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Philadelphia, USA

“The recovery revolution”
Peer specialists on the front line

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The second annual conference of the National Association of Peer Specialists (NAPS) was held in Philadelphia USA . The 4 day event as promised, proved to be an outstanding success in bringing together approximately 400 peers from all over the USA and of course 3 very lucky people from Glasgow!

In America the title ‘Peer Support Specialist’ is most commonly used, but I feel it is important to note that this does not in any way infer that you are a ‘special’ peer! Everyone is special - we are all the same but all individual. In order to never lose sight of this, in Scotland we have chosen the title ‘Peer Support Worker’ or PSW, as I will refer to for the rest of this report.

It is my aim throughout this report to further progress the peer support movement, but just in case there is anyone who doubts that recovery is possible, I would like to share a poem with you that I learned during the conference, titled ‘I’m The Evidence.’

I’m The Evidence

I’m the evidence

For how belief inspires
How hope transforms and
How giving heals the soul.

I’m The Evidence

For what can be achieved
How feeling connected can ground and
How there is invaluable worth in an act of faith

I’m The Evidence

For how an example can lead
How far encouragement can take you and
How one step begins a journey towards endless possibilities.

Anyone who makes the choice for themselves to undertake the long and hard road to recovery and succeeds in the face of all adversity is ‘the evidence’ that recovery is possible.

Believe!

Introduction

It was the aim of every individual present at the conference to learn of innovations, skills and knowledge to help them become the best peer supporter they could be. It was an excellent opportunity to meet others involved in the peer support movement and an opportunity to share ideas and learn how to create a better, more responsive system. A system for children, adults and older adults that supports wellness, embraces hope and fosters true recovery from psychiatric disorders. Building a culture that supports recovery requires the support of health professionals and others to help develop a lasting, effective movement... We can't do it alone!

The lasting success of this movement requires uniting and unifying programs and the fusion of both the recovery and medical models of care. We need to work together and then make it happen!

Recovery from psychiatric illness is a real possibility but in order to do that we must make a commitment to actively facilitate recovery and build resilience to face life's challenges. Recovery is remembering who you are through the darkness and using your strengths to become all that you were meant to be. It is my sole aim, and the aim of all PSWs worldwide to support the journey.

Recovery is a deeply personal and unique process of change and a way of living a satisfying, full, hopeful and contributing life. Who knows better the route to recovery than one who has travelled that path?

It is the aim of this report to provide information on the progress of the peer movement in America and to examine more closely new innovations and possible goals for the future of the peer support movement in Scotland. I will pay particular attention to the role of the PSW in community integration and also methods used to evaluate the great work we are doing. I will also consider how to expand the role of the PSW into all areas with a responsibility of care for others.

It fills my heart with absolute pride, joy and hope to think that we've come such a long way already and yet this is only the beginning of what could prove to be the biggest and most wonderful, life changing revolution, which the field of mental health in Scotland and the rest of the world has ever seen.

In the current pilot scheme being run in Glasgow, PSWs are not directly involved in community integration programmes, that is, assisting people leaving hospital in returning to live independently in the community. This is an area of work which is producing excellent results for PSWs in America, with a significant drop in the number of people being re-admitted to hospital. Therefore in this section I will look more closely at promoting successful community integration and the valuable role we as PSWs could play in implementing this.

Community Integration

When will the system stop asking the question, “Is this person ready to live in the community?” and start asking instead, “What do we need to do to accommodate this person to live in the community?” and then, make it happen!

Recovery is a self-determined and holistic journey that people undertake to heal and grow. Recovery is facilitated by relationships and environments that provide hope, empowerment, choices and opportunities that promote people in reaching their full potential as individuals and community members.

Through a series of presentations and workshops I examined the many ways in which PSWs and other providers can promote community integration for those they serve.

Currently there are many people out of hospital living ‘in’ the community, but not ‘of’ the community. Why is this so when it has been shown that people can live in the community with the right supports? I believe that there are still three main areas of concern, which are preventing successful integration.

1. Stigma and discrimination

Stigma and discrimination still exists as a major barrier for people with poor mental health. There is a growing need to adopt and use recovery language in the community at large, in schools, hospitals and in the media. People living with poor mental health are often discriminated against by possible employers, mainstream social networks and affluent communities who simply do not want this ‘type’ of person on their doorstep, on their payroll, or in their club or restaurant.

