



Peer Support: The Help Users of Mental Health Services Offer Each Other

(The views of 81 people on peer support)

May 2008

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What is HUG?

HUG stands for the Highland Users Group, which is a network of people who use, or have used, mental health services in the Highlands.

At present, HUG has 349 members and 14 branches across the Highlands. HUG has been in existence now for 11 years.

HUG wants people with mental health problems to live without discrimination and to be equal partners in their communities. They should be respected for their diversity and who they are.

We should:

- Be proud of who we are
- Be valued and not be feared
- Live lives free from harassment
- Live the lives we choose
- Be accepted by friends and loved ones
- Not be ashamed of what we have experienced

We hope to achieve this by:

- Speaking out about the services we need and the lives we want to lead
- Educating the public, professionals and young people about our lives and experiences

Between them, members of HUG have experience of nearly all the mental health services in the Highlands.

HUG's aims are as follows:

- To be the voice of people in Highland who have experienced mental health problems.
- To promote the interests of people in Highland who use or have used mental health services.
- To eliminate stigma and discrimination against people with mental health problems.
- To promote equality of opportunity for people with mental health problems irrespective of creed, sexuality, gender, race or disability.
- To improve understanding about the lives of people with a mental health problem.
- To participate in the planning development and management of services for users at a local, Highland and national level.
- To identify gaps in services and to campaign to have them filled.
- To find ways of improving the lives, services and treatments of people with mental health problems.
- To share information and news on mental health issues among mental health service user groups and interested parties.
- To increase knowledge about resources, treatments and rights for users.
- To promote co-operation between agencies concerned with mental health.

Introduction

Ever since HUG was established people with mental health problems have spoken out about how much support fellow users and patients offer each other.

We have lost count of the number of times that people have said that they often get a great deal more support in the smoking rooms of New Craigs hospital than when they meet professionals for more formal treatment.

In many other areas and countries people with mental health problems have repeated this theme. In some countries (especially New Zealand and the U.S.A.) this has resulted in successful projects being established that build on the support and experience that users can offer. These projects are often known as peer support projects or services. In them users are trained to become paid peer supporters who help fellow users on their journey of recovery.

In recognition of the success of these sorts of projects the Scottish Government in its document 'Delivering for Mental Health' made a commitment to the development of peer support services which would employ paid peer supporters.

In Highland a form of peer support has already been piloted on two occasions as part of the Transitional Discharge Project (a research project run by Stirling University in partnership with New Craigs Hospital, and originally developed in Canada). In this project mental health service users supported current patients in their discharge from hospital back into the community and beyond as part of a range of interventions to make the move easier to manage.

HUG had some involvement in this but was not a partner and was pleased that the evaluation of these pilots showed that such an approach was helpful. However despite this the Transitional Discharge Project never became a mainstream service and wasn't continued.

In 2007 we decided to look at the idea of peer support in more detail; both to explore our own belief that we do have a lot to offer each other but also to find out from our members what sort of service, if any, we would like to see established in Highland in the future.

We met in our 13 branches and held discussions with the people present about these ideas using a series of prompts for conversation. These discussions were written up and then turned into this report which was approved by the HUG Round Table (which is the HUG steering committee). In total we involved eighty one people in the meetings.

Most people, whilst being very aware of the support we can offer each other, had little or no knowledge of the peer support projects that already exist and so these discussions were based around the basic issues that we feel need to underlie the development of these sort of services.

Do users have anything to offer other people with mental health problems?

There was almost unanimous agreement that we have a great deal to offer each other and that we already do so. In the network of Drop In Centres and Training and Guidance (TAG) units, amongst social networks of users, in self help, advocacy groups and other groups such as 'Healthy Minds' and 'No More Secrets' peer support is a daily activity that largely goes un-remarked but which greatly enhances the lives of fellow people with mental health problems.

