SeeMe
End mental health
discrimination

See Me response to Independent Review of Adult Social Care, November 2020

See Me is Scotland's national programme to end mental health stigma and discrimination. Our vision is to enable people who experience mental health problems to live fulfilled lives. We are working to change negative attitudes, behaviours and cultures towards mental health by creating a movement for change, bringing people together across Scotland who are passionate about tackling stigma to work as one.

We are contributing to this report because we know the vital role that good social care can play in reducing experiences of stigma and discrimination for people with experience of mental health problems. In particular, we would like to emphasise the potential importance of self-directed support (SDS) for people with experience of poor mental health. As the Self Directed Support Scotland / the ALLIANCE report *My Support My Choice* (2020) notes: "[i]f adequate, person centred support is provided, there are clear benefits of SDS to people's mental health and relationships. However, poorly conducted SDS processes and reductions in support can have a negative impact on people's mental health."

With regards to the ongoing review, we would like to point you towards the following documents that we have found useful in formulating our positions on stigma and discrimination within social care and more generally:

- Audit Scotland, *Self-directed Support: 2017 progress report* (2017)
- Carers Trust, *My Future, My Feelings, My Family: How Coronavirus is affecting young carers and young adult carers, and what they want you to do next* (2020) [this report includes research on the impact of COVID-19 on young carers]
- Health and Social Care Alliance Scotland, *Personal experiences of Self-directed Support* (2017)
- Outside the Box, *Self-directed support and mental health: Paper 3 Practice* (2017) [this report highlights barriers to accessing self-directed support for people with experience of mental health issues, and includes recommendations for practice]
- Pilot Light, People Powered Health and Wellbeing, Scottish Co-production Network, *Case Study: Co-designing a pathway to self-directed support for people who have mental health problems* (2014)

- Scottish Human Rights Commission, *COVID-19, Social Care and Human Rights: Impact Monitoring Report* (2020) [this report shows that a considerable proportion of people who use social care support at home have experienced either a reduction or complete withdrawal of support during the COVID-19 pandemic]

- Scottish Human Rights Commission, *How has coronavirus affected social care and human rights?* (2020) [easy read executive summary]

- Self Directed Support Scotland and Health and Social Care Alliance Scotland, *My Support, My Choice: People's Experiences of Self-directed Support and Social Care in Scotland* (2020)

- Stigma Free Lanarkshire, *Caring and mental health: A survey of carers in Lanarkshire* (2019) [this report highlights unpaid carers' experiences of mental health stigma and discrimination]

- Inclusion Scotland, People-Led Policy [webpage on how to ensure that decisions on policies affecting disabled people are informed by the lived experience of disabled people and their carers]

We would also ask you to consider the following points on mental health stigma and discrimination:

MENTAL HEALTH, STIGMA AND DISCRIMINATION: GENERAL POINTS

- People with experience of mental health problems continue to experience poorer health, educational, employment and social outcomes than the Scottish population as a whole. The stigma and discrimination they face within various public and private settings, including through social care services, contributes to this.

- People often describe the stigma they experience around their mental health through services such as social care as worse than the initial diagnosis of a mental health problem.

- Stigma and discrimination can be exacerbated when poor mental health is coupled with a protected characteristic such as LGBTi or BAME identity, a sensory impairment, or a disability.

- There is also evidence that stigma and discrimination is more pronounced for people diagnosed with severe mental health conditions.

- Social care and self-directed support should be rooted in human rights, principles of mental health inclusion, equalities and equity, and a person-centred approach.

ISSUES WITH MENTAL HEALTH STIGMA AND DISCRIMINATION IN SOCIAL CARE

- Some people with experience of mental health problems report stigmatising and discriminatory behaviour from social care providers. According to the SDSS and ALLIANCE report *My Support My Choice,* "several people reported that health and social care professionals stigmatised people with experience of mental health problems and disregarded their preferences around social care arrangements." Case studies referred to include that of a service user who told their social worker they had attempted suicide due to the physical pain they were experiencing and were told not to "be silly and that it cant be that bad" (53-54). The report notes that "targeted work is required to ensure that people with experience of homelessness, black and minority ethnic people, people with experience of mental health issues and LGBT+ people do not experience discrimination or inequality when accessing SDS."