2. Poor Housing

People returning to the community are often placed in the most challenged or impoverished communities. Areas experiencing high levels of unemployment, exposed to crime, substance abuse and violence. The language of recovery and hope does not exist when people are living in such conditions and inevitably the majority end up back in hospital, or worse. People should be able to live in the community and have the opportunity to be valued like everyone else, with equal access to jobs, education and leisure facilities. Everyone should have the right to have relationships, to be parents, and above all the ability to make their own choices. **It’s all about choice!**

Studies have shown that decent housing and support are essential components in recovery and are in fact cost effective in the long term. More people become employed and are no longer admitted to the hospital, eliminating the ‘revolving door’ of discharge and re-admission and in turn alleviating the strain on the already over stretched resources and finances of the national health service and prison systems.

3. Lack of understanding and support

I have arrived at the conclusion that there is still a fundamental lack of understanding when it comes to community integration and what we as caregivers can and should be doing to alleviate this. It is true that the government funds many projects and support systems in the community and they should be praised for this progression and forward thinking to get people out of hospital and back to living independent lives, after all it was not that long ago that people with a psychiatric disorder were incarcerated in institutions never to return! Society as a whole has come a long way and it is not my intention to discourage this momentum, or indeed to disrespect any organisations that currently exist, as they are invaluable in the community and provide a much needed life-line for many people. However, as things stand are we really promoting full integration into the community? Are the current programmes available actually evolving in line with the recovery model which states that, full recovery, and the ability to live independently with the freedom of choice is possible?

Think of the 'clubhouse' or 'drop-in-centre' as an example. Realistically this is still a segregated setting where people with psychiatric illness, or a history of this, can meet up and participate in organised 'staff-directed' activities. A group like this in the community is still wide open to experiencing stigma or discrimination from the rest of society (especially the groups which pile all the members into a mini-bus with the project name proudly emblazoned along the side to go an organised outing!). This is not really participation in the community, as essentially it lacks the fundamental right of each individual to make choices. To reiterate, there is nothing wrong with the clubhouse, but people should have the choice either to go there or to go somewhere mainstream instead, and use public transport if they wish! There are an abundance of better choices we can utilise in the community such as cinemas, gyms and restaurants. Think! Is someone really participating and becoming integrated into the community by watching a film in the clubhouse?

It is apparent that before we can make community integration work, we have to look at what people really want in their lives and what they need to recover and remain healthy and happy in the community without the need for further hospital admissions. Essentially people living with a psychiatric illness want the same as everyone else for example, decent affordable housing, employment, friends, families, intimate relationships, happiness, security and a sense of belonging. Recovery begins when people experience hopefulness and support, and become engaged in the community and interests of their choice. Recovery occurs when people are empowered with self-confidence and self-esteem.

Specifically, what can we as Peer Support Workers do to promote successful community integration?

PSWs can have a profound impact on the success of such programmes because we are ourselves people in recovery, and have personal experience with mental health problems and all the challenges this brings. PSWs can speak openly about their personal struggles and simultaneously serve as role models and peers in the recovery process while spending considerable time in the community with people,

helping them to develop new cognitive and behavioural strategies for coping with day to day life.

We can help to reduce stigma and discrimination by dispelling current myths that exist. For example, that people with psychiatric illness are violent, will be ill for the rest of their lives and never recover, and cannot possibly obtain and then maintain paid employment. We can become effective 'stigmabusters!' by educating society with the truth and increasing the contact between people with psychiatric illness and the general public. It is a fact that, at most, mental health status contributes a trivial amount to the overall violence in society, especially in today's violent knife and gun culture where there are random stabbings and murders every week carried out by members of the general public. Yet it takes just one act of violence by someone with a psychiatric illness to dramatically regress public opinion and start the irrational demand for people who are ill to be locked up and kept out of sight. This is purely fear caused by a lack of education and understanding, driven by the media in their poor portrayal of people who are ill. The continuing success of the PS movement has the ability to raise awareness of the facts and change public opinion once and for all.

