



CARERS NEED RECOVERY TOO

**An Evaluation of the Use of
Wellness Recovery Action Planning
and its Effectiveness for Carers**

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on behalf of Edinburgh Carers' Council

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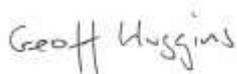
FOREWARD

The Scottish Government believes that there is no health without mental health and that recovery and the principles which underpin it play a vital role in mental health improvement.

We currently fund the Scottish Recovery Network to promote recovery orientated practices, including Wellness Recovery Action Planning (WRAP). WRAP is a 'self-management' tool used to help individuals take more control over their own wellbeing and recovery. It recognises that people are the experts in their own experience and that there are no limits to recovery.

We also recognise and acknowledge the significant contribution made by Scotland's unpaid carers and the importance of helping them to take care of their own mental wellbeing. Caring Together: The Carers Strategy for Scotland 2010 – 2015 published in July 2010, states our commitment to assist carers to maintain good mental health and wellbeing.

This is why this piece of research is so important, and I hope that it will be useful in promoting methods to allow carers to find ways that help them to take responsibility for their own mental wellbeing, and assists them to be in a stronger position for themselves and those they care for.



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SUMMARY OF KEY FINDINGS

- ❖ WRAP can significantly improve the mental well-being of carers. Benefits include:
 - Decreased feelings of isolation
 - Increased ability to cope
 - Acknowledgement of carers' rights
 - Increased confidence and self esteem
 - A safe environment in which carers can vent emotions
 - More energy
 - Reduced feelings of guilt
 - Improved relationships
- ❖ Exploring the meaning of recovery in this study helped to make sense of the process by which carers' and service users' mental well being is improved.
- ❖ There are at least three ways in which carers need 'Recovery'. They are:
 - **Recuperation:** carers may themselves be traumatised or exhausted by the experience of caring for someone with a mental illness. In order to be able to support a loved one in their recovery, carers will often need to take time out to recover.
 - **Revival:** the identity of carer can be all-consuming and carers can lose sight of what is important to them as individuals. Recovery in this sense is about recovering a sense of self and the value of self.
 - **Renewal:** in the same way that a service user is not defined by their mental health diagnosis, a carer is not defined by their role as carer. Instead it can provide an opportunity to recover hidden resources and talents and see oneself in a completely new light.
- ❖ Not all carers in this study recognised or accepted the relevance of 'Recovery' to them *as* carers and some scepticism about the recovery concept more generally was expressed. However, that did not detract from the valuable insights carers gained as a result of developing their own wellness plans. The key concepts of recovery which are hope, personal responsibility, education, self advocacy and support are as relevant to carers as to service users.

- ❖ Edinburgh Carers' Council provides a space for WRAP Groups to continue to meet after the training has come to an end. These on-going groups are found to be an important part of a successful WRAP process and could provide a blueprint for the development of other recovery-related initiatives. Their popularity underlines the importance for carers of having a safe space to meet with other carers in order to reflect on:
 - The importance not just to themselves but also to the people they care about, of taking care of their own needs
 - Their sense of self and how personal relationships, including relationships of care affect the way they see themselves
 - How they can identify and build on existing personal resources in order to achieve a meaningful and fulfilling life.
- ❖ WRAP training materials can be adapted for carers without losing the key elements and concepts of the original WRAP as developed by Mary Ellen Copeland. Crisis planning and post crisis planning require further thought. In particular consideration should be given to the extent to which carers can or should separate out their own crises from the crises experienced by those they care about.
- ❖ Carers were inspired by the recovery story of the trained WRAP facilitator. The training was co-facilitated by a non-WRAP trained member of Edinburgh Carers' Council's staff team who became part of the groups and who continues to facilitate the on-going WRAP Groups. Facilitation during training may have been enhanced because it incorporated the dual perspective of service user and carer.
- ❖ WRAP can help carers to articulate their needs *and* identify the resources they already possess to cope with the challenges that caring places on them. This could lead to them being better able to advocate on their own behalf with service providers and perhaps more importantly within personal relationships. Through discussion of what personal responsibility means, carers can begin to take control over their own lives and at the same time are more able to step back and allow those they care for to take control of *their* own lives too. This is not to overestimate the challenges they face or suggest that carers could ever achieve some end state in which all their problems disappear.
- ❖ There are resource implications if the WRAP for carers' model developed by Edinburgh Carers' Council is to be rolled out more widely. However, savings to the public purse of informal care work and the cost to the health service when carers themselves become unwell would appear to justify investment in an initiative with proven health benefits.