In this we offer the ordinary contact and companionship that is basic to the very essence of being human. However, as users, we are often troubled or sad or in crisis and in these circumstances, as well as the everyday, we offer support, we offer a listening ear, we offer social contact, stop isolation and provide advice, conversation and understanding. We offer a shared experience and empathy, ideas and encouragement to help people in the situation they find themselves in.

We provide moral support and help each other develop a voice in our treatment, we accompany each other to meetings that we are anxious about and improve each others confidence. By doing things together and learning from each other we learn new skills, gain new friends and may ultimately find paid occupations.

We support each other, provide company, a shoulder to cry on and the opportunity to have fun and laugh together. We can go into a drop-in-centre feeling very down and then come back home full of laughter. By offering these things we share experiences and promote kindness, hope, openness, strength, trust and friendship.

This can help us with our motivation and help us on the path to recovery; by being inspired to try out new things and by finding out from each other what works and what doesn't.

Just sitting and listening can be a powerful gesture. Going shopping together or doing something we enjoy, such as music or creative writing, can help us appreciate and get on with our lives. Doing things together in groups can be a great help.

Why is this support so special and how is it different to professional help?

The knowledge that we have been through similar experiences can create an immediate bond and sense of trust that we cannot find elsewhere. We find that we can be more open to each other in ways that we may not with professionals or other people who haven't experienced mental illness.

We often feel that when we are in the company of fellow users we will be free of stigma, and that the judgemental attitudes we sometimes experience from others will be absent.

We find that we don't have to explain ourselves as an understanding of what we have been through already exists.

We often mentioned the cliché, “We’ve been there, done that, got the T shirt” which, to most of us, explains it all. Other ways of explaining the connection are:

“The shared experience of having seen the black times and knowing what it is like in a crisis.”

“We have all been to the same place, although along different pathways so we can help each other through our knowledge of each other’s journey.”

“If you are with people with mental health problems then you can all laugh and joke on a level playing field.”

“People don’t understand the self-consciousness or extra insecurity with mental illness. You can feel made of glass and others don’t understand it but here you can drop the mask.”

Because we have these experiences we may be able to encourage and inspire each other. Because we are all at very different stages in our recovery we can help people understand that there is a chance of a better life. Because we often do similar things when we are ill we may, through that experience, have an insight and perspective that can’t be found elsewhere.

One thing important to us is that in each others company we often no longer have to put up a front or keep up a mask for our own protection. This is something that we may not be able to do with other people in our local communities. We may feel very vulnerable and wary of the community we live in and may find refuge and comfort when we meet people with similar experiences. By being able to help each other out we not only demonstrate our respect for each other we also enhance our own sense of self-worth.

The things that we offer can be different to those that professionals have to offer. We often have a great deal of time to give, which they rarely do. We aren’t meeting targets, we may have a better insight and are perhaps less likely to judge and we have no paper work to deal with when we leave each others company.

It is a different relationship; we are friends who happen to help rather than therapists and as such we see each other because we want to, we share phone numbers and experiences and tell each other things that we may be reluctant to reveal to a professional. We may be in a position to be more spontaneous and take more risks and promote greater freedom and an absence of the sort of rules that professionals may both have to live by and promote.

Despite a number of us saying that professionals may not have the depth of personal insight, the time to spend with us and may be restricted by professional boundaries in how they interact with us, many of us were at pains to point out that the vast majority of professionals have a great deal to offer us and can be the key to our growing wellbeing.

We also knew that, whether they are open about it or not, many professionals have also experienced mental health problems themselves and often have the very understanding we sometimes assume they don’t have. In fact, for those professionals who do provide care, and are also open about their own experiences, we felt that they may already be providing the enhanced sort of service that peer support is sometimes perceived to offer.

A few of us pointed out that the divisions we create, through categorising each other, obscure the fact that we are all individuals with different views and skills. Most of us in some way, have something to offer, whatever our background or label.

Can we hinder each other?

A very small number of us felt that the importance and connection that a shared experience of illness provides means that, whatever our relationship, we cannot see peer support as anything other than beneficial.

The great majority of us disagreed with this. There are all sorts of circumstances in which as peers we can inadvertently damage each other.