Did you know that statistics reported by employers show that attendance and punctuality of people with psychiatric illnesses are better than average and that their motivation and quality of work is as good, or better, than those of other employees? It is a fact that working reduces symptoms and reduces the need for further hospital admissions, so it is in fact very cost effective for the economy. We as PSWs can approach employers to raise awareness of these and other findings by conducting a series of presentations or workshops that demonstrate the reality of recovery.

PSWs in the community can play a key role in treatment and recovery by helping individuals to find services (if the person wants services!), by promoting self-determination (the right to have power over one's life), and by providing encouragement and fostering hope. We have the ability to listen uncritically to the person's interests and wishes and encourage these without being intrusive, but instead, available when needed. Basically, any actions we can do to allow the person to facilitate their own choices and become more independent will alleviate some of the demands on the care giving community. Supporting the person in areas such as parenting, child care, physical health, employment, education, social interactions, housing and transportation will help to eliminate the barriers to living successfully in the community. Taking parenting and child care as an example, over two-thirds of all women and more than half of all men who experience psychiatric illness in their lifetime are parents. It is one of life's most significant social roles. Lack of parenting supports and lack of accessible and understandable information about legal rights where parenting is concerned is simply not acceptable. People with psychiatric illness, like most other people, want to be the best parents they can be.

It should be the role of any organisation that promotes community integration to simply 'ask' the person what they want. Find out their hopes and dreams by getting to know them. Know their strengths and skills but also their barriers by building up a rapport and bringing mutuality to the relationship. Who better to do this than ourselves. We as PSWs can model recovery and behaviours and instill the belief that knowledge is power and with this power comes freedom of choice and personal responsibility.

In this, the second section of my report, I aim to look at evaluation of our services, the purpose, or need, of this evaluation and methods available to successfully measure our achievements so far.

Evaluation

In this current pilot scheme we are building the foundations to create an evidence based practice. Even at this early stage I am confident that the statistics will speak for themselves and show the true value of peer support.

Through attending a series of presentations by the University of Pennsylvania I aimed to decipher simple and safe ways to measure how we are performing. The simplest way is to think of Evaluation is as a 4 part story, for example:

1. What do we have? – This is our ‘inputs’ or resources such as money, employees, equipment etc.
2. What do we intend to provide? – Our work activities and programmes etc.
3. What do we provide, and to whom? – The immediate ‘outputs’ of the work that is delivered to the consumer (in our case, the people on the wards)
4. What do we expect will happen in the short term and in the long term as a result of our project? – This is ‘outcomes’ or the long term results of delivering outputs.

Firstly, we have to look at the inputs, or what we invest in order to implement the programme. For example, funding by the government, the use of hospital resources, and trained PSWs. Next, we must consider the overall function of the service or what we intend to provide, as PSWs what is our mission and purpose? In order to do this we have to clearly define our activities, for example to provide peer support daily between 10am and 2pm (naturally there are considerably more activities we as PSWs are involved in, which would be documented at the time of the evaluation proper). The outputs or deliverables are what we deliver in quantitative or numerical terms, for example facilitate 30 support groups a year, or provide peer support to 100 people.

Most programmes in human services are designed to create change in individual lives but can sometimes serve whole systems and environments. This relates directly to our role as PSWs on the wards. It is our aim to deliver a first class, quality service to our consumers but also to gradually promote a more regular and highly visible practice of the recovery model amongst ward staff and medical professionals. It would then, perhaps, be an idea to involve both consumers and staff in the evaluation, as it is important to directly relate our outcomes to whom we are targeting (bearing in mind at all times that the change has to be achievable!)

The key ingredient to any evaluation is the importance of measuring final outcomes, it is quite possible to waste valuable inputs (time and money) on work activities, or indeed produce outputs without achieving the desired outcomes. Realistically, it is these impacts, or long term results that are the only justification for doing the work in the first place!

We have to begin by defining our outcomes, that is, what we expect from our programme, then list any activities that would serve to promote these results

(remember that in simple terms, outputs are what we do, and outcomes are what happens because of what we have done).

