



Introduction

In April 2009 Edinburgh Carers Council were awarded £4680.00 to address the issue of isolation and stigma experienced by carers caring for someone who attracts a diagnosis of personality disorder. This group of carers experience stigma and isolation more than any other mental health disorder.

Aims:

The aim is to address the issue of stigma and isolation experienced by carers in the first instance by bringing them together. Often carers in this category become even more isolated from family, neighbours and friends due to the lack of awareness and understanding of personality disorder by society at large. People assuming that the service user is in control of their actions and behaviours. Initially we addressed the issue of stigma and isolation experienced by carers using the Recovery model tool WRAP (Wellness Recovery Action Plan).

Objectives:

As the word objective means 'being the object or goal of one's efforts or actions'.

Carers are often exhausted by their caring role and this is made harder by the fact that there is little or no help available to carers. Our objective is to help carers see that they are not alone and that they need to take care of themselves and their own mental health and well being. Rona McBrierty who works for the Lothian Recovery Network and myself Co facilitated the training for carers. WRAP, which is a recovery tool, used by service users in order to help them take care of their own mental health and well being. Rona utilised the WRAP model and geared her training to meet the needs of carers. WRAP enables people to think what they need in order to maintain mental health and well-being. It allows for individuality and the importance of interdependence, which is key for both carers and service users.



WRAP Training for Carers

We ran two sessions for eight weeks to two separate groups. An afternoon group and evening group. The WRAP training consisted of the following programme:

Recovery Awareness Session: This was the beginning and it was about setting the scene, comfort agreement, hopes, fears expectations. Inspiring hope and sowing the seed of the narrative research from the carers' perspective.

Overview of WRAP – The role of hope – motivation – identity: A brief overview of WRAP as a self – management tool linking it to carers – motivation – looking at what is the motivation to take care of yourself as carers. How do you motivate yourself – identity – Who are You – How do you take care of your needs. Linking the role of Hope

Personal Responsibility – Education- Knowing Your Strengths – Self Esteem:

Two further Recovery concepts – personal Responsibility – Education – Getting to know yourself – Building on your strengths – improving your self esteem. What makes you feel good about yourself – what are your interests?

Self Advocacy – Assertiveness – Confidence Building + Emotional

Confidence: Self Advocacy – what would enable you to feel that you could speak up for yourself and what do you need – confidence building – being assertive – building emotional confidence. Creating your own support network – what type of support

Support – Creating your own support network: What works for you – What is available – How can your needs be met – Making space to have fun time.

Wellness Tools – Triggers: These are things you do to keep yourself well and things you do to help yourself feel better when you don't feel well. Triggers are external events or circumstances that may make you feel like you are getting ill. They are normal reactions to life events if you don't respond to them.



Early Warning Signs – When things are breaking down: Early warning signs are internal and may be unrelated to reactions to stressful situations. They are subtle signs of change that indicate you may need to take further action. When things are breaking down – you may begin to feel worse – but you are still able to take some action on your own behalf. It is necessary to take immediate, assertive action to prevent a crisis.

Crisis Planning – Post Crisis Planning: The plan will involve instructing others about how to take care of you when you are not well. It keeps you in control even when it seems like things are out of control. Develop this plan slowly when you are feeling well.

Celebrations: This gave everyone an opportunity to celebrate having got to the end of the training and for carers to appreciate that they had achieved this and had begun the process of seeing they are individuals in their own right, that it's important that they too take care of their own mental health and well being.

The aim of the above is very much about encouraging carers to concentrate on who they are – what they need and providing them space to learn, feel listened to but also to recognise their own strength and inner resilience.

It's about providing social contact and encourages carers to have quality time for themselves, to provide them with a self management tool that they have created. That will develop self awareness and control to promote self directed Recovery

Week 6 – 8 would build on the first 5 weeks bringing in the discussions and learning from the sessions. Ultimately people would feel empowered to move towards their own goals aspirations and dreams. Creating more of a inter dependency between themselves and the person they care for.



