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RIGHTS FOR LIFE CONFERENCE
SCOTTISH RECOVERY NETWORK AND SEE ME
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Hello

Many thanks for inviting me here today – it is a wonderful opportunity for me to speak with you and to pass on some of the experience that I have gained over the years with members of HUG.

HUG is a group of about 500 people with mental health problems in the Highlands who speak out about their experiences. Put simply we want to change the world, put complicatedly we want to change the world but we have a huge variety of opinions about what we think of mental health and mental illness and how we want that change to occur.

Despite having differences of opinion we do have a great deal of consensus about what the key issues are for us – we developed a list of about 30 priorities for action earlier this year.

It should come as no surprise to you that Austerity or cuts in services is the biggest priority for us followed by stigma and especially self- stigma followed by welfare reform and employment.

I want to weave some of these priorities into my talk but first of all I want to reflect on the subject of this conference.

Human rights summons up images of banners and placards and marches and demonstrations, it also summons up solemn court cases and more recently statements by the UK government on the scary future of our rights.

But let us go back a wee way. The United Nations Declaration on Human rights was developed by countries across the globe in response to the horrors of the second and first world wars, it was an instinctive and humane reaction to the most terrible crimes against humanity and at its heart and its future development was the plea that no one be punished, excluded, discriminated against because of their race or their sex or their disability or their religion and so on – it was that statement that says never again will people be slaughtered because of perceived difference. What

it is, is about the essential dignity of all people, the recognition that whoever we are we still have rights and these are about far more than just the right to life.

And the preservation of those rights is there to make sure that we can walk around with freedom in our step, with the knowledge that our lives are safe and our health will be looked after, that we can have families and children and privacy, that we can have an education and the chance to work as well as other essential ingredients to our daily living.

It is not just some of us that have the right to this, it is everyone, no matter who they are or what their background.

I would say that is the core of human rights but I would go back a wee step and reflect on a HUG focus group meeting we held before this conference and say that human rights in essence is something very, very, simple and very difficult to achieve.

It is the chance for us whoever we are to live with dignity and respect and the chance of equality, it is the chance for us to be confident in the communities we live in and the communities that impact on our lives.

It is, in other words, knowing that we all have huge value.

And to be valued, to feel worthwhile, to feel that people care about us and respect us is such a tremendous wonderful thing. In many ways it is all I want from other people. If I felt that I had that in my life I think in many ways I might be very content.

And although I am now in my fifth year of detention under a community treatment order and so could be said to lack freedom and by some people to have my rights neglected, I feel more cared about and respected than ever I have done before.

I am in love, I have wonderful friends, I have a job, I have a good income, my life is kept safe even when I try to discard it, I have a health service that for me, suits me to a 'T'. I bicker with my Nurse and my psychiatrist and disagree about my diagnosis and what keeps me well but I turn to them when life, as it occasionally does, becomes dark and grey and almost unbearable and generally somehow they and the people who love and care for me help me put me back on an even keel.

And saying that, I think to myself am I an appropriate advocate for human rights when I am so blessed? and I think I am sometimes but maybe sometimes I am not as aware as I should be when our rights are more a token gesture, more a gloss.

However I think human rights are more likely to be upheld when we get our relationships right and when we learn to how to speak to each other even when we have wildly different opinions.

Human rights are sometimes at their best when we can love and respect the people who in other ways may seem to take away our rights and they in turn can love and respect us.

And that is maybe very naive but I believe it, without a fundamental respect for people and for difference we can never achieve what we want when we look at legislation and the long march for justice.

Because justice is also at the heart of this,

Sometimes I think to myself that we really do not need to study the law to know when our rights are being broken.

At the time of writing this I am just coming from an interview with STV about the closure of Cairdeas cottage a drop in centre in Inverness – by the end of this week we will have appeared in almost all the local media and some of the national media about this. In terms of our priorities this is a key area to campaign on, and it doesn't matter that the NHS may justify closure on grounds of cost or value, it matters that some very, very, isolated people will no longer have a service, some people who shrink from all forms of contact with the NHS will no longer have a safe and welcoming place to gather and a community that has built itself and cared for its members over the last two and half decades is going to be ripped apart.