We often exchange information and give advice and although everyone has a right to do this, the knowledge that we have may not be correct and, given in the wrong circumstances, has the potential to create a lot of damage.

We can be vulnerable to other people; their sadness may provoke our own sadness, their descent into crisis may trigger off our own crisis and the death of fellow users can be as hard as losing a family member.

We are not always as consistent as we might like to be, through no fault of our own illness and the world our illness creates can make it hard of us to be there when we may be needed by others. It may be good to mix in a drop-in-centre but it may be a misplaced trust that invites any fellow user into our own homes to combat our isolation when we are also open to exploitation.

Sometimes our own need to help may obscure from us the reality of what would really help someone else, our own need for support may make us at times a burden for fellow users to help with, our own need for company may occasionally make us overuse the phone numbers fellow users have given us.

Our need to be helpers could make us take over other people's lives and unintentionally make them dependant on us.

The damage caused by our own experience of mental ill health may also sometimes make it hard to support and share with fellow users.

Some of our relationships may be turbulent but may assume an even greater significance if we rely a great deal on another user who may also be vulnerable.

When we are in crisis we may have a great need to contact our peers for help but they may not have the resources or resilience to provide this sort of support at delicate times such as this.

However, the fact that a relationship has its ups and downs and may be draining doesn't necessarily mean that it is damaging; by interacting we grow and take risks and relearn social skills as well as learning to stand up for ourselves.

Sometimes the tension and emotion in the places we meet can be difficult to deal with and the wear and tear of high emotion grinds the benefits of peer support away. However if we have a person, such as a professional, who can take on some of the emotional intensity on our behalf then the support we can offer each other may flourish.

The very fact that we are all users may mean that we become over-involved. We have a great investment in mental health and what we are all going through and therefore we may become disproportionately damaged by the emotiveness of our lives.

When our friends are very ill we may not have any idea about the safest and most effective way of helping them. When we assume a connection with another user we may be mistaken; we may share some experiences but equally many illnesses are different and as individuals we are certainly different; the bond we assume that we may naturally have may not always be there.

Sometimes the negativity of what we experience and sharing that negativity with fellow users may, far from inspiring us to find solutions, reinforce our own pessimism. We may sink into the role of invalid or become comfortable with constant illness.

In summary, this section of our report clearly shows that we routinely offer peer support to each other both when we go to mental health facilities and through our own networks.

We believe that despite some of the risks and limits this support can attract it is a positive, natural and inevitable part of the gift we give each other by the very fact that we live in each others company.

This support is especially important in that it is drawn from a perspective of shared experience, mutual co-operation and inspiration. It is often very different to the sort of therapy we get from professionals and shouldn't be seen as a replacement to that therapy. It may not even be anything to do with therapy but it is very much to do with our quality of life and enhances the other supports we get for our mental health.

We see the informal support we offer each other as very valuable and as something that needs to be enhanced and built upon whilst acknowledging the very real limitations that it can also have.

Developing a formal peer support service

Despite a great deal of agreement about the value of peer support we had a wide variety of opinions when we came to looking at the idea of making this a more formal part of our recovery journey. We discussed the idea of either having paid peer supporters and/or voluntary supporters as part of a peer support project and had the following observations to make:

1. A great number of us think the idea is a brilliant one and long overdue and that we should develop peer support projects as soon as possible.
2. There are workers within the mental health field who are already users. When we find this out we usually feel a greater sense of connection and empathy with them.

They not only have skills to offer but a shared connection, which we value greatly. This is visible proof to us that peer support could be very positive.