BPD (Borderline Personality Disorder) Training

Dennis Lines has been a BPD carer for over 16 years. He is the PD carer lead for the National Personality Development programme. He has worked alongside people with PD for many years and has a deep understanding of their issues and also those of their carers. He has served as a Director of Borderline UK and has also been the carer representative of Borderline UK. Dennis provided the overall BPD carer input to the recently published NICE (National Institute of Clinical Excellence) 2009 BPD Clinical Guidance Recommendations. As well as this Dennis, who possesses a wealth of information on all aspects of caring for someone with BPD, was invited to Edinburgh Carers Council to talk to our carers. This two day session was well received by ECC carers and it is our intention to invite Dennis back in the New Year. I recently attended a two day training course for staff at The Royal Edinburgh Hospital on Personality Disorder. It was an opportunity for participants to understand what is personality disorder, how does it feel for the person who attracts the diagnosis. There were discussions on, how staff may experience working with a service user who has this diagnosis, in terms of the transference and projections and what they can do to take care of their own needs. I hope to set up training for carers that is geared to addressing their needs in a similar way, however, this will be dependent on future funding.

BPD Group

The BPD Group developed from a need, that carers in this category found it difficult to talk in other groups about the issues surrounding BPD. They often experience shame and guilt amongst other things resulting in them experiencing so much stigma and isolation. The monthly meetings give them an opportunity to discuss any current issues they may be experiencing. This Group has provided carers the opportunity of developing confidence within their own group and in time move on to participate in other mental health groups for carers. Every alternative meeting we invite a speaker along. We have invited on three separate occasions two service users to discuss BPD and how they manage their symptoms. It has also allowed carers the chance to ask them questions, which pertains to their own caring situation. Carers have found this really helpful and its given them insight into what it is like for a service user with BPD and what may be the best course of action, particularly in relation to how does a carer respond to the person they care for in certain situations. This is helpful to both carer and service user when managing a crisis. One of the service users has been working on a 'Toolkit' for service users with BPD. This Toolkit will also be helpful to carers. However, it is hoped that we can develop something similar for carers in the future. The aim of the Toolkit would be to explore carer's experience of supporting someone with BPD. What works well and what doesn't. Furthermore it would address the stigma that carers experience raising awareness and understanding of BPD amongst both carers and professional alike. My hope is that carers would be involved in developing and delivering this.



Conferences

In the past year I have attended three Personality Disorder Conferences: Two of which were organised by the Scottish Personality Disorder Network and the third was organised by L-Pin. This gave me the opportunity of meeting Chris Young and Naomi Salisbury both of who have attracted a diagnosis of personality disorder. They have presented at two of our carers sessions. Carers found it insightful and helpful and they have been invited back to talk in the New Year. At a recent Conference I had an opportunity of discussing WRAP for carers at a workshop with HUG (Highland Users Group). I also attended a two day training course for staff at the Royal Edinburgh Hospital on Personality Pathways; working with personality in Mental Health.

Self-Harm Training

The Edinburgh Carers Council and the Royal Edinburgh Hospital Self Harm Service have been working in partnership to offer information and support sessions for carers. Although there has been some change in the stigma around self harm, it can still be hard for people to talk about, and access help. The sessions have so far covered facilitated discussions as to what do we mean by self harm, and how to help support someone who does. The third session focused on the feelings and effects for those who do the caring. The group has continued with dates set for the next six months as a regular facilitated support group.

WRAP Group

The WRAP Group developed from the WRAP training. Carers disclosed much information about their caring roles and they talked openly about what they were experiencing during the training sessions. Often reflecting on their past, linking this to their caring role, from this they developed a bond.