1 INTRODUCTION

This is the final report on a small evaluative study carried out at Edinburgh Carers' Council on that organisation's use of Wellness Recovery Action Planning (WRAP) with carers.

Edinburgh Carers' Council has charitable status¹ and provides advocacy and information for carers of people who have a mental disorder. The Mental Health (Care and Treatment) (Scotland) Act 2003 defines 'mental disorder' as "any mental illness; personality disorder or learning disability as defined by the Mental Health (Care and Treatment) Scotland) Act 2003" and defines carer as:

an individual (other than a paid or voluntary worker) who provides, on a regular basis, a substantial amount of care for, and support to, the person; and includes, in the case where the person is in hospital, an individual who, before the person was admitted to hospital; provided on a regular basis, a substantial amount of care for, and support to, the person (s329)

These definitions are used by Edinburgh Carers' Council. Their definition is non-specific and inclusive in recognition that family, partners and friends may be involved in providing different types of support which is impossible to quantify.

WRAP² is "a self-management and recovery system" created in America by a group of long-term mental health service users led by Mary Ellen Copeland. The movement to promote the Recovery model in the field of mental health has been gathering momentum. However, the idea that 'Recovery' could have conceptual or practical significance for carers is a much more recent idea. Edinburgh Carers' Council's adoption of the model in their work with carers is pioneering.

As well as providing initial WRAP training, facilitated by qualified WRAP trainers, Edinburgh Carers' Council provides on-going WRAP support in the form of monthly WRAP Group meetings. They currently support three WRAP Groups. Some members of these groups attended the original WRAP for carers training which took place over two and a half years ago. Edinburgh Carers' Council commissioned this evaluation in order to gain a better understanding of the process by which and the extent to which the use of WRAP might improve carers' mental health wellbeing and act as a model for other organisations to use. The research was carried out with carers who took part in the original training courses as well as with Edinburgh Carers' Council staff members and WRAP facilitators.

¹ funded by NHS Lothian and City of Edinburgh Council

² On the Mary Ellen Copeland Site the system is cited as Wellness Recovery Action Plan

Caring in Context

Roughly a fifth of the population will experience mental health problems in their lives (Goldberg and Huxley, 2006). In 2003 it was estimated that throughout the UK, there were about 1.5 million people caring for relatives who were either experiencing mental ill health or who had been diagnosed with dementia (Wilkinson and McAndrew, 2008, p.393)

The work that carers do is increasingly recognised in government rhetoric. In their 2009 publication *Supporting Scotland's Unpaid Carers*, the Scottish Government acknowledged carers' contribution.

We recognise unpaid carers as key partners in the delivery of care in Scotland, and acknowledge their expertise and the quality of care they give.³

'Respect for Carers' is one of the ten 'Millan guiding principles' which formed the basis of the Mental Health (Care and Treatment) (Scotland) Act 2003.

