People First Highland

SPIRIT Advocacy

Strengthening People In Raising Issues Together

Incorporating HUG Action for Mental Health (HUG), People First Highland (PFH) and SPEAK (Stigma Prevention through Education, Advocacy and Knowledge)

HUG (Action for Mental Health) Speech

by Sue Lyons, SPIRIT Manager

to "Imagine Inverness" – 26th May 2022

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I'm Sue Lyons. I manage Spirit Advocacy which incorporates HUG (Action for Mental Health) I'm delighted and pleased to speaking here today.

HUG is a collective advocacy charity - a membership organisation that works collectively with its members to campaign for better rights services and treatment of people living with mental illness and to challenge stigma. All of HUG's members have lived experience of mental illness. Whilst everyone's experiences are different, we believe that there is a need for our voices – our expertise – to be heard by those responsible for providing services and designing legislation for we who live with mental illness.

In 2019 we carried out a piece of research into what happens to people when they are experiencing a crisis and try to access support or when someone tries to access support for them. Towards the end of 2017 and into 2018 we had heard and recorded what seemed to us to be a steady erosion of mental health support in Highlands. We were experiencing a number of people coming to us for individual advocacy and we were signposting them onwards. Members were reporting that it was becoming increasingly difficult to get help when their mental health had deteriorated. At one of our regular meetings we heard from the NHS what should happen when people were in crisis but this was not the experience of our members.

We also recognised the suicide figures in Highland remained higher than the national average with figures that show that "suicide is the leading cause of death in males aged 15 - 24". There were other issues being discussed and reports appearing in the press. Borderline Personality Disorder was the subject of two key reports by the Royal College of Psychology and the Mental Welfare commission. Both these reports suggested that people with personality disorders were struggling to access help and support in times of crisis.

We developed a series of broad questions, and recorded some case studies which looked at specific experiences of people and which highlighted excellent ways in which services worked together or ways in which there were complete failures. We spoke to 135 people – this was done through a series of group and one to one meetings right across Highland. The value of this work lies in its recording of the collective voice of people across Highland speaking about the actualities of crisis support.

If you ask people not involved in mental health work - in your families, in your circle of friends, people on Facebook and Twitter or just around your dinner table what they think would happen if they suddenly found themselves in a mental health crisis and people tend to think they would be "looked after". The hospital, the mental health team, their GP or in the worst cases the police would look after them. People think that, just like if I had a heart attack right here, an ambulance would take me to hospital and I would get great care until I was well enough to go home safely with minimal risk of readmission.

When we ask professionals from NHS Highland what happens when people are experiencing a mental health crisis, we are told what should happen – someone would be seen, someone would be assessed, admitted if necessary and given the support that they need to save their life. When we have raised the issue of someone who hasn't had that support and service we

are often told that it is an “individual case” and can’t be discussed or isn’t representative of the service as a whole.

The evidence we gathered showed us that there were good, bad and frankly, some unacceptable experiences. At the heart of many of the good experiences was empathy and kindness. The bad experiences often stemmed from ignorance and perhaps lack of training or staff shortages – things that can be rectified with some work and a desire to continually improve our practice, our services and the experiences of the people we work with.

The downright unacceptable were the things that still keep me awake at night and for which we could find no excuse and no comprehension of why it was thought to be ok to treat people this way.

We found evidence that being looked after and cared for when they need it is not the experience of many of the people who spoke to us. That far from being supported they felt abandoned, a nuisance and left to sort themselves out. Most of us believe that the role of mental health services is to protect us from harm when we cannot protect ourselves but this is not reflected in the treatment that many of us experience.

We found that support services can be difficult and complicated to access and the stresses of trying to find help and failing, can exacerbate a crisis. We found that anger was seen as a barrier to accessing services even when that anger was caused by the difficulties accessing services and the treatment of individuals.

One mother spoke of waiting in a day room for several hours for her son to be seen whilst he became more and more upset and angry culminating in what the mother called a “meltdown”. The person that they were waiting for came in and gave her son something to calm him down whilst commenting that she was dealing with someone who was seriously ill and left them in the day room. They were then told that the member of staff was “stressed” and so had gone for her lunch” making her son feel ignored, unimportant and his anger increased. He was refused support because of his anger with no acknowledgment that this was exacerbated by the treatment he had experienced

People talked about how important it was to be respected and given back their dignity and often professionals are at the heart of this. This is sometimes difficult to find but where people get a quick response, a kind response, then that can help hugely.

- “The doctor who helped me the most was the one who said – I don’t know much about this illness can you help me”
- “I saw my CPN and it really helped”
- “Here is brilliant I get a cup of coffee and a chat and I feel much better.”

The evidence showed that service provision was inconsistent across Highland. It is worth noting that Distress Brief Intervention at this time was only available in Inverness but it has rolled out more widely and today many of our members have had a positive experience from the support from DBI. Staffing issues can also lead to inconsistency in the services

available. Some participants felt that they were ignored because of where they live. This was particularly mentioned in relation to remote rural areas.

- "The CPN left and there's no one to see now"
- "I have seen five different doctors in the last two years"

We heard many comments to indicate that people are turned away from services or are unable to access services. Some of the case studies in our report also highlight this.

- "I had to give up my job because I'm so depressed, I got a letter back saying that I didn't meet the criteria for a referral."
- "The Hospital wouldn't let me in the door"
- "They seem not to care – I can't get an appointment – I got a letter saying I didn't meet the criteria"

Many of our conversations highlighted the stigma people felt when they tried to access help during a crisis. "I don't want to be seen in public" was one comment and others echoed the feelings of shame that many felt at their own crisis. This prevented people seeking any sort of support

- "I fear losing my kids if I open up"
- "I worry about my job (at the NHS) if I tell the truth"

Others spoke about the attitude from professionals at times when they really needed support.