The WRAP Group meets once a month for two hours and it gives carers the opportunity to discuss how they are using WRAP as a tool to take care of their own needs, while at the same time it allows carers the opportunity to get things off their chest in a positive way giving themselves permission to look at how they can manage their caring role. While at the same time setting the boundaries between themselves and the service user to say, "well yes I can do this but I won't do that". It is a time for carers to reflect and care for themselves, and let go of any guilt they may be holding on to because they are finding it difficult to manage everything,



Further WRAP Training: Planned for the Spring of 2010

We have WRAP sessions planning starting on the 3rd of March 2010

Evaluation

In terms of evaluating the various groups and training we have asked carers to feedback to us how they have experienced the training and how it has either helped them or hindered them. At this point we have not evaluated things in the form of a questionnaire, as we wanted to encourage carers to be reflective on how they felt. (using their WRAP to think about how they felt). Below are some of the responses we received. We plan to do a similar exercise with the carers from the BPD Group and the Self Harm Group.

Some comments from carers so far

“The WRAP group saved my sanity. It has offered me so much on how to handle my emotions and other things“

” The Group was very well run and presented. The rules made a difference and created a group that felt free to be able to speak without anybody judging them.”

“I had been on a two day WRAP course before but it was never aimed at myself as a carer. Although it was difficult at first to concentrate on myself and not the person I care for. Rona was brilliant at bringing the focus back to ourselves. It was great as it was a bit of me time”.

“I consider it a real honour to have been given the chance to attend the WRAP Training. The timing was just perfect for me as I was pretty drained emotionally. Having a safe haven to replenish the spirit each Thursday for 9 weeks was a gift from above!”



Conclusion:

As you can see from this report much has been developed and achieved since receiving the funding from the SeeMe campaign. In developing the above groups and training opportunities for carers we have been able to tackle the issue of stigma and discrimination experienced by families who are caring for someone who attracts the diagnosis of personality disorder. The WRAP sessions and continuing WRAP Group has created a framework that has and does help carers set boundaries, encourage family strengths and supports (for carers & services users alike) 'Be There. Be Yourself. The number of carers when we started the BPD Group was four, it is now fourteen and is growing through continually raising awareness of what we are providing for carers both through our newsletter, networking and word of mouth.

The funding has helped us achieve our aims and objectives, as you can see we have provided carers with training in order to understand personality disorder but more importantly we have provided carers with training on how to take care of their own mental health and well being. Particularly as caring for a loved one who is struggling with the symptoms of personality disorder, impacts tremendously on the carer in their caring role. The above groups and training have given carers the opportunity of hope for their future and the person they care for as well as building on their confidence, self esteem and well being.

They now have a much better awareness and knowledge that they are not alone in what they are experiencing. There is on going support and information. It's certainly reduced their level of feeling shame, guilt and has helped enable and encourage a mature separation between themselves and the person they care for.

ECC is now providing a service that didn't exist. We are the only organisation so far in Scotland that has provided WRAP training for carers to use to take care of their own needs.

The above training and group sessions have provided carers with an opportunity to get together and talk about their caring role, share their lived experience and learn how to set boundaries for themselves.

I have found it a real privilege this past year meeting and working with the carers that have attended our training and continue to come to our Groups. I have seen them grow and flourish from the training and contact they glean from each other. For me this piece of work has been tremendously rewarding. I'd like to thank SeeMe for providing Edinburgh Carers Council with the funding to help us initiate and start up all of the above.

Edinburgh Carers Council



for those supporting people with mental health difficulties

Our Hope for future development:

Our hope is to continue developing what we have set up and to provide further training and development for carers caring for someone who attracts the diagnosis of personality disorder. There is much more work needed to do in this area. CAPS have developed a Toolkit for service users with the diagnosis of PD it would be good to develop something similar for carers. There is much need for training, encouraging and raising awareness about personality disorder. Carers are desperate to understand and know how to cope and what to do when the person they care for is experiencing PD. In order to develop this further and to provide a service and fill the obvious gaps for carers we hope to get future funding from other sources.

Linda MacLeod Edinburgh Carers Council 2/12/09

see me...The logo for 'see me...' features the words 'see me' in a bold, lowercase, red sans-serif font. To the right of 'me' are four red circles of varying sizes, arranged in a slightly descending line from left to right.