Those who provide care to service users on an informal basis should be respected in their role and experience, receive appropriate information and advice and have their views and needs taken into account (Millan Committee, 2001)

However, evidence suggests that this principle has yet to be translated into action. In 2009, The Scottish Recovery Network commissioned a small study of carers' attitudes to recovery and their role in the recovery process (Parr, 2009). Despite being "well placed to influence the progress and direction of recovery because of the intimate knowledge of the person they are supporting", carers in that study reported feeling undervalued and unsupported in their role. Similarly researchers in England found a mismatch between theory and practice in mental health service workers' attitudes to carers in 'acute psychiatric settings' (Wilkinson and McAndrew, 2008). Carers in that study reported finding it difficult to access the information they needed in their caring roles and their views were often ignored. This left them feeling disempowered. Other commentators have remarked on the extent to which carers' needs are ignored by professionals and the impact that has on carers' mental health and their relationship with the people they care for.

Carers are often kept 'outside the loop', but expected to keep on caring however poor their circumstances. Many carers feel that they are undervalued and treated unequally, as professionals often want information about service users problems, but give little or no information in return....Being uninformed has been noted in several studies to induce feelings of isolation, anxiety, depression, resentment of the service user, anger and fear. Feelings of hopelessness, fear, guilt and isolation leave carers demoralised and unable to cope (Gray et al, 2008)

³ <http://www.scotland.gov.uk/Publications/2009/10/26093958/1>

Carers are much more likely to suffer ill-health than the rest of the population with reports of carers suffering from poor sleep, problems with their weight, higher levels of physical pain and mental distress (Barrow and Harrison, 2005).

Because of the lack of support for carers in their caring roles and associated health implications, it is not surprising that the literature on carers tends to focus on the negative aspects of caring. Moreover, the prevalence of terms like 'carer burden' in medical and other journals serves to characterise the care relationship in such a way that it undermines the agency and dignity of the service user. This corresponds with what has been and to an alarming extent, continues to be the characterisation of people with substantial mental health issues as "hopeless and dependent" (Heller and Walsh, 2009, p 274). Since mental health diagnoses are often presented as if they are a life sentence, it is no wonder that at this point carers' hopes and dreams for the future of their loved ones *and* for themselves disappear into thin air.

But too much of a focus on the negative aspect of mental illness and caring belies the complexities and reciprocal nature of personal relating which has to be viewed over the lifetime of a relationship and cannot be captured by taking a snapshot during a period of illness. Furthermore, the conventional 'life sentence' approach to mental health has been displaced, in theory at least. The most significant change has been the replacement of a medical model of *complete* recovery with a new model of recovery as "a way of living a satisfying, hopeful and contributing life, even with the limitations caused by illness" (Anthony, 1993, p15). This has important implications for carers as well as for service users.

Carers' Interests

Quite often carers' interests and service users' interests are characterised as oppositional. This portrayal of relationships of care is maintained by the use of terms like 'carer burden' and the continued dominance of the personal tragedy model of mental illness which can make it seem like service users will always be unable to live an independent and fulfilling life. The perceived antithesis between the interests of carers and those of service users is weakened by taking a different approach to disability. This different approach involves recognising that it is not mental and physical impairment that disables people (a medical model of disability) but the ways in which societies are organised and the sorts of decisions that are made in terms of resource allocation that reinforce stereotypes and favour dominant groups (a social model of disability).

The author of this report agrees with Harris and Roulstone (2011) that "situations where informal care is produced by a close family member in the community, the relationship between the disabled person and carer is a dyad; both are equally likely to be oppressed and equally likely to have unacknowledged and unmet service requirements" (p122).

The words 'disabled and 'carer burden' would have little meaning in an inclusive world where the right sort of adjustments and supports were in place.

WRAP with Carers

This is not the first evaluation of the use of WRAP with carers. In 2009, Jacki Gordon and Jan Cassidy reported on an evaluative study of WRAP training with black and minority ethnic women. They spoke to a mixed group of women, some of whom were carers and some of whom were service users. The women in that study were positive about the training they received and appreciated the "mutual sharing and hearing from each other" (p. 55) but at that point in time had not gone on to develop their own WRAPs. A conclusion of the study was that consideration should be given to the provision of on-going support for the "development and refinement of personal WRAPs" (p.58) after training is completed. On-going WRAP support is a significant element of Edinburgh Carers' Council's WRAP delivery programme, as discussed in Chapter 8 of this report.