This is something people who work in the field of policy and mental health sometimes neglect to understand – the NHS is also the maker and breaker of communities, in hospital wards, in community mental health teams, in drop in centres, we grow together, we share together, we support each other, we learn from each other. It is this everyday sense of family and belonging, these mini communities where all the buzz words like recovery and resilience and peer support have a huge resonance but are rarely vocalised, the places where the real stuff happens, not for everyone by any means but for a large number of us.

It is those places where we are able to drop our public, smiley coping masks and know we will be accepted and respected that can make such a difference to so many people. So when the very communities that promote this; that get away from the emphasis and concentration on the clinical, the goal orientated, the outcome measures that are beloved of some and despaired about by many, when these communities where compassion and support thrives are cut and abandoned because we are not quick enough to recover or get into employment or learn our d.b.t. skills, it is at these times that human rights loom large in my mind.

And I am reminded of the focus group we held on this subject and Simon from the recovery network reflected on something we were saying. He said it could be good for all of us to become more challenging and less accommodating.

It might be good when a life saving service creaks at the seams if, instead of saying

'There is nothing we can do about this, it's how life is nowadays'

We paused and questioned why we accept what happens to us.

Because on one level if we are to speak out and work to improve services we need at the very least to look at all the people who are working in this area and try to understand where they are coming from, sometimes that raw shriek of

'How dare you do this to us?'

Is all that is needed but at other times we need to think if we have little money what is the best way to spend it, if we provide a service to ten people at great cost and that means that 200 others get no service then we need to look around us, to use

our emotion but also our logic and our reason and our understanding of why people do what they do, why they believe taking away our lifeline is sometimes justified.

But there is a limit to understanding and there is a limit to the faith we have in each other,

When one of our members talks about how embarrassed she was to go to the toilet in front of the cctv cameras in a police cell because she had been lifted because she was suicidal then that limit is reached,

When a man is imprisoned because he set fire to himself and the NHS would not provide the background reports about his mental health that limit is reached,

When we watch the twitter feed of a woman discharged from hospital against her will, taken back to hospital by the police from the bridge she was about to jump off, discharged again to the point where that very day she drove into a tree and died that limit is reached.

There are limits to our patience and our understanding everywhere – the use of police cells when we are in crisis, the lack of hospital beds or a safe place to go to when we are suicidal, the appalling fear people have each time their benefits come up for review, the huge number of people with mental health problems in prison, the high suicide rate of transgender people, the absence of meaningful local services for so many young people, the despair older people feel when they find people do not care any more for them and write them off in so many hideous ways and the terrible, terrible, isolation so many people experience.

We could go on and on, the pain our carers feel, the stress the services are under even the decisions the managers are having to take daily.

And the temptation is to shout out and to stand witness and to say:

‘This must stop!’

Much as I am doing now and I would agree with anyone who would say we must bear witness to the rising despair so many people feel but I would also say.

When I speak of injustice so does my c.p.n. and my psychiatrist and my m.h.o. When I look at people making difficult decisions and assume that they do not understand and are the enemy then I am creating my own stereotype.

I remember a recent planning group meeting I went to where I knew that 80 % of the professionals present had also experienced mental illness; they were just not so overtly public about it in the way that I am and so who is our enemy? –can we make people into enemies so easily because of their status and assume they know nothing of our world?

Maybe when we look at human rights and the need to challenge, we need to build partnerships and sometimes set aside difference and resentment, maybe we need to look at the issues we have in common.

The Royal College of Psychiatrists were talking about parity of esteem as a key issue at least eight years ago and yet such words have only just started to be used

by the user movement, the Scottish association of social work were holding conferences and campaigns around welfare reform ages ago, maybe they are our natural partners, the Scottish government seems to put more store by recovery and challenging stigma than some of us do, maybe we should treasure that. Mary Scanlon; the Tory MSP in Highland from a party that many of us choose to hate has been committed to the field of mental health for decades.