3. Although we like the idea a great many of us would not have the strength to become formal peer supporters ourselves. It would create too much pressure and anxiety and may cause us to get ill again rather than enhance any bonds we create.
4. Formalising what is in essence the opposite of a professional relationship could destroy the very thing we value. We would become another sort of professional, bound by the rules of our work and profession. This would undermine the equality and informality on which peer support is based. To some of us this is OK as although it would not be like the everyday peer support we value so much it would be a helpful addition to our care and if based in a set of standards based in the belief in recovery could be very helpful. However some of us feel that it would undermine the very essence of peer support and would create barriers and promote a status in the supporters that detracts from the whole idea of a shared journey.
5. Who becomes the supporter and who becomes the supportee? And what does that signal to each person?
6. A few of us worried that this would be a way of promoting a new brand of poorly paid work (or voluntary work) that would be a cheap way of providing new services.
7. Although we have a lot to offer as a result of our experience some of us felt that this doesn't mean that we have the skills to deal with people with mental health problems on a more formal level. We may, in a well meaning way, do more harm than good.
8. Many of the people who provide care and treatment to us have spent years and years learning skills to provide safe and effective treatment. Why would people expect that we would have these skills on the basis of our past experience and why is there an assumption that we could learn them quickly? Maybe some of us may actually damage our supportees because we lack the knowledge to help them effectively in their recovery journey. However with training and appropriate recruitment this may not be a problem.
9. As users (especially in rural areas where we would probably already know each other very well) we may become over involved and end up with confused roles and boundaries which have to be developed to support us in this new position.
10. We may just convert ourselves into a person with all the disadvantages a professional role may carry and few of the advantages, and by becoming peer supporters we may provoke resentment in the people we end up supporting.
11. It may be better to enhance the completely informal support we offer each other routinely already.
12. Some of us just didn't know if it would be a good idea.

"The big difference is it's me and my friend; no one can say I can't have a phone number, no one can dictate the hours we do it."

"It has the potential to help people, especially people who are most ill and who are isolated. Those who are most in need of support are those without carers; we need peer support then. However if it becomes a job then they have to be accountable and monitored. It could be good to develop it, it could do a lot of good as we know we can help each other and already do. But peer support is different to what we offer each other as friends."

Should peer supporters be paid?

Again we had a mixed view on this subject. Most of us thought that if we are undertaking a formal role as peer supporters then that job should be paid for and the pay should reflect the value of what we do.

Some of us thought that a peer supporter may be broadly equivalent to a support worker employed by a Community Mental Health Team but some of us commented that although this may be the case we didn't think that support workers were paid enough anyway. We felt that if peer support became a defined role in a formal service then it should definitely be paid. Quite a few of us said that we would like to have a job like this.

However, some of us felt that being paid to deliver this sort of role diminished and devalued what we were offering each other and also wondered who gets the pay when we provide peer support; peer support is usually mutually beneficial so who should be paid and who shouldn't?

"To volunteer and not be paid. This is enough, it would be very different if someone were paid."

A few of us thought it would be an ideal voluntary position where we would learn new skills, help other people and help ourselves. Some of us felt that once we had gained the appropriate skills it should move from voluntary to paid work.

Some of us raised the point that the sad reality is that as users we may often have to take sick leave and that, at present, paid work doesn't adapt to an erratic work record even though what we could do when we are well may be very valuable. This didn't mean that we shouldn't be paid but did mean that it could be complicated.

Some of us also said that pay should be made to reflect our ability to motivate and pass on skills but the pay shouldn't by its existence professionalise what we are doing.

A few of us also said that whilst pay is good when it reflects the value of what we do, it also brings pressure and responsibility that we wouldn't have in a voluntary role and in a practical sense may cause some of us problems with the benefits we are already receiving. This may mean that there should be a combination of roles that span the spectrum from friendship to volunteering to paid work.

Where should peer supporters work?

We had no firm ideas about this.

Many of us thought that there should be posts created in Community Mental Health Teams for this sort of work but a few of us worried that if this were the case it may put some people off or 'medicalise' what we are offering; it may create the wrong image.

Some of us thought that peer supporters would be ideal to help people out of hours and in crisis (although some of us also said that that would be the last place we should work).

Some of us said that they could be very helpful with people who are newly diagnosed or discharged from hospital.

