigma have resulted in many older women being silenced in their need to attain freedom from abuse (35).
- or**
- for those where the service attitude is to prioritise risk management and focus on what an older woman cannot do, leading to discriminatory barriers for those older women with mental health difficulties (36).
- People in prison or who are homeless, or people with learning disabilities who have a major predominant service need by which they are identified results in a form of discrimination through the failure to recognise them as whole people with other needs, leading to them being less likely to have mental health difficulties addressed particularly when older (9).

In theory, health and social care integration may lead to more holistic practices (37), however, we await the outcomes of this change and, in any case, not all excluded groups are high users of health or social care services.

Although the Scottish Government's Mental Health Strategy promised to address inequalities of service provision, it appears that collating basic data about ethnic background and other information, for example, monitoring of gender, sexuality and disability, which would provide a basis for identifying inequality gaps, has not even become a requirement (14;26).

Specific issues

Even within groups of older people with mental health needs, studies indicate that some groups face greater discrimination than others.

Suicide

A study of suicide in Scotland (38) recognised the role stigma plays in the suicide of older adults. Anti-stigma initiatives such as the 'See Me' campaign, can perhaps be credited as part of a possible contribution to the recent reduction in the suicide rate in Scotland, with the greatest reduction being in the suicide rate for older people.

Psychotic illness and schizophrenia

Support in Mind's study (39) indicated that even within mental health, there is a hierarchy of stigma, citing in particular society's perception that people living with schizophrenia and psychosis are dangerous and violent. There is a predominance of news stories referencing schizophrenia in this way.

Despite discriminatory practice being known to play a part in reducing the life expectancy of people with Schizophrenia by 15 years compared to the general population, local and national strategies do not propose anti-discrimination strategies to overcome this issue (40).

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Conclusion

This literature review has been valuable for two main reasons. Firstly, it reaffirms how little research and evaluation there is about older people's mental health, with the exception of dementia, and an even lesser amount about stigma and discrimination in relation to mental health, particularly for older people who, it can be argued, can be affected by stigma and discrimination in mental health and ageism. Much of the literature available precedes the introduction and implementation of the Equality Act (2010). We have therefore found it difficult to make any meaningful correlation between mental health stigma and discrimination **and** ageism or age discrimination, but we accept that either can be a cross-cutting theme for the other.

Where we were able to identify how service planning and delivery continues to impose age capping on service eligibility or 'transition' from adult services into 'old age psychiatry' thereby constituting a form of structural discrimination, we believe that by undertaking a qualitative enquiry this may lead us towards a better understanding of how health and social care attitudes and behaviours have greater impact on individual older people, particularly in terms of self-stigma development.

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Age in Mind: Mental well-being for people over 50

Age in Mind, a three-year project to challenge mental health stigma and discrimination of people over 50 in Scotland, is a collaborative partnership between the **Scottish Mental Health Cooperative** (a company comprising of many of Scotland's local mental health organisations) and **See Me**, the national campaign against mental health stigma and discrimination.

Action in Mind, the local mental health organisation working across Stirling and Clackmannanshire, leads this national project, under the auspices of the Scottish Mental Health Cooperative, and is working across four project sites in Scotland, supported by the Project Management Group.

The key objective of the Age in Mind project is to identify one or more issues of stigma and discrimination that affect older people's mental health and well-being and to create positive outcomes through the creation of change networks in each of the project sites in Scotland. At the heart of the project, and central to each change network, are older people with direct experience of mental ill-health working together with local organisations and services.

The Age in Mind project will report on its findings and outcomes in October 2017.

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