When I said human rights is about difference I meant it, but it is not only about accepting our difference it is about understanding the difference of those people some of us assume are our enemies and oppressors – it is about us accepting we make people alien too when we generalise and make assumptions about them.

I am going to finish by talking about how we promote human rights in HUG.

We do it just by speaking out, the very act of a community that is marginalised gaining a voice is an expression of human rights.

In HUG we try to do this by expressing the huge range of opinions of our members and expressing that great range of opinion and on occasion the great consensus most of us have on key issues. We also do it by assuming that we have many natural partners, by assuming the number of people who actively hate us is tiny but the number who are ignorant or confused or worried by us is high and that with dialogue we can learn from each other.

We also do it by recognising that we do not have all the answers, just as a jag in the bum is not the cure for psychosis neither is ecpr or a wrap plan – all sorts of actions and interventions help us and those people who have the arrogance to assume they have all the answers, whether they be service users or professionals is something we need to be suspicious of.

In many ways 'mental health' deals in fundamental issues, the despair anyone is capable of and the joy people seek, as well as illness;: not even the most charismatic faith leader nor the greatest philosopher nor the most skilled politician has the answer and the means to solves these issues so it seems to me that we would do well to celebrate the fact that we are trying to find answers that people have sought for millennia and yet to have the humility to know that the answers we come up with are likely to be seen as faulty a scant few decades from now.

I've already mentioned austerity, how do we challenge this. Earlier I mentioned that we had been very visible in the press over the closure of a drop in centre, in fact we had a week of what seemed like back to back interviews, but that only happened after we consulted over 100 people on their views, developed plans together, contacted NHS Highland in advance, enlisted the support of MSP's and councillors and only after we had given the NHS prior warning did we seek to reverse their decision by embarrassing them publicly.

I do not think we have a chance in succeeding in our work on this subject and it is there where I can see the need for a more co operative approach,..... if we were able to speak with more than one voice we may have more results and more efficient services, if the various professional groups and the third sector had joined us on this issue maybe we would have had more chance of success.

Maybe that is a lesson for all of us, I fairly frequently see pronouncements by major organisations at a national level often on the some of the issues I have highlighted today and yet very, very, rarely do I see such bodies making their announcements in partnership with other organisations and even rarer do I see joint statements made either by the third sector or the statutory sector with service user or carer organisations. It seems to me that either these organisations shy away from the rhetoric of service user and carer involvement and empowerment or that they are wary of organisations that represent users and carers, if they are wary of us they should do something about this, either by offering their opinions of where we are going wrong or by trying to further support and develop and resource us .If we are run ethically and efficiently we could make a huge difference and be ideal partners on many issues.

What else do we do to challenge austerity? We speak with our politicians, we comment on policy, we canvass the views of our members and try to act on them. We also try to find solutions because just saying something is wrong may give us a good feeling which is in itself important but rarely results in a constructive action.

With stigma, well we have been working on this for the past 18 years, we choose to address it by creating dialogue and learning.

Stigma is a fairly bland word to describe, prejudice and bigotry, to describe misinformation and discrimination and to describe shame and guilt and the most terrible loneliness isolation and lack of hope. And it is not as clear cut as some people would like to say, some behaviours and experiences are too much for people to live with, sometimes the isolation is not purely a result of exclusion it is because those who love and care for us cannot bear the pain they witness in us or experience from us.

Tackling stigma has always been a positive thing for us. It is always lead by people with direct experience of mental illness and is never that horrendous situation where in the name of training a person demonises and victimises the audience they have been given the privilege of speaking with .

That just doesn't work.

And yet we work with people who have sectioned us, who have taken our children off of us, who have refused us benefits . There is room there for tension, I am always struck by the dignity with which our members speak about the most traumatic events but without going into the ;

'It's you, it's people like you who did this to me and how dare you do this to us!'

The story, the conversation, the connection, the chance to see each other in safe neutral spaces does far more than the pointed finger and the turned back. It allows all of us to learn and grow. It allows people to reflect and change.