- "They said I was a liar"
- "They laughed at me"
- "They said I was lying about my depression"

The stigma and judgements made about self- harm were often highlighted particularly by women.

- "I hurt my foot and they thought I had self-harmed and were really cold. When I explained what happened they changed completely..."
- "I went into a hospital after an overdose ...the nurse asked me why I was being so silly"

People spoke about the importance of places of safety or safe places. There is a specific meaning from the Mental Health Act but here, people were mainly talking about the need for a safe space where people can go and get the help they need to reduce their crisis. Some hospitals have historically had a safe space for people having a mental health crisis but many of these have disappeared.

We heard from people who were sent home from hospital after a suicide attempt and just left for three or even six months whilst they wait for an appointment. Many reported long

waiting lists to see a clinician or nothing happening at all after a referral for a CPN. Some are just referred back to resources they have already accessed because there was nothing else.

Whilst people recognise the staff shortages and the pressure that staff are under there is a feeling that not enough is being done to sort out these issues and that they pay the price when they are simply left without any help or support

- "I just got a piece of paper with a self-management plan – there was nothing else"
- "After I left hospital there was no one to check up on me. I wasn't assigned a CPN or anything"
- "The fact that M didn't get a phone call back made him think that no one cared about him at all, so what was the point of living if even the people that are supposed to care won't help him. Six days later and following an overdose and an admission to hospital still no one from the CMHT has phoned him back"

There were positive comments about the police and the telephone helplines and some thought that new initiatives were interesting and helpful.

- "The Samaritans were really useful"
- "It's good news to have the app about suicide prevention"
- "NHS 24 were fantastic and DBI has really helped"

Our findings showed that there are few services around Highland that are self-referral. That option further reduced over lockdown so even some of the places where you could just walk through the door became referral only. HUG would like to see more opportunities for people to self-refer to services so that they can get quicker help when they are feeling unwell. A strong feeling was expressed that the focus of funding and services and new initiatives related to longer term wellbeing and not the immediate treatment of emergency mental health crisis

- "I can do a writing group but not get an emergency appointment with a CPN"

Overall our report showed that people want to be safe, they want to be believed and they want to have places where they can go for help. I think we can all agree that people should be able to access the help they need to be well and live a good and happy life.

And yet that isn't happening in Highlands for many people.

If you remember I said that empathy and kindness were at the heart of the good experiences people have. This needs to be recognised and built-in, right at the heart of the crisis support people receive. When it is lacking then it leads to situations like we heard from one of the participants -

- "At A and E after an overdose they sent someone to see me – I begged them not to discharge me and told them I was going home to finish the job. He said "That's a risk we are prepared to take"

The impact of this comment on the person themselves was devastating – he felt alone, ignored and that his life was worthless.

As I said – much of the evidence that I am speaking about here was collected in 2019, before the pandemic messed with us and exacerbated mental health issues right across the world. So where are we now?

Well, last year we produced the results of a survey into the priorities of our members. We called the report "Listen to Me" a plea we heard again and again in the responses.

These results showed that 73% of respondents said they were NOT getting the help they needed to live life well with a mental illness and 60% said their mental health had worsened over Lockdown. Some are trapped within their homes, some are completely unable to access services, some are trapped on waiting lists and some feel they have been badly let down by services which should be helping them. 71% of respondents wanted HUG to work to encourage the development of crisis and peer support services.

The comments included

- "Someone to speak to me when I'm having a bit of a crisis would be really good – I don't have anywhere to go"
- "immediate access to crisis intervention care"
- "Some help with suicidal thoughts"
- "There's no help when you are suicidal and New Craigs says they won't help you"
- They tell me I have capacity but I don't want to have the capacity to kill myself"

For many participants, it appears that services just do not feature in their lives – they either can't access them at all, or they have accessed services and found them unhelpful, judgemental and stigmatising.

Whilst members recognise that we need more wellbeing and self-management initiatives that focus on recovery they also highlight that we desperately need real crisis support for people in Highland and we need it now.

HUG has long spoken of what we have been told are 'idealistic' models of one stop shops and all under one roof 24/7 provision, recovery focused, peer led, with kindness and empathy at the heart of a service which is meeting people where they are in their crisis, supporting them to work through their feelings in order to tackle a devastating and exhausting and otherwise potentially fatal mental health crisis. A service where statutory health organisations work closely with third sector and peer supporters to provide something more effective in dealing with the immediate needs of people in crisis. A safe space where people can stay and be treated with kindness and empathy and where they can begin a process of recovery. The Joshi Project sounds like what we have talked about for years

In the end, HUG can produce a thousand reports. We can place them directly in the hands of key influencers and decision-makers, at national, local and clinical levels. Today in 2022, we might even get a response – something that we never had from our crisis report in 2019. But unless we put people with lived experience right at the heart of the design and delivery of services, unless we see the power to make change shared with those who know what we need, people will continue to struggle when they hit a crisis, isolated, alone and ignored. The suicide figures will continue to be higher than other parts of Scotland and lives will continue to be more difficult than they need to be.

Those of you who have the wherewithal to take decisions and make recommendations and commission services, must consider the experience of the people who have contributed to the reports that I have discussed here. We need you to look at imaginative, innovative ways of working together more closely to ensure that no one is left without support at the time they are most vulnerable.

This feels to our members and to us like a crisis in crisis care. It needs to be different, I hope that working together with the Joshi Project we can help to make that difference so that we can change – and save - the lives of people living here.