This submission to the Equal Opportunities Committee on Age and Social Isolation has been made by AdvoCard Community Collective Advocacy on behalf two service-user groups: Community Voices, an open collective that campaigns for positive change in relation to mental health services and related issues for service users living in the community, and trainees who attend the SAMH service of Redhall Walled Garden.

The qualitative research material in this submission has been collected / collated and written up by members of these two groups; it has been edited by the AdvoCard Community Collective Advocacy Development Worker to fit the required format.

Social Isolation: issues for mental health service users - and in particular, the isolation and loneliness faced by ‘self carers’

Forsman et al (2012)¹ argue that being engaged and proactive in maintaining social contacts enhances mental well-being in (older) people. Work undertaken by a collective advocacy group of mental health service users has identified that lack of social contact is a critical issue for all mental health service users, of all ages, as there are already many barriers to regular socialising and increased/increasing social capital that are both regulated and perpetuated by stigma and discrimination.

The research done by Community Voices² identified that for many mental health service users – and particularly those without regular and casual interaction/s with partner, family and close friends - access to socialising and increased social capital are minimal and often confined to contact with staff working for service providers and/or other service users.

What defines a self-carer?

Although this submission includes issues of social isolation faced by mental health service users of all ages and situations, the focus of the Community Voices work has been on ‘self-carers’ – those who have chronic mental health issues and who have no default informal support: no family, partner, friends or social mechanism automatically available to support them.

In terms of social isolation, the reality of being a self-carer is that their emotional and/or practical needs are often unfulfilled and there is no-one outside service provision to ensure that the service-provided support that self-carers require is available to them. This applies both when an individual is relatively well and able to function socially as well as when they are ‘in crisis’ - although many service users


are unable to recognise when they are becoming unwell, so if someone is socially isolated, their deteriorating condition might go unnoticed until it escalates to a critical point (or indeed, until that person has taken critical action that might include self-harm or suicide).

**Prevalence of social isolation in urban and rural settings**

Everyone who contributed to the discussions live in urban areas. They are aware that there are likely to be some different issues for people with mental health conditions who live in rural areas but also believe that loneliness can be felt when someone is in a crowd as well as when someone is isolated.

**Impacts of social isolation, for instance loneliness, ill-health**

For the self carers who participated, the key issues of the impact of isolation included

- being a self-carer compromises care because the fact that there is no one to help and support them is not taken into account; this leaves them isolated and vulnerable
- isolation and loneliness has a significant detrimental impact, particularly as they are already managing their conditions and facing stigma and discrimination. This is especially true when people are faced with a crisis or when they go home after a stay in psychiatric hospital, when so much has to be put in place and organised as without a partner or family to support them, they are, quite literally, 'on their own'
- self carers felt that there needed to be greater understanding, recognition, and support for - most people with a carer/family have basic support – just the simple things of meals and drinks being made, opportunities for support being researched – but there is nobody who does that for self carers – and no difference in understanding and/or adjustments made to address the greater need of self carers.
- not everybody with a mental health condition is able to recognise when they are becoming unwell – for many people, their carer/s, family and/or friends will see when someone is becoming unwell but self carers living alone might go under the radar and their mental and physical health may suffer as a result
- self carers are more likely to miss appointments as they are isolated and have no regular unpaid support; this can lead to issues with health providers who understand them to be wasting time and resources
- more people with mental health conditions are now living in the wider community rather than in institutions or supported housing – there has been little (nothing?) done by the authorities to ensure that people with mental health conditions are accepted into the wider community, understood by the wider community and encouraged to participate in the wider community as active citizens.

Self carers are likely to have low incomes – this means they may not have access to the hardware required for digital communication (mobile phones, computers/laptops/tablets) and/or may be unable to afford internet service provision; this means they are unable to access information portals and appointment booking systems, unable to participate in online surveys or engage in social media. This is hugely isolating in a society that increasingly relies on and utilises the internet for communication
• Self Directed Support can be more isolating/divisive for those who live alone/are self carers.

• need for services and the wider community to have a greater understanding that it is hard for someone to admit they can’t do things and that service users fear that they might not be taken seriously

• there needs to be a much greater understanding and appreciation in wider society that not everyone has ‘someone’ (partner, close family) to support them and that loneliness and isolation is a key issue for service users - social contact is vital to human beings, and it is painful and difficult just living/existing in isolation: quality of life is important to mental health service users too!