We run some sort of stigma session at least once a month, the last one was with patient transport, the one before that with health centre staff and the one before that with home start staff.

The ones coming up are with student nurses and student mental health officers. These all have a bearing on human rights such as for access to health care, the right to life, the right to freedom, the right to family life to name just a few.

We also go into schools or to be more accurate SPEAK; the fantastic young people's project we run is frequently in schools, speaking to whole year classes, speaking to p.s.e. classes, discussing issues with staff in guidance and the wider education field.

Having young people and older hug members tell their stories and show dvd's they have made to people in schools makes such a difference, equally taking plays round the schools achieved similar results as did the distribution of postcards and our continued involvement in the youth philanthropy initiative.

Challenging stigma has been our priority for so long, it makes such a difference to our lives to see people understand and in turn share their views and opinions and as part of that to find our expression of difference and bewilderment, our vision of justice and friendship, our vision of what real inclusion may mean is being heard; well that is wonderful.

When I talk of welfare reform I find more consensus among our members than anywhere else, the brutal imagery of the media and many politicians excludes alienates and does indeed drive some of our members into illness or thoughts of suicide, it prevents many from even applying for the very benefits they have a right to, it alienates and impoverishes whatever vision many of our members may have felt about being a part of a caring society that would treasure the different levels of contribution we can all bring to it.

And I know I have been calling for a form of understanding of others when we look at what may be seen as oppression, even if only to help us plan how to speak out properly but in some areas it really is the people who can pore through legislation and human rights acts that we desperately need.

We have, amongst our volunteers in HUG, two very skilled welfare rights workers, their knowledge of the field and ability to give an expert opinion is wonderful. These members among others have given speeches on the subject at a Highland level and a National level and have created a great bond with the Highland network of advice bureaux.

But they and others have also helped with our training of psychiatrists and benefits staff and our submissions to committees looking to change legislation. And our successful work to see more funding for specialist mental health advice by advice bureaux.

One of our members posts frequently on our facebook page about changes in legislation and provides information that will affect us, hard things to look at but useful and important. As our facebook page has over 800 likes and over 1500 visits a week it is one way of getting a point of view across and basic information to our members.

I am a wee bit fed up with my words now which is a great pity as I really want to engage with you and interest you but even the most engaging speaker loses people after 20 minutes or so, so I will begin to wind up now.

The last of the priorities I mentioned was in the area of employment. We haven't done much here lately but it gives me a theme with which to finish on when we are looking at human rights.

We spoke last year with over 100 members of the Care Inspectorate on a healthy workplace. The talks that one of our members gave were wonderful and, we feel, resulted in a real willingness to look at how the workplace can be kept mentally healthy in a large busy organisation.

We had a volunteer, in fact he still is a volunteer, someone very busy with ideas around peer support and recovery. He has raised its profile in a major way in Highland and now has employment as the first peer support worker in highland and that is where my last point rests.

Human rights and mental health is everyone's business whatever our elected politicians may think, they are the bedrock on which communities and individuals can feel safe and secure and respected, without that protection many people in society especially those people who are already excluded are very much at risk.

But our volunteer who got himself a job who took personal action is something to remember, our members love the fact that we speak out together and create change and that sometimes we do it in a fun way too – we are just finishing a three day weekend at Scotland's creative writing centre, creating art work and writing for an exhibition on mental health but also the travelling community as I write this. It has been a time of laughter and joy and yet, when I look at self stigma which many of the people here experience that can be all the negatives: the shame, the guilt, the isolation, the lack of confidence .

If we are to challenge that then we need to work to find and give each other the skills to take our own action as a community and as individuals and that involves more than talking about how awful life is. It is also about having fun and sharing and supporting and communicating and making positive change both for us and others, it's about giving each other the courage to step beyond the awful staleness that a lack of motivation in our lives creates and an alienating society imposes on us .

When we know that some things are fundamentally wrong and when, as a community we can speak up about this, then change is really on the way and when other communities join us and we join them to highlight the value every human has whatever their background, origin, skill base or status then we can really start to see something wonderful happen.

Thank you