STIGMA

Mental ill Health

from the perspective of
a service user and a carer

As presented at:

“Living with Schizophrenia”

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NSF
SCOTLAND
Support and action for people affected by mental illness

Stigma in Schizophrenia

A Service User's Perspective

I work for Highland Community Care Forum as the advocacy development worker. This really means that I work with HUG, the Highland Users Group, who represent people with a mental illness, and with another advocacy group that represents people with a learning disability, People First in the Highlands, and lastly, in the development of a Highland advocacy strategy.

A couple of weeks ago a friend gave me an old second-hand copy of a book written in the year that I was born – it is called **Stigma**. I've only read a few paragraphs of it but it seems to me that the stigma that I have grown up to experience in this new century is very similar to the stigma that Erving Goffman wrote about in 1963. Public attitudes to people with a mental illness have really changed very little in the last 37 years and this is very sad.

I have a mental illness which has been diagnosed as schizophrenia. Sometimes the things that I go through are horrible but for the vast majority of the time I live a happy and enjoyable life.

However, as we all know, for many people mental illness can be a debilitating and traumatic experience. It is an attack on fundamental perceptions of self and reality and the possibilities of happiness.

Once people have become mentally ill it is possible

- to be excluded
- to be seen as different, as a threat or a burden or an embarrassment.

It is possible

- that you will be avoided
- talked about maliciously or as a problem
- that you will lose your friends

and in extreme cases

- that you will be actively persecuted.

I could almost stop here. It is frankly obscene to think that people who through no fault of their own have slipped into an illness from which there is sometimes no escape and little hope should then, on top of that,

- be looked on as separate and inferior
- be put apart as different to everyone else
- be judged on something that they could do nothing about.

It is something for which we have no excuse, no let out, as a society which has a responsibility to treat its members with respect and fairness, a society which should embrace the different experiences we can all bring to it. We have to stand up and admit that we have all failed people with a mental illness.

Whilst I believe all that I have just said, I would, however, say that stigma is more complicated than this. It is everywhere but it is not always intentional. Stigma can be both melodramatic and subtle and we, people with a mental illness, can ourselves live up to its stereotypes denying it even exists or even encouraging it.

Our perceptions of mental illness are a medley of our upbringings, our cultures and values; everything is swirled around and mixed up – nothing is really black and white. As a person with a mental illness, I do not consider myself to be a permanent victim. I do not feel oppressed by society, or the words used about people like me, and yet at the same time I do.

I am going to use myself and those around me as an example of how stigma is confusing because, like many members of HUG, I have never felt overtly discriminated against. No one has spat at me, no one has refused me service or denied me employment because I have been ill, and yet the feeling of difference exists.

My son is eight years old, and along with my wife, he is my joy – he is the most important person to me. I love him and he loves me. We go bicycling together and walk along rivers and every night we read his bed time story together and often he will talk 'nineteen to the dozen' and I will ignore him and he will get cross - in other words, we have an ordinary family relationship.

Yet every day my son will call me a nutter or a weirdo or sometimes a lunatic. Sometimes I feel a tightening in my heart and I want to cry out to him to stop it. Sometimes I feel angry and I want to shout at him that yes I really am a nutter and does it matter?

He has picked up these words from the playground. He has little sense of what the words mean and no idea of how offensive they really can be. They are just fun and its nice to use them with daddy because we all know he doesn't really mean it and that daddy will often laugh.

I suppose that with those innocent actions we embrace a whole world of stigma.

Most people use language about us that is derogatory, that demeans us as a matter of course

- in the papers
- in the jokes
- in the films and comedies.

It is a device for a few laughs and a compelling headline. It is both deeply malicious and completely irrelevant to our lives.

The other side of his comments is the fact that he has no idea that I have ever been really mad or really a nutter. He knows that I have an illness but he does not know what it is and is not very interested in it at all.

How do you sit down with someone who is unaware and unprepared and talk about the times when life is unbearable.

How do you say to someone who is so good at enjoying life that his whole body wriggles with excitement that

- sometimes his daddy takes a razor blade to his own skin
- once his daddy's only wish in life was to continue stubbing cigarettes out on himself
- sometimes his daddy thinks that he is so evil that he wants to be isolated from everyone else.

I don't know how to do this. I know I should but even as I write this I feel my stomach churn with the hurt of it all. To talk so close to home to a child to change our illusions and perceptions about who we are in each others eyes – it frightens me.

Stigma, as I think I have just shown is not an 'other people' thing – we are all fully signed-up participants – we are all people who have been brought up in it.