In the Gordon and Cassidy study, carers' motivation for attending WRAP training was to "help others" although they also "acknowledged that the training may be personally relevant too". In contrast the key thing about Edinburgh Carers' Council's delivery of WRAP training is the shift from focussing on the needs of service users to those of carers. This research is focussed entirely on how WRAP works with carers and the on-going WRAP Group process.

Some notes about this Report

This report is a narrative. It begins at the beginning with an outline of the research design and the methodological approach which influenced the way the study was conducted. In Chapter 3 the scene is set by consideration of the development of the Recovery movement which underpins the idea of WRAP. In Chapter 4 the story of the decision to deliver WRAP to carers is told, drawing on the understandings of Edinburgh Carers' Council staff and facilitators. The next stage of the story involves carers signing up for WRAP training – why did they do it and what did WRAP mean to them (Chapter 5)? What carers say about WRAP introduces an element of mystery into the narrative because they do not necessarily buy into the whole WRAP package. This raises interesting questions about how WRAP works with carers who do not see themselves as in need of recovery. The story continues as the narrator charts her own journey of discovery through an examination of the evidence to establish the significance of the recovery concept to carers (Chapter 6); explores the five key recovery concepts with carers in mind (Chapter 7) and investigates the training methods used to introduce carers to WRAP (Chapter 8). Chapter 9 tells the story of the on-going groups and their development potential. Finally the ends are all tied up and the story is concluded, for now at least (Chapter 10).

Although this story is not narrated in the first person, readers are reminded that the narrator is *always* part of the story. The researcher and author of this report, Dr Sue Kelly, has carer experience, attended a WRAP for carers training course and continues to attend a WRAP Group. Her own experience of WRAP has provided her with insights which have been invaluable. However, the researcher/narrator has not used her own experience to write over what other carers told her about their own experiences nor has she reported on anything heard or shared in her own group.

The names of participant carers have been changed. The original WRAP facilitator is identified by role. One of the carers in this study also trained as a WRAP facilitator. This carer has a carer name but when referring to comments she has made about the delivery of WRAP, I refer to her by her role, thus helping to maintain her anonymity. I mention all three staff members by name and role with their consent.

2 RESEARCH DESIGN AND METHODS

The overall aim of this research was:

To gain a better understanding of the process by which and the extent to which WRAP improves the lives of carers and might act as a model for positive change.

Although feedback from carers about the delivery of WRAP by Edinburgh Carers' Council had been positive, there had been no formal appraisal of the scheme. An independent evaluation would provide formal recognition of the value of the initiative and evidence which could be used to promote WRAP more widely. The objectives of the study were therefore to

- a) document the extent to which the WRAP initiative had improved the lives of carers
- b) explore the process and the key elements involved
- c) determine what lessons had been or could be learned about the development potential of the WRAP for carers model, including any limitations or unresolved issues.

Methodology

The researcher adopted an 'emancipatory' approach to research, developed by the disabled people's movement (Beresford, 2002). This approach is based on criticism of traditional research practice which treated disabled people as objects to be studied rather than active subjects and "ignored and devalued" their views, in favour of the search for objectivity and value neutrality (Beresford 2007).

An increasing number of researchers have now come to believe that far from being value neutral, researchers are inevitably "influenced, whether consciously or not by [their] own personal, political and theoretical biographies" (Mauthner and Doucet, 1998). Research must be methodologically robust and convincing. The main way of achieving this is by making sure that the researcher

- is self-aware and that her/his presence and assumptions are not hidden behind a veil of so-called objectivity
- tries as far as possible to represent the perspectives of those who took part in the research and not drown out their voices with her/his own
- checks what s/he has learned by asking the people who provided the evidence whether or not s/he has got it right.