We had an idea peer supporters could be based in the hospital. They wouldn't be assigned a supportee but would be encouraged to mix with patients in hospital striking up conversations, inspiring, encouraging people to get involved in activities and breaking through some of the anxieties and boredom that some patients may experience. However a few felt that some patients, especially if they are very ill, may find this a bit overwhelming.

Some of us said that finding out that a peer supporter is someone you already know may cause problems.

Some of us were keen for peer support projects to be based in and developed by user groups and a few of us liked what they had heard about peer support in New Zealand and hoped that we could follow their way of working.

However, a few of us were doubtful about basing them in user groups and said that we need to guard against the pressure this may cause and the need to provide adequate supervision and safety. A lot depends on how the user group is structured. By basing peer supporters in user groups we may promote equality and dissolve the attitude of "them and us."

The skills a peer supporter needs

A few of us said that by having been through illness themselves peer supporters will inevitably, by that experience, have developed all that is needed to be a peer supporter. However although we agreed that they needed personal experience of mental health problems most of us had suggestions for other skills that may enhance their role, including:

- Assertiveness skills and knowing how to establish, and maintain, boundaries
- Organisational and administrative skills
- Counselling skills and communication skills
- Being warm and approachable
- An awareness of body language
- The ability to make connections with people and find common interests
- Being non-judgemental, empathetic and having good people skills

- Patience and understanding
- Knowing how to put their personal experience to positive use
- Understanding their own illness and other illnesses
- An understanding of Mental Health First Aid and what to do in a crisis
- Anger and stress management
- Dealing with relationships

People also said it was important that the peer supporter was stable in their own mental health, and that they focussed on recovery.

What problems may a peer supporter face?

As we have said already, we worried that peer supporters may get over-involved and may be unable or reluctant to develop the boundaries that they may need for their own protection. This may be especially the case in rural areas where we all know each other well. In some places everyone knows where everyone else lives and what we do and don't do. Developing boundaries in such places is a process that requires mutual agreement and cannot be imposed.

We worry that some may be vulnerable to the suffering of those that they are supporting. The same may occur if they find that the assistance that they are offering doesn't help.

There is a possibility of creating dependency and on another level as peer supporters we may not be as reliable as we would wish to be because of the problems our own illness may have created.

The pressure of the job and the need to do it well may make us ill again.

What support and protection do peer supporters need?

Peer supporters would need much the same sort of support as any other mental health professional or volunteer. This would include:

- Financial support – wages if paid, expenses and access to transport if a volunteer
- Supervision and training, in such things as counselling, understanding the mental health system and community care, Mental Health First Aid
- Support tailored to their own needs provided by appropriate professionals
- The use of dedicated phones and the ability to keep private life private
- Knowing who to contact in a crisis
- Support to create a division between peer support and friendship
- Access to back up and support for situations they find difficult
- Choice about who is the supporter and supportee
- Emotional support
- Vetting and screening of supporters
- Help in dealing with anger
- Help to stop them becoming overprotective, and
- Guidelines in how to deal with some situations.

Should peer supporters be 'well'?

Most of us felt that in order for them to do an effective job peer supporters should be generally well and their illness well managed, and be a long way down the road to recovery.

However a few of us challenged this idea and said that wellness and how we view it should change. For instance, someone who is a bit high or on the edge of illness may bring all sorts of qualities, questions and ideas to their supportee that cannot be gained if we insist on stability and 'normality'.

Witnessing ill health in a supporter may, far from causing damage, enhance and bring to life a relationship. In some ways if we had a set of peer supporters who were always 'well' then we may be presenting a false image about us and how we live. The very fact that peer supporters are users means that some will inevitably become ill. To try to hide this may give the opposite message about the value of peer support to the one we want to promote.

What status should peer supporters have?

We felt that they should have equality with any other mental health professional and tended to put them on a similar level as support workers or home carers. However when we said this, some of us said that these workers have traditionally had a low status which we didn't agree with. We wanted to be sure that we didn't convey low status on peer supporters too.