We have all been brought up into the idea that life is about laughter and loving. It is about, ideally, success and glamour and possessions. We are meant to be dynamic and rational and healthy and good at talking and socialising - we are meant to be in a world where life is all about living.

And so, for some of us, the greatest stigma comes from us and colours our lives and is reinforced by the illnesses we have, so that although we can say this life is purely a result of my illness and not our fault- many of us can't believe it.

So when for us

- the sun loses its joy
- when life becomes a pale mockery of what we had wished for
- when those around us echo back our pain
- when we lose our jobs and don't complete our education
- when there are devils in the glitter of a summer's day,

we feel that we have sinned not only against ourselves but also against those we love and all those things we have been taught to wish for in our lives.

It all turns into the question of how bad we really are to ourselves and those we love. It is not so easy to say that the sadness is not our fault that we are not responsible when everything, ourselves, the nature of our illness and our society conspires to say that it is.

Not talking is the cloud that creates stigma. When I first became ill – when I first wanted to die – we agreed that my grandmother would not be told because she was from a culture and of an age that could not accept such things. And yet, although I know she wouldn't have understood, I think I would have liked her to know, especially as she also nowadays spends a lot of time wishing that she too could die, that she often thinks people are stealing from her and very rarely has much memory of who her grandchildren are and almost none of her great grandchildren – this secrecy, this desire to protect, only damages ourselves and reinforces the ideas or wrong-doing.

Stigma is the clouds of blame we wheel around ourselves. There has always been a moral question about illness and its causes.

For me, I became ill just at the end of the time when it was still fashionable to blame families for illness, and really what better reason when you are young and angst-ridden than to blame your family?

I hated my family in those years that I was becoming an adult and blamed them for what I was going through – and sometimes I still do.

The first my parents knew about my attempted suicide was when they received a benefits form to fill in from the hospital. Sometimes I try to understand what they went through. To know that your child wants to die must be a terrible blow but to be told that he won't see you and that he blames you for his misery is a shock and a blow that must be a wrenching agony to live through.

I remember that they often said that if only they could go through what I was going through they would understand. I remember they reached out and I would not respond. There you can understand stigma because there are wounds that will never heal, that will always be feared and not spoken about for the very pain that they cause.

Mixed in with it is a shame that cannot be justified and cannot be shaken off and in that guilt and fear we build up differences that set us apart. Stigma is not just about pain it is about an illness that is full of social consequences. No illness exists in isolation - it can damage and wound all those who you hold dear to you because illness of whatever kind is not pleasant and easy to bear.

Recently I was sitting down with my wife, and we remembered a time I had forgotten about, a time when I was trying to convince the doctor's surgery that it would have to be sterilised after each time I visited it. And at such times you remember that once life was a place of optimism, when the phrase of 'in sickness and in health' was a glibly given promise, a freely given commitment with little idea of what can happen.

When my reality splintered, those shards were not pretend - for a time the commitment we had given each other was also close to bursting. When the person you love is in another world, when they have become a stranger to you, all the promises and hopes you give so happily to each other become a mockery to your dreams.

It is only with huge effort that you can both keep together and try to build lives that you hope will sustain themselves in the future even in the face of uncertainty and fear of what could happen all over again.

And when those that are close to you find that the pain is too much and curse the illness that has stolen you, you can understand how people come to fear it. And in the disintegration of love and family you can see the growing power of stigma.

I shall not carry on my story too much longer but I do have a few more examples of the way stigma and shame can enter our lives so easily.

The services that we use have a history that cannot be ignored – however much they may ultimately help. They can also be about a form of control that is hard to accept and can seem (through their own, at times, barbaric history) not to be the place that people inevitably turn to when they fear they have become ill. They can come to symbolise fear and failure and punishment.

I am sure that those are some of the feelings that went through my sister's mind when a health visitor suspecting post-natal depression made arrangements for her to see a psychiatrist, an appointment that she wanted to keep but did not attend for fear of what would happen to her and her baby.

Psychiatric services have a huge image problem to overcome before we can feel free to ask for help and to be open with those who are there to help us. When we fear the very services that help us then the existence of stigma is of little surprise.

As you might have gathered, a lot of my identity is based on what I have gone through when ill. Illness and disability is as much a part of my self-image as those events in my life where I have experienced times of beauty and joy and wonder. I find it hard to feel comfortable with people who have not experienced illness. There are things that other people cannot understand or appreciate if they have not seen it or felt it.