This is the most effective way of learning something new and useful as opposed to confirming what the researcher already believes. By handing more control over to research participants, this approach is more likely to be transformational, resulting in positive and valuable change.

Throughout this study, the researcher has been mindful of the importance of issues of empowerment within the research relationship and has adopted a collaborative approach to try and minimise the hierarchical nature of that relationship.

Methods

It was anticipated that participants' experiences would vary and the end result would be a variety of different stories which would all provide insights into the way that WRAP worked for carers. Qualitative methods are appropriate to achieve in-depth accounts which retain individual context, experience, understandings and highlight the important complexities in and differences between accounts. The main data collection instruments were individual interviews and (focus) group discussions. Information about the study, the researcher and the sorts of questions that would be asked in interviews/focus groups was provided to participants in advance to enable them to make an informed choice about their participation and give them more control over the data collection process (Appendices 1-3). Interviews were mostly carried out in Edinburgh Carers' Council rooms but some were held in other locations to suit individual needs and preferences, including in participants' homes.

Individual Interviews Seven semi-structured interviews were carried out with carers, all of whom had participated in the original WRAP training that Edinburgh Carers' Council provided. All but one of the carers still attended an on-going WRAP Group. One of the carers had since gone on to train as a WRAP facilitator which added a further dimension to the evidence she was able to provide.

In addition interviews were carried out with the WRAP trained facilitator of the original WRAP training and with Edinburgh Carers' Council staff. The WRAP trained facilitator was able to provide valuable information about the WRAP concept and the development of a WRAP programme for carers. Edinburgh Carers' Council staff provided historical detail and explained how WRAP fitted in with the work Edinburgh Carers' Council did. Linda MacLeod is not a trained WRAP facilitator but developed the WRAP idea at Edinburgh Carers' Council based on what she knew of its benefits. She co-facilitated the WRAP training and continues to facilitate the WRAP Groups so has an overview of the project from the beginning to the present day.

Group discussions As well as individual stories, there was also a group story to be told. The focus group method was adopted, using the two established groups in order to allow that group story to be told.

This provided insights into group interaction and how the group worked as a group. It also enabled the construction of common understandings of the value of WRAP. As an advantage of the focus group method is that it is designed to imitate the way people “naturally discuss topics” (Kitzinger, 1994) it made sense to include Linda who is normally part of both groups. All interviews and group discussions were recorded on a digital recorder.

Documents The researcher familiarised herself with documents and training materials relevant to the delivery of WRAP by Edinburgh Carers’ Council and the use of the recovery model more generally. Mary Ellen Copeland’s website was used for information about the development of the WRAP concept. One carer brought along a written account of his views on the training which he spoke to during the interview. A highly focussed literature review was carried out to establish what was already known about the following:

- Carers – their needs and the challenges they face
- The Recovery Model

The literature was used as data in its own right and provided context. It was not used to confirm interview and discussion data which was valued on its own terms.

Sampling and Access Issues There were no sampling issues as all members of the groups, a facilitator and all three members of staff were invited to contribute to the research. It was anticipated that some might not want to be interviewed and there was an invitation to contribute in other ways. Access was gained through Linda MacLeod.

Analysis and Reporting

The researcher has adopted a narrative approach to analysis which means that the analytical process is viewed as the construction of a series of stories about the world. It is based on the understanding that all knowledge comes from narratives which we find more or less convincing, valuing people’s subjective accounts as knowledge. It is described by McCormack as follows:

Stories re-present the outcomes of a series of reconstructions. The initial reconstruction is by the participant as she/he recalls an experience and then describes that experience for the researcher. The researcher then reconstructs this experience as she/he transcribes, analyses and interprets the experience. A further level of reconstruction occurs as the reader reads and reacts to the experience. (McCormack, 2007)

In line with this approach the researcher assumes that:

- the insights revealed by individual narratives are all of equal value
- stories are not once and for all accounts but are a glimpsed reality captured in time and space and only make sense within that context
- the differences in narratives are as significant as the commonalities.