A few of us said that they were so different that it would be hard to compare them. We pointed out that sometimes the years of training that some professionals have been through may merit a gradation of status. But others said that first hand experience merits its own status and recognition.

How do we stop a peer supporter becoming another 'professional'?

The use of this label is maybe unfortunate but perhaps reflects a shorthand for those professionals who we feel reinforce the 'them and us' attitude. Who keep themselves distant from us, may assume that they are superior to us and may believe that they have the right to tell us what to do rather than join us in our life and journey.

We didn't want users to give themselves a different status once they became peer supporters but had a feeling that it may be inevitable.

We did feel that simple things such as making the peer supporters aware that we didn't want this to happen, would be good as would developing a set of values that peer supporters abide by.

We felt that other peer supporters could play a hand in this and also felt that we could foster an atmosphere that promotes the idea of peer supportees themselves moving on to become peer supporters.

Equally it would be good for peer supporters to keep contact with their own networks of peers to reinforce to them where they have come from and why they do what they do

How would we measure the success of peer support?

First of all we agreed that this would be difficult. But we suggested that we should ask everyone connected with the process for their views on it and that this consultation should have a particular focus on users.

We also felt that if we could show that the supportees became healthier then this would help decide if it worked. Equally if supportees start doing things again and making contact with other people then this could be a sign of success.

If supportees make it clear that they don't want to see a supporter then it is likely that it is not working. But then again a different peer supporter may be the solution to this.

Conclusion

Many of us feel that a formal peer support programme in the Highlands could enhance the care that can be offered to people with mental health problems. Some of us disagree strongly with this but then some of us disagree with a whole variety of mental health services. Peer support could be a useful addition to the range of services that we can benefit from but should not replace other services or be a service people are pressured to use.

However, we do have very real concerns that in order for peer supporters to provide benefit to other users they need adequate training and supervision that builds on and enhances what they already have to offer by merit of their shared experience.

We think that a formal peer supporter may help a lot but that by the very fact that they have a defined role distances them from informal support.

We are unsure of the exact way in which peer support should be promoted and see merit in peer support projects being based in user groups but also in Community Mental Health Teams or in the hospital.

We could usefully learn from the way in which peer support has been developed elsewhere and by learning from other people avoid some of the pitfalls that some of our members worry about.

APPENDICES

APPENDIX 1:

Support from the community to make the transition from hospital to home

Supporting others in the community and hospital when you have your own problems can seem at first a little daunting for somebody especially if they have had a period of illness themselves recently.

However, with the right kind of support, safety measures and ready access to hospital for the person making the transition from hospital it can make the job in hand far more easy to cope with for the supporter.

The first thing is that the supporter is contacted through the transitional nurse and not directly by the recipient. There are rules like females support females and males support males. I would like to add at this stage that no relationships of an intimate nature are tolerated between the supporter and transitional patient. Neither is the supporter or recipient allowed to go into each other's homes. This allows for a safety gap which is needed in the case of the supporter who can also be suffering slightly from his/her own problems.

I embarked on a pilot project run in the Highlands between 2001 and 2002 by the Universities of Stirling and Western Ontario, Canada respectively. The first step is to meet the person in hospital along with the transitional nurse and the contact number is given to the supporter so that telephone conversation can be established up to 3 hours a week or so depending in the circumstances. About once a week or so a meeting is arranged in a public place.

The buddy process then continues for a set period of time until the patient is ready to get by with a reduced period of support. Knowing that you can talk to somebody who has gone through the same sorts of periods of illness and is empathetic encourages the relationship between buddies.

The supporter keeps a diary of how he or she thinks things are going and this is looked at by the transitional nurse from time to time. If things become difficult the transitional nurse can take over for a short period or assign another buddy.

I have personally seen people benefit whom I have supported and this has given me a sense of value. It is good to see someone get better day by day who might have otherwise been kept in hospital long term.

It is also my opinion that this should neither reduce dialogue between community mental health teams and patients.