• there is currently a lack of a single dedicated source of information about social support, opportunities for volunteering, jobs that welcome applicants with a mental health condition, collective advocacy groups and peer support groups – this needs to be addressed (positive discrimination is needed for this)

**Best practice and ideas that could be shared across Scotland, including examples of targeted support or initiatives (including housing, health, third sector)**

• initiatives that enable the service user to be the person in charge of the review or meeting, so enable the service user to be (and feel like / be recognised as) and active participant in their life and treatment and to diminish the feeling that they are ‘just’ a passive recipient/consumer of services. Once a person feels that they have more power in and control over their own life, they are more able to speak out for themselves and engage in the wider community

• wider practice of social prescribing:

• collective advocacy; people who attend the various Advocard-facilitated groups have described belonging to a collective advocacy group in the following ways

  “being with like-minded people in a group where you can share ideas and concepts…people who want to work together to improve things that are unfair or wrong is very validating”

  “it boosts your confidence, being among other voices. Out there (in wider society) you are just one little voice but with collective advocacy you come together as many voices creating one loud voice…and that is empowering because you are standing up for yourself. Being in a group like this…well, it all becomes a shared thing…we all thought we were on our own with the things we were dealing with…but together we can be extraordinary and achieve so much. Being united gives us strength”

  “…and then I found this collective thing…a community, people with shared experiences who are like minded and united with wanting to change things for the better for people like us…otherwise we would be quite solitary…hiding away with our mental health condition…it is hard to feel part of something good but this does it. People don’t always know about collective advocacy. It should be better promoted…but that means more funding. Somehow the powers that
be need to let everyone know that people like us can be part of something really good…really strong"

“this is a fellowship where you don’t feel judged”

“being part of collective advocacy can be very cathartic…here lived experience is valued and that can be life-changing because you realise you are not alone”

“on your own it is unbearable as everything goes unnoticed (by other people) so you hide away even more…you feel shame. With mental health issues you come from a very isolated place as a self carer but collective advocacy is a place, a forum for your voice and somewhere that you know you are valued”

“there is something about being part of something, taking on something bigger than your own issues that diminishes your own issues and puts them into perspective…you realise it is not ‘just you’ …that there is a fellowship and a camaraderie…somewhere you belong”

“collective advocacy is not just about the group…it can open up a whole new world and bring opportunities to create a circle of friends”

“It does help to belong to something and there is often nowhere that you fit in…so collective advocacy is a lifeline”

**Potential ideas for improvement and influencing policy**

- “Self-carers” should be recognised as a specific category - like Patient and Carer already are; the additional needs of self carers need to be recognised, accepted and legislated for at local and national level by the NHS, by government and local councils and by all support services including third sector providers
- the Self Carer category should be included in strategic documents and more consultation done with self carers to ensure that the right policies and action plans are developed
- the information from mental health assessments should become more centralised and accessible to the different professionals involved (GP, CMHT, Psychiatrist and other support services) to ensure that isolation and loneliness are understood to be an issue and thus factored into the way that self carers are treated and supported – for example, “self carer status” should be highlighted in notes and care plans
- development of a ‘one stop shop’ for the mental health support system where people can feel confident that they will get the appropriate support for their clinical, emotional and practical needs from a human being, not an Internet resource.
- More investment and development of ‘social prescribing’ that links people up to activities in the community that they might benefit from / connecting people to non-medical sources of support.
- there needs to be positive discrimination to ensure that self-carers are included into the communities where they live and enabled to be active citizens
- include service users / collective advocacy representatives at high level meetings in NHS and government to ensure that service users, who are a very
marginalized group feel included in the decision making processes that determine their lives; positive discrimination needs to start from the top!

- bringing children with learning disabilities and those with (well managed) mental health conditions together in effectively managed environments – to have fun, make music, play games, have hugs

**Effective awareness-raising within communities**

- anyone in office or in a high profile position who has had a mental health issue speaking out about it to make people with mental health conditions less stigmatised and discriminated against in wider society
- higher visibility to the wider community of the achievements of those who have mental health conditions (SMAFF to be covered on TV more etc)
- far simpler apps than Ginsberg!
- education about mental health throughout schools
- balancing the “don’t talk to strangers” message with information on what loneliness feels like and how it can affect people

**Individual statements from self-carers**

Self carer #1: T

I remember in the couple of months run up to attempting suicide in March 2014 saying to my once-a-week support worker that I’d realised that the only people I saw/spoke to from week to week were paid to see me or were the most casual of contact: grandmother who works in corner shop, the postman, pharmacy staff. It doesn't do much for your sense of ‘self’ and self-worth, the idea that no-one interacts with you unless paid to!