Recently I met a friend of a friend who knew I worked in mental health but not that I had been ill. When after a little tentative and frightened discussion we realised that we had both been mentally ill, the tension of do I or don't I admit it disappeared, to be replaced by a feeling of ease. You can see this in drop-in centres or places that we meet.

Sometimes I think, when seeing my friends and acquaintances at ease and making jokes of the most awful situations, that some of us who have a mental illness do have our own culture.

Although we are equal members of society we also have an identity that should not be subsumed by attempts to make us normal or ordinary or conventional in the name of inclusion. Equality does not have to automatically mean integration. Sometimes it is easier for a time to be around those we consider our own.

For me, being diagnosed was a liberation. It gave justification to what I was feeling. It gave legitimacy to what I was going through. It gave me something to come to terms with but, as we all know, some diagnoses carry with them echoes that determine how we treat people, not as individuals nor how we respond to a person's problems, but how we slice a person into a set of generalisations that have little to do with that person's identity or reality.

I have felt this as a father, when various sets of people have in turn thought that my son may be epileptic or having Aspergers Syndrome or perhaps Attention Deficit Disorder and there you can see the dangers of our labels.

To put a series of disorders, layered and bound-up with assumptions and generalisations, on to anyone is wrong. To do such a thing to an eight year old just beginning his life feels repugnant. And in this belief, where we fear even to name the problem, we can see the power of stigma.

What I have been trying to do is to show that even in a family such as mine, or maybe yours, that would normally say it has been free of stigma, that we are not. The stigma of illness is in all of us whether we want it or not. Our actions are coloured both by the image and mythology of illness, our perceptions of how people should act in our society, our own self image, the illness itself and the history and actions of the services that are there to help us.

Fundamentally it is our belief in what is normal and acceptable that damages us. We all set impossible standards of success and happiness, and when we are not berating ourselves for our own so called failings, we can leave those who don't succeed behind on the different margins with which we draw up our pictures and images of the worth of other people.

I haven't given much of a rural context to this. In HUG we do a lot of media work, but whilst I have said that I have never been discriminated against, I don't give my personal story to the media.

In the back of my mind is what could happen to us with the wrong sort of rumours in the village in which we live. It's not a paranoid fear either, although local communities can give a support and backing not found elsewhere, the lack of anonymity and the ability to come to the wrong conclusions have led to a few people in the Highlands being beaten up, shunned and even forced to leave their communities.

This type of action is not something that just rests with prejudiced people coming to ignorant conclusions. I know of doctors who have called people with a mental illness wicked and evil, who think that it is a problem confined to the homeless and unemployed, who call a cry to be helped a sign of attention seeking and manipulation.

In their own way those sort of actions are just as damaging.

Do any of you know those times when life is so hard that you cannot do basic things like deal with money without fumbling it and getting confused? A friend of mine did this on the bus not so long ago, and in scenes that take you back to the 60s, the driver said that he didn't know why people like my friend were ever let out of hospital, and yet, here is the difference and the reason groups like HUG can exist.

Although my friend left the bus in embarrassment and anger, a fellow passenger saw what was happening and complained and the driver was disciplined. Stigma hasn't gone away by any means but we are standing at the point where we can all give it a shove to send it away.

It is tempting to leave desperation behind. Sometimes now that I am happy so often, sometimes when I am sitting at the base of one of the trees in the garden with a whisky in my hand and horses and rabbits on the field below, I have yearnings to forget all about this.

In HUG we try to give a wider view. Mental illness is widespread and is horrible to go through but it is possible to live with it and

- to enjoy life
- to make friends
- to find work
- to have families.

It will be a great deal easier if people let go of the fear that they think that they have of people like me, so that we can all be as open as we like about our experiences without fear of retribution.

Graham Morgan 22 September 2000

Stigma in Schizophrenia

A Carer's Perspective

I have spoken in public on this subject before and not much has changed over the years. I have, however, made some changes to my talk because I believe it is not just stigma that we should be talking about, but discrimination.

Changes do need to be made and talking about schizophrenia and the discrimination it brings with it, is a first step on the road. Stigma means different things to different people and this could be why there's a problem in tackling it.

For me, stigma means ignorance, prejudice and fear. It's something which makes other people feel acutely uncomfortable, and why? Put at its simplest, it's because the person being stigmatised is seen as somehow different from what society calls "normal people". You can be different for a whole range of reasons which do not attract stigma, but the extra bit which creates the stigma is I believe, fear – fear of the unknown. Somehow the person who is different seems to pose a threat or challenge to us.