If it can be seen that there would be definite safety measures and not substitute measure then Peer Support in the Highland would take a giant leap forward. As we all know the support starts in the hospital wards between patients as real life experiences are related.

Research papers about the New Craigs transitional discharge scheme include:

An exploration of factors affecting the implementation of a randomised controlled trial of transitional discharge model for people with a serious mental illness. Shirley MacIvor, F Cameron, Reynolds W, Lauder W, and Veitch T. 2005 Journal of Psychiatry and mental health Nursing.

The effect of a transitional discharge model for psychiatric patients. Reynolds W lauder W MacIvor S Veitch T 2004 Journal of psychiatry and Mental health nursing

APPENDIX 2:

An Interview with 'Healthy Minds' (Badenoch and Strathspey) a group whose members provide mutual support to each other

Our main activities and aims are to provide local community support to people coming out of hospital or those who have mental health problems in the community as well as people who are isolated.

We do group activity and meet with other people to help progress our rehabilitation

We teach positive coping strategies about illness, about recognising the warning signs and health education and the promotion of healthy lifestyles.

The group is also there to support people who feel ignored by the medical profession or whose treatment has been terminated.

When a new member joins we meet with them and go through the basic stuff of what Healthy Minds is about but we don't make it too deep as that can be off putting.

Pam will phone everyone up on Sunday night to say what will be happening each day of the next week . We get together in a members house on Monday nights and we discuss anything we want. We go for a meal on Tuesday or have a games night or a quiz night and maybe on the Wednesday we go for a walk.

It's all optional and flexible we can change days and activities to suit everyone.

The group is absolutely brilliant. It's because of everyone who is there. We talk to each other but outside people don't talk to us; they think we are headcases.

We know about things like sleep patterns, being isolated, not being able to answer the phone or get out . We are bonding so much and we all realise the need to keep what we say confidential. You can't beat what we have.

When I first came here I had had nothing for months and then I met Pam and I have never looked back

We look at life before we became ill, at life now and how we see the future. We show what we can do and have empathy with each other because in different ways we have all been through it. We know what its like to shut the door and never go out or what its like to take panic attacks.

Now we have the discussion group; it is so good, everyone contributes and gets it out their system. We look out for each other and take people to see the doctor if they need a companion.

We all have fun, we have a great time , we laugh together and we face challenges together.

Simple things like exercise , going for walks , going to the gym, aqua aerobics, complementary therapies; stuff that gets us out the front door.

We are all available to each other and keep in touch on the phone.

We try not to put pressure on anyone or vice versa. It's all about respecting each other.

We are all equal in the group

People can go from being very quiet and in themselves to speaking and joking and laughing.

We are all involved, we all vote on our aims and what we do. We all take part

We use the community car to get people in from different villages as transport can be an issue We phone people up if they have been away for a time, not to pressure them, but to help them come along if they want to.

We look to see what everyone can offer each other. Everyone has skills, even if sometimes we feel that we can't do much, but opening the house up offering hospitality or making coffee is a skill too.

Normally it all ends up in a giggle, the rapport is excellent.

When Pam who does nearly everything had to go back to work due to the benefits changes we all realised we had to help out too and in the end it made the group even better.

I get a lot from it too it makes me happy seeing folk getting better and beginning to laugh. I've created something worthwhile.

When I got out of hospital I was very isolated my c.p.n said "What about healthy minds?" it took me two months to go but you get such a buzz and after you get out and go for a walk together you come back feeling high as a kite.

APPENDIX 3:

Recovery and Systems Transformation by Larry Fricks *(edited by HUG)*

Beginning in 1999, Georgia was the first state in the country to set up an independent service called Peer Support delivered by a trained workforce of Certified Peer Specialists.

Public sector officials and consumer leaders concluded that, in order to achieve stable funding for peer-support services, the services would have to be developed in a way that made them eligible for Medicaid funding under Medicaid's psychiatric rehabilitation option. Accomplishing this objective required melding two cultures: the consumer recovery movement with its informality, vision, and energy and Medicaid, with its complex bureaucratic requirements.

