A submission on behalf of

HUG (Highland User Group: action for mental health) acts as a voice for people with a mental illness in the Highlands; HUG (Action for Mental Health) is part of SPIRIT* Advocacy

SPEAK/this is me: a project of HUG and is a voice for young people in the Highlands about mental health

User and Carer Involvement, Dumfries and Galloway

Acumen: a support network that enables mental health service users and carers in Argyll and Clyde

The Mental Health Foundation / VOX a National Mental Health Service User Led organisation

Part II of submission: THE VIEWS OF THE HUG THURSDAY THINK-IN

We discussed the issue in a Thursday think-in group; involving 8 people of whom 6 were over 50 and came up with the following thoughts: Overall, we think this is a major issue for people with mental health problems. We have just run a recent round of HUG meetings looking at the support needs of our friends and relatives and at each of the 12 meetings held so far a substantial number of the participants said that they did not have any relatives or friends with whom they were in meaningful contact.

Isolation and Loneliness have been identified as a feature of many of our lives because of the following key issues

geography

Many of us live a long way away from our families – some of us have our nearest family members up to 400 miles from us. Many of us have moved to the area and find ourselves lonely and isolated because it takes a long time to set up support networks and meet friends, this is especially difficult if we are also struggling with mental illness.

attitudes

Some of us suffer exclusion because of:

- the stigma of mental illness. We often feel that stigma is even more prevalent in rural areas where we are unable to keep our lives private.
- our own self stigma
- our behaviours; the fact that in small communities people may remember actions and behaviours that stretch back many years and were caused by mental illness that have been neither forgotten nor forgiven.
This can all serve to increase our isolation and loneliness

**illness itself**

Because our illness is debilitating and hard for other people we can be very wary of burdening other people and therefore do not reach out to make friends. It can also be hard to get out to meet people, we may find that we lack energy, motivation and confidence as a result of mental illness.

Some of us are paranoid about other people and find it extremely hard to trust and make links with people. We also often struggle to communicate effectively and engagingly and mental illness may lead to self neglect which can cause people to avoid us.

**finance**

Many of us are on benefits and cannot afford to meet people outside of the home: we cannot afford transport, meals, drinks, cinema and other similar social activities

**transport**

This is often inaccessible and therefore we cannot meet people. It is inaccessible because provision is limited in rural areas and it is not available at night time when we may want to visit a city or town

It is too expensive if we do not have bus passes – and some of us cannot use public transport because we cannot face being in the close company of other people, especially strangers – yet we often cannot afford cars or cannot drive cars because of illness or restrictions to our licences

**meeting people / reliability / communication**

Many of us find it difficult to talk to people, hard to socialise and struggle to go a to a group situation.

We can struggle to make appointments whether of a social nature or for our health and wellbeing because our health is so unpredictable – as a result we avoid doing so to avoid letting ourselves or others down.

**new places**

We can find it hard to go into new buildings; Not knowing what is happening in new places is hard so we avoid these situations

**Other disabilities**

Some of us have other disabilities, which make mixing harder.

You can be lonely in crowd - we are often isolated because although we are with people we cannot communicate about key aspects of our lives. Talking about mental health and our own mental illness is not encouraged and can be frowned upon. Not being able to talk about this isolates us and feeling that our friends and
family do not understand us and do not wish to understand us makes us even more lonely

People never ask about our mental health and if they ask how we are they usually do not really want an answer. This means that sometimes we put on an act to appear confident and charming because we cannot or dare not show anything else – this can isolate us within ourselves

age and culture: those of us who are much older – many of us don’t speak about these things we don’t want to burden others. We have to appear to be independent

power imbalances: we can feel controlled by our relatives and friends and therefore very lonely

adaptations: some of us our physically challenged – we can’t really be solve isolation until we have a flexible and adapted transport system in highland

Not fitting in: we are often single and without family –and can therefore feel very isolated when mixing with couples and families.

Part II of submission: stories from HUG and SPEAK.

STORIES FROM SPEAK: an organisation that provides a voice for young people experiencing mental illness, speaking out about their personal experiences in relation to isolation and loneliness

 from a young person involved with SPEAK

“In Rural areas travel is even harder for young people most of whom do not have access to anything other than public transport or their parents cars Mental illness is still taboo and not understood well by other young people. We have less life experience and knowledge of relationships, we have less life skills less self management ability which increases our isolation.

We are more exposed to social media showing people having a good time while we are alone at home. It is definitely harder to establish friendships; we think no one will understand us: there is so much pressure to be friends even if they don’t treat you right.

In school if you are open about it you can be excluded and often we are quiet and can’t make friends.

If we are anxious and in school, we may not be able to go to groups or stay in the canteen

If your friends are hard on you, you can take it more personally and blame yourself

We are often self conscious , anxious, isolated and shy.”

 From “Liam”: a 17 year old on his experience of loneliness and isolation

“This is my story on loneliness. Isolated is how I would describe most of my life. I was always avoided for being different in my earlier years because I didn't know what I did wasn't "normal". I was always talking to myself because I would always get a reply. I only had one real friend at the time and he was never in school.
Back then it didn't bother me because I didn't understand what was going on. Then I got older and the bullying kicked in, literally. I was getting attacked almost every second day - physically and verbally. My friend ditched me for someone else. I realised there was something different about me so I withdrew into myself. I became detached from people and avoided them whenever possible. I genuinely thought I was a monster, evil on the inside, I still do. I rarely spoke to my family or anyone for that matter and I repressed everything.