Who is affected by stigma? The person who is ill, as well as their family and friends. Stigma may also affect the psychiatrists and other medical professionals.

There are other reasons why stigma occurs. One reason is due to the many myths and misconceptions about schizophrenia. These myths have been with us for a long time - such as schizophrenia means having a split personality, or, all schizophrenia sufferers are violent towards others, or, and my least favourite, that it's a relative's fault, and in my case, the mother's.

Two very unpleasant assumptions are made;

- one is that schizophrenia is someone's fault
- and the other is that that someone is the carer and the carer's family.

These and other misconceptions exacerbate stigma and discrimination on a massive scale.

Schizophrenia and stigma have always been with us. They were there, in the past here, in the present, and they may well still be around for many years to come – let's hope not.

When I spoke with my mother about my son's illness, she seemed to take it in her stride. Not that there were no tears and anguish, but my mother who comes from Eastern Europe, told me that when she was in her teens in her native village, there was a young priest who behaved in a bizarre way. No-one stigmatised him or pointed a finger at his family. Everyone recognised that he was mentally ill, they'd seen similar through the years. The villagers just got on with their lives but at the same time helped the young priest's family to cope as and when they needed it.

At times, when the young priest became extremely erratic, he was locked away in the barn - there were no hospitals, no doctors with medication, nor would he have been sent away even if there had been. Each of the villagers in turn helped his family with support, by providing food or respite. There was no discrimination - it was a case of "there but for the grace of God - it could happen to my family". The problem was coped with and shared by the whole community.

My mother's story was quite surprising to me because my understanding of the past was that yes, someone acting strangely would be locked away, but firstly they would have been taken away - out of sight, out of mind.

I suppose my earliest recollection of something similar was when I read about, and then watched, the film of Jane Eyre and the mad first wife, locked away in the attic.

That was in the past when there were large asylums, the custodial approach, with no-one talking about the person who was ill, and treating the professionals as though they were infallible.

In fact, there were two pasts: the first being the rural society of pre-industrial days where the extended family of the community cared for, and managed, those who were inflicted with mental illness, and then came the second past. The urban conglomerations of the 19th century where scientific rationalism and a morbid fear of abnormality, together with the beginnings of the fragmentation of the family, caused the mentally ill to be rejected and locked away in asylums.

My son became ill eight years ago. Was that still part of the Victorian past or does it belong in the present? Because he was also put in an asylum with a custodial approach to care, so marking him as different. Someone to be locked away from society or as we now call it, the community. It was also the first time that I felt an accusing finger being pointed at me. I was his **mother** - it was my fault he was acting this way - and so I hid inside myself, ashamed that this was happening in my family and to me.

Our son is now recovering and fitting into the community, but when he first came home from hospital it was particularly difficult for me to cope with questions from friends and neighbours asking about him. They knew he had gone away to university but within the year he was back at home doing nothing. They saw him to be just another young man without a job, scrounging off his parents and on benefits and making no real effort to get back into the work place.

How could I explain that my son who **looks** perfectly well is **genuinely** incapable of full time work without telling them the truth and bringing upon him the very stigma I am trying to avoid. Therein lies the heart of the paradox of stigma.

By being open about schizophrenia, instead of helping to defeat stigma it can have the opposite effect particularly on a personal level. So I lied - I lied by omission. I said that he didn't like university and he was now looking for a job, but was being quite choosy.

Yes, as we all know, mental illness does affect the whole family. Not only does the person change but so do those close to him or her.

It is the fear of stigma and discrimination that changes things. It adds a further barrier and an additional burden to the user, carer and their families. It can turn the illness into a vicious circle. The result is people being shunned and isolated, with the possibility of deterioration and relapse, and for families a sense of shame, embarrassment and rejection.

This reminds me of a carer I met from Belgium, who had long suffered the emotional impact of her husband's mental illness. She was asked to appear on TV to give her view of how it was to live with someone diagnosed with schizophrenia. The result was a positive response from viewers, but her own family disowned her - they said she had brought shame on them.

For many carers like her, stigma brings on a feeling of resentment, not towards their loved one, but to the world outside for failing to understand, for not trying to demythologise the ignorance and fear surrounding mental illness and especially schizophrenia.

I have on many occasions in the past compared the stigma of cancer to the present stigma of schizophrenia. Cancer is now so openly talked about, cures are being found, and the fear of the illness and its consequences have been decreased due to research and effective treatments.

If we can take the fear of the unknown away, we may remove some of the stigma. Find a cure for schizophrenia and you will find the stigma melts away. If it's perceived to be no worse than any physical illness, the fear vanishes. But that's some way off.