- There are also issues around lack of choice in social care for people with mental health issues, which can constitute a form of discrimination. Audit Scotland's 2017 progress report on self-directed support (see above) notes that: "not everyone with support needs is getting the choice and control envisaged in the SDS strategy. This includes people with mental health problems, who often need more flexible support,...some people feel they have been denied the opportunity to access more effective ways to improve their quality of life" (11).

- Self-stigma – which can be caused or exacerbated by other forms of stigma, and by discrimination – may also prevent people from accessing or making the most of the social care services they need. Self-stigma could have a particularly negative impact on the likelihood of people engaging with SDS; reductions in structural stigma (stigma created through organistaional policies, practice and procedures) would have a positive effect on any such dynamic.

- People with experience of mental health issues may know less about the option of self-directed support than other groups. Research included in a 2017 report by the ALLIANCE Personal experiences of Self-directed Support found that: "noone with a mental health issue indicated they know a lot or feel very informed about SDS, compared to 35 per cent of those with a physical disability, 64 per cent of those with a learning disability and P39 per cent of those with both a learning and physical disability.” (p21) and "Around one third of respondents who identify as having a mental health issue have not talked about SDS with a social worker." (p63)

APPROACHES TO REDUCING MENTAL HEALTH STIGMA AND DISCRIMINATION IN SOCIAL CARE

- One way of reducing experiences of stigma within social care settings would be to ensure that Community Care Assessments do not feel pressurising, judgemental, or too ‘high-stakes’. This might mean allowing people to include family, friends, or advocates in the assessment process, giving options around location and form of contact (face to face, phone, online, etcetera), not making decisions on single meetings, and ensuring that the social care workforce involved in assessments – and in general – is adequately trained to recognise and respect mental health issues and respond in ways that best meets the needs of the individual. In this respect, we would direct the review board towards the section of SAMH’s review response on “access to social care and assessments.”

- Peer support accessed via social services can help to tackle self-stigma, as the following case study from the Self Directed Support Scotland and the ALLIANCE report *My Support My Choice* highlights: “[my social worker] started suggesting groups that I could go to so that I wasn’t on my own all the time. It would be peer support with people who also have mental health; people with lived experience. So, I went along […] and it took me a wee while to settle in, but I settled in. And it was very helpful.”

- The ALLIANCE report also noted that “most people would appear to find out about SDS through personal interaction”. Therefore, to resolve the relative lack of knowledge of SDS options amongst people with mental health issues, "social work departments should prioritise direct discussions about SDS with people who access services during any contact about reshaping their support. Particular attention must be given to this in mental health settings.”

- Workforce development should include social contact; introducing all staff to the realities and experiences of living with mental health problems doing so can reduce myths and lead to a significant reduction in prejudice. Training should also incorporate a focus on diagnostic overshadowing, by which legitimate mental health concerns can be belittled or written off as subsidiary to other issues – from disability to economic adversity – that claimants may be experiencing.

- It's also important to highlight to social care providers the value of lived experience, and the need to listen to care service users, their families, carers or advocates in order to place a care package that will work for them.

CARE PROVIDERS

- The review must consider the mental health stigma and discrimination experienced by people providing social care, as well as by those receiving it, including, crucially, those offering informal or unpaid care.

- Social care workers are under high pressure and their own mental health (and physical health) should be protected and supported, both at their workplaces and outside the office, for example when providing home visits. It is important that the social care workforce feels confident and informed to respond openly and compassionately to the people they care for, and to help them with their own mental health.

There are specific issues associated with unpaid carers that the review should take into account. For example, young carers (including adults 18-25 years old) may have difficulty accessing employability services and education. STRUCTURAL STIGMA AND POLICY CHANGE

- Structural stigma – the way in which the norms, rules, policies, and practices of institutions and services restrict the rights and opportunities of people with mental health problems – must also be borne in mind. Commitment to end mental health stigma needs to be embedded in policy and practice nationally and locally, and greater use should be made of the policy, political and legal drivers and levers available to influence change.

- See Me's experience highlights there is great value in involving people with lived experience in the design ,development and implementation of policies and practices that affect them. Their access to and experience of the service they receive is significantly improved and their personal outcomes more likely to be achieved as a result