Outcome indicators are the knowledge applied, any changes made, the level of satisfaction achieved and the empowerment demonstrated. There are short term outcomes such as increased awareness, learning and knowledge. Medium term outcomes including actions, behaviours, practices, decisions and policies. These are followed by long term outcomes or the consequences, for example is the programme replicated or similar programmes funded?

Traditionally outcomes would be measured using figures to show for example, a decrease in hospitalisation, better symptom management and increased medication compliance. However, now using a recovery focussed outlook, the outcomes would be measured and hopefully reflect for the consumer, an increased involvement in activities or interests, an increase in the sense of control over their lives, an improved quality of life and a dramatic decrease in hospitalisation because there are more, better alternatives in place (basically avoiding the problem).

So what can we as PSWs use to measure performance? This will have to be an organised way to describe the outcomes achieved. Once the outcomes are determined and clearly stated a performance measurement system can be designed. Tools which can be used include surveys and easily constructed questionnaires which can be used on a recurring basis or as a 'one-off'.

I found a new satisfaction survey that is proving to be very useful in the field of mental health called the process indicator. This ascertains what the programme participants knew and practiced before they participated in the programme compared with what they knew and practiced after they had participated in the programme. This kind of process indicator could possibly be used to measure any change in beliefs or practice amongst the medical professionals on the ward. For example, what they knew about the benefits of actually practising the recovery model and using recovery language (as opposed to having just learned about it) before PSWs arrived on the ward compared with what they know and regularly practice after working as a team with PSWs for a defined length of time. I believe the results could be very interesting, but then I'm probably just being controversial again!

The advantage of using surveys is that they are relatively quick and easy to implement but if properly designed can give very useful feedback on individual perceptions which are relevant to outcomes.

Having considered all the information I obtained at the conference around evaluation, I came to the conclusion that there is a definite need to create some form of local evaluation of our role as PSWs. Firstly, to emphasise and raise awareness and appreciation of the excellent work we are doing. Secondly, to ensure we are doing the right things with the right group of people (in my next section I will look at the role of the PSW in other areas of care and consider the benefits of these for Glasgow and Scotland) and finally, to ensure the funding of this programme for years to come which will in turn support more training of people to become PSWs, more specialised training of already qualified PSWs, and the provision of greatly needed, available paid employment. We are currently in a situation where there are qualified PSWs with fantastic strengths and abilities who could contribute greatly to the community, that simply cannot find employment. In the next section when I consider the variety of areas peer support could, and should be utilised in, it will become apparent that this is simply not acceptable.

Personally I would like to see more public awareness of the services that can be offered by PSWs, perhaps through the use of the media or indeed by holding our own annual conference for peers and medical professionals alike.

The Future Of Peer Support

In this, the third, and final section of my report (believe me when I say there could have been many more!) I thought it only fitting to highlight the future possibilities for PSW in Glasgow and Scotland. This section illustrates briefly the amount and variety of work currently carried out by PSWs in America, and is meant to be thought provoking, inspirational and a source of encouragement and determination to evolve and succeed for anyone involved in the journey,.. and for anyone wishing to fund this revolutionary movement!

The one thing that struck me more than anything else at the conference was the sheer amount and variety of work available to PSWs in America, in their hospitals, communities, educational establishments and correctional facilities, but to mention a few. It soon became apparent that although initial funding was required for training in specialised roles such as:

1. Working with children
2. Working with youth groups
3. Support of people and families living with HIV and AIDS
4. Gaining respect for lesbian, gay and transgender groups
5. Working as part of a social work team
6. Being present in Accident and Emergency rooms
7. Liaising with people in prison and their families
8. Working in all areas of the hospital for example
 - *Admissions
 - *Acute receiving wards
 - *Intensive care units
 - *Rehabilitation units (including discharge)
9. Community integration

This funding was a sound investment as the role of the PSW in all these areas is highly respected and very successful in promoting recovery, reducing hospital admissions and reducing the financial strain on health care providers. More people are living full and contributing lives independently in the community, maintaining employment, raising families and successfully modelling recovery.