The peer specialist role is the pivot of Georgia's effort to manage its services for people with serious and persistent disorders in a manner that promotes consumer friendly recovery values.

After two weeks training, peers must pass a written and oral exam that demonstrates they have the working knowledge of a set of core competencies. More than 300 peers have been trained and certified in Georgia with the Peer Specialist's role being to provide direct services designed to assist consumers in regaining control over their own lives and control over their recovery.

The aim of peer support is to provide an opportunity for consumers to direct their own recovery, and to teach and support each other in the acquisition and exercise of skills needed for management of symptoms and for utilization of natural resources within the community.

In addition to providing direct services, peer specialists are trained to act as change agents in the mental health system, promoting strength-based recovery with their unique insight into self-directed recovery gained by their lived experience.

The Georgia training curriculum was designed by Ike Powell, Director of Training for the Appalachian Consulting Group (ACG) based in Georgia. ACG has written a resource kit for national distribution and has trained peers in Hawaii, South Carolina, Michigan, Iowa, Connecticut, Wyoming, Florida, Massachusetts, Washington, Illinois and Texas.

The Georgia and ACG national training focus on the Five Stages in Recovery, and the training incorporates three things that contribute to the disabling power of a psychiatric disability – symptoms, stigma and negative self-image. The five stages are five different ways that people relate to the disabling power of a psychiatric diagnosis at various times in their lives in regard to symptoms, stigma and negative self image.

The stages are: 1) overwhelmed by the symptoms; 2) give into the diagnosis, see no possibility and become dependent on the system; 3) begin to question how much their lives are really limited by the diagnosis and how much by their own belief system; 4) begin to challenge what they had originally seen, or had been told, were limits; and 5) begin the process of moving outside or beyond the system for their supports.

The Georgia/ACG national training helps the peers to understand and identify each stage, how people get 'stuck,' and interventions that enable people move on with their lives.

Georgia's pioneering work in peer support was driven by a very well organized and outcomes-focused consumer movement. A statewide organization – the Georgia Mental Health Consumer Network with a membership of some 3,000 – holds an annual conference every year. At that conference five top priorities are determined and, for almost every year of the 15 years of conferences the number one priority has been employment.

This resulted in a statewide effort that began in 1998 to move 20 % of consumers in day treatment to community jobs with competitive pay by the end of 2000. The goal of putting some 2,500 consumers to work within two years was not only exceeded, it was accomplished six months early.

With a historic emphasis on employment that addresses the crushing poverty so many mental health consumers confront it is no surprise that Georgia consumer leaders were unanimous in advocating for a new workforce of Certified Peer Specialists to provide peer support services.

Georgia's consumer leadership exemplifies recommendation 2.2 of the report of the President's New Freedom Commission on Mental Health (2003) regarding system transformation. On page 37 of that report it states, "Consumers who work as providers help expand the range and availability of service and supports that professionals offer. Studies show that consumer-run services and consumer-providers can broaden access to peer support, engage more individuals in traditional mental health services, and serve as a resource in the recovery of people with a psychiatric diagnosis. Because of their experiences, consumer-providers bring different attitudes, motivations, insights and behavioural qualities to the treatment encounter."

Georgia's research of its data shows that peer support is both cost effective and efficient with day treatment annual average cost per person at \$6,491 compared to peer supports annual average cost per person at \$1,000. Over a 260 day period, data from the treatment plans of more than 300 adult Medicaid recipients diagnosed with schizophrenia, bipolar and severe depression showed a statistically significant improvement in peer support services over day support services in three outcome measures: symptoms/behaviour, skills, and needs/resources.

ACKNOWLEDGEMENTS

With thanks to all the members of HUG, and other mental health service users, who contributed to this report.

Please feel free to photocopy this report. The report can be supplied in large print or on tape.

However if you use this report or quote from it or use it to inform your practice or planning please tell us about this first. This helps us know what is being done on our behalf and helps us inform our members of the effect their voice is having.

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