The aim is not to synthesise accounts into a single set of meanings or truths about the world but to value different meanings, different truths and different realities while still saying something useful and important.

Included in the analytical process was a research diary which not only tracked the progress of the research but was also used to reflect upon the data and the researcher's own response to the data; note taking immediately after interviews and group discussions and during transcription, capturing thoughts and insights and making connections.

The transcripts were read and re-read so that the researcher became immersed in the narratives. At the same time labels (codes) were loosely or provisionally attached to pieces of the data and the coded data was gathered together in separate word documents. Initially codes tended to follow the contours of the initial interview themes and questions, reflecting the original ideas that shaped the interview guides. However, the researcher was also listening for themes which had not been anticipated before the interviews began. By the end of this early stage in the analytic process, all of the data had been coded and more often than not, pieces of transcript had several codes attached. Decisions were made about issues that seemed to be important to participants within the parameters of the research aims and objectives. These decisions were reviewed during the writing up phase of the analysis. Transcripts were re-read to make sure that nothing had been missed from initial readings and to ensure that the perspectives of each of the participants was properly reflected in the final report.

Because of the small numbers involved, the probable familiarity of group members with each others' stories and the possibility that service users might recognise themselves in accounts, carers' narratives have been disassembled in the process of analysis. The aim was to hold onto important insights revealed in the narratives without compromising confidentiality and anonymity. In the case of WRAP facilitators, their role has been acknowledged for the sake of clarity. However, every effort has been made to leave out any details which might be sensitive or are not already in the public domain. In the interests of clarity, the roles of Edinburgh Carers' Council staff members are stated. Quotations are only included in the final report after gaining the express permission of the individuals concerned.

The final draft was shown to all those who participated in the study and their feedback shaped the final analysis.

Research Ethics

The researcher was committed to ensuring the safety and wellbeing of participants. She was respectful of the needs and voices of those taking part, mindful of the responsibilities attached to representing the experiences of others and sensitive to the impact that anything placed in the public domain may have on carers as a group.

All materials were checked by participants themselves before publication for confidentiality and anonymity purposes. No-one was identified and no quotations used without the permission of those concerned. The researcher was sensitive also to those who might be mentioned during the course of the interviews but who were unable to give their consent to information about them being shared with others. The researcher was at pains not to reproduce any talk about third persons which might identify or stigmatise them when the report becomes public.

Informed consent demands that participants are fully aware of the purposes of the research and how the research will be conducted. Signed consent forms were used but it was always made clear to participants that this did not remove the need for vigilance throughout and beyond the process. Participants were made aware that they could opt out of the research or withdraw their consent at any time.

3 THE RECOVERY CONCEPT

WRAP is a wellness recovery action planning workshop aimed at service users. It would be strange to try to unravel the mystery of how WRAP works for carers without first understanding what WRAP was intended to mean for service users.

What is Recovery?

The Scottish Recovery Network define recovery as:

..being able to live a meaningful and satisfying life, as defined by each person, in the presence or absence of symptoms. It is about having control over and input into your own life. Each individual's recovery like his or her experience of the mental health problems or illness, is a unique and deeply personal one.

This understanding of recovery contrasts sharply with the more common usage of the word and its embeddedness in a medical model and culture of health care. When someone has a mental health diagnosis, they might be told that they are likely to be on medication for the rest of their lives. This can be seen as evidence that this is a condition from which they will never recover. A culture in which this meaning of recovery is dominant is likely to undermine hope and lead to service users and their carers seeing the diagnosis as a personal tragedy. It has been argued that the persistence of the view that there is no recovery from mental illness makes it less likely that people *will* recover and increases stigma (Allott, 2004).