I was completely amazed and in awe of the innovative work being carried out by an organisation of PSWs working in the Riverview psychiatric hospital in Maine, USA. It is the mission of these dedicated PSWs to foster a community for people who are facing mental health and other life challenges, develop peer services and advocate for changes to the mental health system, which are based on a strong belief in recovery, and respect for the individual, unique, voice of the consumer. Everyone is treated with dignity and respect with people viewed as experts in their own lives and in their recovery and for this reason their input is regularly sought after. Although nowadays this group of pioneers are having an outstanding impact on the hospital where they are based and are highly respected, it was not always like that.

When the concept of peer support first arrived in the hospital it was met with fear and hostility from the majority of staff. Initial reactions were that PSWs were

there to tell them how to do their jobs, they were classed as 'mental patients with keys' who displayed poor boundaries. The group was often made to feel unwelcome with access to information and certain areas of the hospital being restricted. There were several barriers put up against change, with staff unwilling to evolve the existing model of treatment to embrace recovery. Stigma and discrimination was high and countertransference was the norm for example, when someone was admitted with a diagnosis of Bi-polar disorder the staff already had a negative image of that person and fully 'expected' certain patterns of behaviour to occur, often instigating this and exacerbating symptoms by their own actions. However in recent months the attitudes and beliefs of the staff have changed so dramatically that they are barely recognisable from the early days. The positive, recovery focussed influence of PSWs on the team has encouraged hospital procedures and policies to be adhered to more closely, with recovery language now being the only language accepted. Now surprisingly more and more staff than ever before are becoming open about sharing their own personal recovery stories which is a huge leap for the movement.

At the Riverview hospital a PSW is present when someone is admitted to the hospital. It has been shown that just having the comforting influence and support at this time of crisis can instantly calm and settle the person. I believe that the first person you come into contact with in the hospital has a significant affect on the overall outcome, whether it becomes a good or a bad hospital experience. When someone is admitted in crisis they may be understandably frightened and apprehensive, as are their families or loved ones. At this crucial point the skills and knowledge of the PSW can help to diffuse the situation, whether it be simply holding the hand of the person or offering comfort, support and reassurance to the family. It has been shown that family members really appreciate this interaction by a PSW who models recovery and illustrates to them clearly that it is not the end of the world, that there is indeed still hope, and recovery is possible. It is quite normal for the PSW to make 'follow-up' calls on someone they admitted to check on their progression. They can be present with the individual, if requested, when they meet with their doctors, this not only provides reassurance and a feeling of security in a sometimes overwhelming situation, but also allows the PSW to discuss later with the person any issues that they did not understand or wanted to discuss further. A PSW is always present at all treatment team meetings, morning and community meetings and discharge and planning meetings. No executive or leadership meetings are conducted without the presence of a PSW who are also highly involved in facilitating staff training workshops and even the hiring of key staff. Basically, changes are no longer made without the input of a PSW. I am fully aware that this concept may ruffle a few feathers in Glasgow if suggested, but I would urge everyone to think of the benefits to this new way of working. Think of the planning of a new hospital ward: Although executive committees strive to do the best for their staff and patients, they may not always get it right. Certainly the staff are probably asked for their opinions on any changes proposed, but are the consumers? A PSW can always offer input from a different perspective simply because they have the ability to visualize things from the viewpoint of a consumer.

In addition to the list of roles currently filled by PSWs it is important to note that they are also available everyday until 9pm, taking into account the reality that the night can be a very lonely time for some people. There is the availability of a 24 hour 'warm line' that is, a telephone service manned by a PSW in the hospital that

people in crisis, or people who just need someone to talk to can call anytime. There are designated drivers who can take people in the rehabilitation stage of their recovery journey out into the community to look at housing, to arrange benefits, or to see what's available in the community where they will shortly be moving to. This is an extremely important part of the recovery process and successful community integration so should never be overlooked. It is vital to remember that recovery is holistic and the number 1 reason for returning to hospital is isolation. Naturally, there are dedicated teams of PSWs working in the community to orientate people to really become part of the community. This involves tasks which may seem very simple or mundane to you or I, such as finding out about local transport, obtaining bus time timetables, providing telephone numbers for local services like the doctors surgery or pharmacy. They may go together with the person to local shops, cafes or the cinema until they become empowered with the confidence and self-esteem to do these and other things alone, and with friends. All these things the PSW can do educates the person and empowers them to be able to have the freedom to make their own choices and participate fully in the community. This is an area that I am confident would be particularly beneficial, and should definitely be considered when funding future peer support programmes in Glasgow.