Things went from bad to worse as the voice started repeating everything the bullies said. Freak. Looney. Worthless. I started to believe the things it was telling me. Every night the voice reinforced the negativity, fuelling the self hatred, causing me to spiral downwards. I self-stigmatised so much that I didn't speak to anyone for the best part of 1st year. I spent all my intervals and lunch times hidden away in the stairwell.

Today, I don't self-stigmatise as much as I used to, but I still avoid most people. I still don't speak to my family much either. SPEAK is helping me hugely, it gives me a sense of purpose and belonging but I'm still isolated. I'm really lucky to have the support of all the incredible people at SPEAK and my amazing girlfriend which is something that others in situations like this are going without."

from “Louise” (age unknown) a young woman on her experience of isolation and loneliness

“My experience of depression was extremely isolating and debilitating. I often felt that I was alone in how I felt and in my day to day struggles. As a society we put a huge amount of pressure on having everything ‘together’: having the perfect job, the perfect body, the perfect relationships and the perfect life plan. Feeling inadequate in the face of these expectations and isolated from the world around me only exacerbated the imprisonment I felt and the distorted view I held of the outside world, a world which I felt unable to participate in. Only with the support of others and the realisation that these expectations of us are false and unrealistic could I slowly take apart the walls that depression had built up around me. The most important lesson I learned through experiencing depression was to accept and celebrate that we are all perfectly imperfect and that a smile from a stranger or a friend holding your hand can make the biggest difference in the world.”

• from “Jamie-L” (24) another young woman on her experience of isolation and loneliness

“Growing up with a mental illness made me feel like I wasn’t normal, like no-body understood me. I couldn’t tell anyone how I felt because I wanted to fit in with all of my friends.”

STORIES FROM HUG: a network of people with experience of mental health problems based in the Highlands

• from HUG member: Heather

“This is such an important subject. My initial thought is that a person can be lonely even when surrounded by family and friends. It is not enough to be with other people. We each need to feel valued, understood and accepted for who we are. Sometimes it can even lonelier with the ‘wrong’ people for us, than alone.”
• from a HUG member: Lesley

“Feeling lonely isn't always about being physically alone. The greatest loneliness I have suffered has been as a result of feeling socially excluded, marginalised or misunderstood. These days I find more comfort walking alone in the woods than I do in a room full of people who don't understand. This is the burden of carrying a secret, of trying to escape stigma or avoid being judged by people who just don't 'get it'. It's a rare and precious commodity when someone enters our room, just to be together, as we are. This is what I crave.”

Part III of submission: Additional input

“On isolation, I think the issues outlined in the HUG report capture a great deal of what I've heard from around the country. The other key issue I would raise is that cuts mean many drop in/ social projects are being seen as "low level support" and closed or downgraded. This can take away the one chance many isolated people have for social contact with peers in a safe place and therefore increases loneliness and acts against recovery from mental illness.” Gordon (organisation unknown)

“users and carers involvement” organisation, based in Dumfries and Galloway

“Our landscape while not as vast as Highlands is very rural with small towns interspersed across the region. One of our findings is that farmers who may suffer from stress or mental illness are also extremely isolated. People with mental illness are also proportionately much more likely to live alone than the rest of the population. We also have a very poor transport infrastructure with very little access to trains and a shortage of public transport in general.

So in essence I am giving my support to the paper that Graham has written.”

Carolyn

Acumen: a support network that enables mental health service users and carers in Argyll and Clyde

“Very much in agreement. ACUMEN members have consistently identified isolation as one of the main challenges affecting mental health, mood and general wellbeing. It is nigh impossible for most individuals, particularly on being discharged from long or medium stay in hospital to have a meaningful recovery experience in isolation and loneliness.

There is for example a distance befriending project running in Argyll and Bute which is one way of tackling disconnection, but in many urban as well as rural areas it is the face to face contact afforded by support groups that provide the social nourishment required for good health and wellbeing. Link Clubs, while often viewed as an outdated model, nevertheless provide a lifeline in a way that services often can’t and it is community groups of whatever primary function that provide the “safety net” that can mean a world of difference when someone is becoming profoundly unwell. A case in point is the mutual concern and care for each other’s wellbeing that leads to one member intervening on behalf of another, often someone currently not receiving a service.”
Lives are saved by community groups in this way and official home support services owe them a debt. I can’t help but think that the challenge will become more acute given the ageing demographic and my fear is that a failure to support the range of often niche initiatives, who are currently combatting isolation as a primary or secondary function, will see the problem of loneliness become unmanageable.

Like Gordon, our members see “low level support” being under threat at a time when the true value of these community groups is becoming ever more relevant.

Social isolation is actually an important enough element of health and wellbeing to be tackled as a standing Scottish Government issue, much like exercise or obesity and measures to combat it merit being an audited target.”

David

The Mental Health Foundation / VOX (a National Mental Health Service User Led organisation) also contributed the findings of a previous consultation on the mental health strategy undertaken by VOX

SOCIAL CONSEQUENCES OF MENTAL HEALTH PROBLEMS

- 85% of people with mental health issues face isolation.
- social isolation is a key challenge to mental well-being.
- We should design services to challenge this (e.g. value of drop in etc).
- Commit to address the social dimension of mental ill health.

Members felt that the mental health strategy should consider how the issue of isolation is addressed. Many members are not in relationships, do not have family and friends around them and feel isolated.

Members suggested that this should firstly be acknowledged and secondly reflected within the outcomes of the strategy as it would offer a wider recognition of the influence of social and economic factors.

Members highlighted a range of activities which they found beneficial, for this reason looking at social prescribing within the strategy may be helpful. This could include access to supported education and employment; community arts based activities and various group activities etc.

Patricia Rodger
Advocard Collective Advocacy (on behalf of multiple organisations)
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