In the meantime, we must do what we can to push back the wall of ignorance which surrounds mental illness, and schizophrenia in particular.

We can tell the people who say that the mentally ill are dangerous and a threat to the community, that most people suffering from a mental illness are far more likely to harm *themselves* than anyone else. We can confront fear with facts.

Given the reality that there is no cure at present, we must fight ignorance, fear and prejudice with facts. We must challenge the legislators. The Government passed Acts of Parliament to stop racial and gender discrimination, and it has also produced a disability discrimination law which includes the mentally ill - although that does nothing to prevent the tabloid press from continuing the stigma with its sensationalist headlines!

We may not be able to change human nature, but, with the backing of legal action, the law can only help. We can change the way people behave. Take for example seat belts in cars - people didn't always ‘clunk click on every trip’ (in case you're too young to remember, that was an advertising slogan from the past)
but once it was made illegal to travel without a safety belt on, people began to automatically fasten themselves up, their behaviour changed.

Perhaps similarly, we may be able to use the law to get people to ‘belt-up’ about stigmatising the mentally ill?

We cannot take away the pain of suffering - yet - but we must work to diminish the pain of stigma and discrimination that we all feel and which imposes an additional burden on all our lives.

Until a cure is found, stigma will remain with us, but it is vital that we all continue to fight against it and do our best to turn schizophrenia into just another illness to be challenged and treated as best we can.

Turning again to a more personal note and how stigma has affected me as a carer. Of course, I too was and am affected by schizophrenia and the stigma and discrimination that encompass them.

I became withdrawn and isolated, refusing to go out. I cried when I saw young people out enjoying themselves, thinking that my son would never have that same pleasure. I feared talking to anyone in case they turned away from me or worse, pointed a finger and started a whispering campaign.

However, slowly, one at a time, family and friends were told a little about the illness, then more when they asked. And so a wider circle became less ignorant, better educated, and a few small steps were taken towards mitigating the fears and prejudices that schizophrenia aroused in them and which contribute towards creating stigma.

My life changed also. I now work as a volunteer with NSF (Scotland) to help in anyway I can to bring awareness to people generally. In the past when I spoke in public, as I am doing today, I used a pseudonym. It is only with permission from my son and the fact that I am not on home territory and near to people we meet daily, that I am able to use my own name.

We live in a rural part of Scotland, a little isolated, but where the local people seem to know everything and everyone. Sadly, the present countryside is a reflection not of our rural heritage with its strong sense of community, but of our urban past **and** present. The situation now in the countryside is, if anything, worse than in the towns and cities. The few in the community who may support you are far outnumbered by the many who would shun you and make lives even more difficult.

Despite the fact that I'm standing here talking to you about stigma, maybe I'm a bit of a hypocrite. Here I am telling you all to go out and tell the world to stop the stigma by talking openly about schizophrenia, and yet I do not do this unconditionally myself. I select the people I take into my confidence and with whom I talk about schizophrenia. I discussed my son's illness first with family, then with other carers, now that organisations such as NSF (Scotland) have helped bring them together, and then slowly and carefully with close friends.

I have not yet managed to be open with neighbours, distant friends or acquaintances unless it is in general terms and not from a personal viewpoint. But this may be the only way to go at present. I cannot change the world single-handed and need to be able to live in my locality.

Stigma then is still a reality for us all as carers, and especially so in the countryside. It is one of the side effects of mental illness that must be recognised and challenged by professionals, carers and users, and the general public alike.

What of the future? We all expect the future to solve our problems. In five to ten years' time, surely the genome project and medical advances will have wiped schizophrenia and other mental illnesses off the face of the earth and at the same time do away with stigma. Right? No, wrong.

I suspect that stigma will be with us in one form or another for many years to come but, thankfully, there are great moves to combat stigma such as those by the professionals

- like the World Psychiatric Association which has set up a Global Educational programme against stigma - as well as
- the Royal College of Psychiatrists' campaign called 'Changing Minds'.

Initiatives are also being made by voluntary organisations such as

- EUFAMI - that stands for - the European Federation of Associations of Families of Mentally Ill people   - and of course by
- National Schizophrenia Fellowship (Scotland)

-   and last, but by no means least, by people like yourselves.

You may have seen the advert for UNISON on TV - one small body calls out 'move' and is ignored, but when a large mass of small voices shout together 'MOVE' the noise is deafening and people have to listen. That's **one** way I hope we'll ultimately overcome stigma.

Oksana 22 September 2000

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