I was trying to cope with social work assessments and being told that there were funding issues. When I called MHAS, I was told “get myself to Royal Edinburgh Hospital” - yet as someone living alone and in deep distress, I could not even work out how to cross the room in my flat, never mind manage public transport. After eventually being seen at the hospital, I was discharged home alone whilst still amnesic. As a human being, you are utterly isolated in that situation – and for me, personally, no-one seemed to take account that I was alone at home, vulnerable and feeling as if nobody cared.

I have learned that being a self-carer with a fluctuating condition and who is not working means you are isolated and that being isolated means there is no 'cushion' …so that if I am going through a bad patch, there is nobody who can just do a bit more for me for a few days. Always having to be responsible even when you can barely articulate your own needs.

I used to work full-time, have hobbies and social life – but being a victim of workplace bullying left me without support from work colleagues; when disciplinary action began, I was banned from any contact with work colleagues, which meant I lost my support network. I became ill and when my sick pay went down to 50%, I could not keep up other friendships as couldn't afford to join them in the usual social activities like going to the pub, seeing a film or theatre production or going out for a meal. I felt that I could only spend time with other people who don’t
work/have similar health problems. And during Christmas and New Year, services close for holidays – so while everyone else is out having fun, you get a single support service visit in two weeks.

I also found that you can be in a busy place and still feel very alone e.g. in a coffee shop where most people are in groups and you only have contact with staff and your solo status is highlighted by the social groups around you.

Self carer #2: L

Over the years I have become aware that having mental health issues can make people feel more isolated and lonely compared to others.

This is true even although you may be involved with many different groups and projects, where you may make friends through the common bond of experience. But in society, there is still an attitude of ‘us’ and ‘them’, which isolates survivors of psychiatry, even if they do mix with others, they won’t be regarded as peers.

Survivors and self carers walk a fine line between isolation and loneliness. Feeling remote even though you are involved and mixing with others, and also the feeling of sadness that is caused by the deprivation of friendship due to living on your own.

Self carer #3

I became a widow at a very young age when my husband committed suicide. I also lost my home and savings, all which went to repaying debts run up by my husband before he died. I became very depressed and socially isolated – I think people find the idea of being around someone who has lost someone close to suicide very scary. They don’t know what to say to you and cross the road when they see you coming.

Having lost my home and all my savings and developed depression, I could not work. I also lost all my support...my personal and professional social capital - old friends did not want me around – the women thought I would try to steal their husbands, the men thought I was too needy (or needy enough to want to sleep with them); the few single girlfriends that I had just wanted to have fun and didn’t want to be dragged down by someone in mourning and becoming increasingly mentally and emotionally damaged and vulnerable.

I went back to university to try to get a higher level vocational qualification and build new relationships but most of the students were youngsters who were just out to have fun (not that I blame them) and didn’t want some 30-something depressed woman hanging around with them. I was self-caring all this time as I was 500 miles away from my mother and sisters; they had never liked my husband so they had little sympathy for my situation. I managed to get my degree but then found that nobody wanted to employ me because of my history of mental health problems. Nobody every offered me support to find the right job or to find a social group that might help and I often has suicidal feelings – but I knew how devastating it is when someone you love takes their own life and I couldn’t do that to my family even though they were not supporting me.
It took a very long time to find a job and even though I now work part time and see people at work every day, I am still very isolated and often feel very lonely because I cannot share how I am feeling with workmates – it is too intimate and I know people will judge me and think I am too needy to be their friend.

Being isolated and lonely can have a horrible domino effect on a life – the more lonely you are, the more other people think you are needy and will want too much from them. So they will be pleasant to your face but will not invest in any real friendship with you.

I wish there was a way to bring all the lonely people together without it looking like a club for freaks – everyone deserves to have a hug each day, everyone needs some social contact to understand themselves in relation to the world. But everyday I wake up and know that it is another lonely day.

When I discovered [the project self carer #3 attends] about two years ago, though, I felt I had finally found a community where I felt I was part of something. I recently became involved in collective advocacy too, which is very empowering.

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