Clearly PSWs both in the hospital and the community have a very full and challenging role and are now viewed as a vital and highly respected part of the organisation. As a result belief in the recovery model is growing rapidly, expanding and evolving at such a rate that there is a need for the teaching of recovery (peer support in particular) throughout the education system. In America there is currently a focus on academic collaboration and education, in simple terms 'teaching the teachers' and 'teaching the doctors'. PSWs are in high demand at colleges and universities to promote the recovery approach to medical trainees and to encourage the fusion of the medical and recovery models of care, that is, to 'fix the doctors before they're broken!' Trainee doctors and nurses are best placed to learn about recovery principles and are more receptive to the ideas than some of the older, more 'experienced' staff, but even these barriers are being torn down by the strength and inevitability of this movement. It is refreshing to hear of trainee doctors being paired with PSWs during their hospital placements and more psychology students facilitating tutorials on recovery.

I firmly believe that it should be the primary focus to continue and expand the education of medical professionals from as early into their learning as possible. This is an area which I am particularly passionate about and hope to become involved in. I believe that when the medical and recovery models of care meet, we get the best of both worlds. It is not our job as PSWs to attack doctors, we are not anti-psychiatry but we do command and fully deserve the same level of respect and input into the care of the individuals we serve.

Having attended these workshops it became apparent that the opportunities for trained PSWs are limitless with their skills and expertise in high demand in all areas of care. I sincerely hope that I have managed to convey this very real possibility and provide the necessary food for thought for all our associates.

Conclusion

Wow! What an experience and an absolute honour to attend this conference. More than ever I believe in the power of recovery and peer support. It's going to take vision and leadership skills to roll this out, to get the right people on board and to really make things happen, but we can succeed, individually, and together. Remember, although we have great challenges we also have great people and resources – we can do this!

With recovery as the focus, a new day is dawning in mental health with hope lighting the way. Resistance that is entrenched is still our biggest challenge but this is a time when a new enthusiasm and optimism is spreading and peer support is building up momentum. We must be fierce and resolute in implementing change strategies, all the while innovating a new and just future.

PSWs need to come together as a united and formidable force to share ideas and concepts, to learn which fights to fight and to keep the programme relevant and forward thinking. Individual recovery is individual power and as we know only too well, change isn't easy, it's a real struggle which requires real life heroism. Embracing the liberty of recovery means taking great risks in order to be the hero of your own life. Working in peer support has benefited me in many ways that I had previously not thought possible, it is extremely personally rewarding to watch people get better and to be part of a very beneficial, mutual and reciprocal relationship. Prepare to ask yourself the question, "Are you ready to become your own hero?" and then watch as you become all you were meant to be.

I believe that the future of peer support is in our hands. Using a combination of hard work, undying determination and the development of unity and greater understanding between the medical and recovery models of care, the possibilities are endless.

To finish I would like to briefly report on the work of one particular PSW I had the great honour of meeting and learning from during my visit, Gina Calhoun. This woman was truly inspirational to me and yet everything she said during her presentation was related exactly to how I feel but have never had the opportunity to express until now. The subjects she spoke about truly encapsulated the meaning of peer support and will remain with me and continue to inspire me forever. Although in my own words, I hope what you read next does justice to this pioneer of peer support and touches you so deeply that you are ready to destroy any barriers in your way and join me in the recovery movement;

‘Sometimes when people are very unwell it seems impossible for them to escape the darkness that surrounds them every minute of every day. However, an important point to remember is that, it is scientifically impossible to see the darkness of your own shadow unless there is light – so shine your light! Light up your soul and light up your world! Even the smallest flicker of hope is important and we must keep this lit. In my soul there is a candle burning bright – I cannot light someone else’s candle, as much as I would like to – but when that person is ready to do it for themselves, they can reach out to me and light their candle from mine. It costs nothing to light one candle from another and yet it is one of the most valuable gifts you will ever share with someone – the gift of helping someone to facilitate their own recovery and bring the light back into their lives.’

Always remember that I am the Evidence and you are the evidence that recovery is possible.