Service users themselves helped to develop the 'new meaning' of recovery which has become "a familiar part of the language of mental health policy, services and research literature" (Ramon et al, 2009). Recovery is no longer about curing the person of illness or symptoms and far from invoking the language of personal tragedy, this different meaning of recovery has hope at its core. It promotes positive expectations built on the new opportunities presented by the changes individuals experience as a result of their mental illness. Responding to what service users themselves have said about their own experiences, much of the literature on recovery is around the idea of recovering a new sense of self.

Conceptualizations of recovery involve more than just symptom amelioration and include the development of hope, meaning and self-identity (Clarke et al, 2009)

Recovery is about empowerment and self determination but that does not mean managing or coping alone. Under a more traditional model, support from others can be seen as disempowering. The person needing support becomes a burden to others. The new model of recovery is about interdependency or relative autonomy, recognising that the entirely autonomous individual is a myth. Each individual's personal history includes more or less reliance on others for nurturing and on-going support (Donchin, 2000).

However, the ethos of self-help is strong which means responsibility for decision-making and action lies with the individual. The individual has a right to take risks and a right to make mistakes without those mistakes being put down to a failure to do as they were told or listen to the advice of others.

The Recovery Themes

Each person's recovery needs and story will be different. However, the Scottish Recovery Network has identified a number of 'themes' which help to clarify the concept.⁴

Recovery as a journey This will include good and bad experiences, challenging the idea of recovery as a single state of being symptom free or *recovered*. Hence the preferred phrase "in recovery".

Hope, optimism and strengths Hope is arguably the single most important aspect of the new concept of recovery. Positive reinforcement: focussing on what *is* possible and on individuals' strengths, stimulates hope.

More than recovery from illness Being symptom free is not a prerequisite for living a fulfilled existence. The point is not to be defined by illness or the symptoms of illness. The idea of "recovering a life and identity beyond the experience of mental ill health" is a powerful one.

Control, choice and inclusion Having control over decision-making is seen as imperative to all human well being and to a positive identity. This is not to underestimate the challenges involved, not least because of the social exclusion that people with mental health issues experience. The need to address wider issues of exclusion is implicit in the new model of recovery.

Self management The use of self-management techniques, notably WRAP are being promoted in Scotland through the Scottish Recovery Network and the Long-term Conditions Alliance⁵.

Finding Meaning and Purpose Developing a strong sense of identity and purpose cannot happen in isolation but comes from seeing oneself as an active member of a community. This raises tricky issues e.g. access to paid or unpaid employment, training or other opportunities, especially in the current economic context.

⁴ <http://www.scottishrecovery.net/Key-themes-of-recovery/key-themes-of-recovery.html>

⁵ <http://www.ltcas.org.uk/>

Relationships The recovery journey is easier with the right sort of support. What that is will depend on the individual but will at the very least promote rather than undermine respect and dignity.

The recovery concept is underpinned by a view of what all humans have a right to expect on the basis of a shared humanity. Arguably, these themes are simply the ingredients of a happy and healthy life.

The Politics of Recovery

The new idea of recovery is not without its critics. In the current economic climate, an emphasis on the individual taking control of their own recovery can seem like a justification for cuts to services. Proponents of the recovery model may come across as evangelical, as if faith in recovery is all that's required for success and there is a risk that personal and social barriers to empowerment are underestimated. Not everyone will accept or be able to make sense of the new idea of recovery and the notion of empowerment is difficult to reconcile when someone is facing hospital detention or an enforced treatment order. Furthermore, a mismatch between the rhetoric of recovery and the availability of appropriate training and support, may lead to expectations being raised which cannot be met. Although the development of the new recovery model presents a real and welcome challenge to traditional theory and practice, it is also important to recognise its limitations and to be mindful of "the need to critically analyse the rediscovered concept" (Ramon et al, 2009 p. 321).

The idea of WRAP

The key principles and concepts of WRAP are explicitly aimed at people who are struggling to come to terms or cope with mental ill-health.

According to the Copeland Centre website there are five "key [recovery] concepts.

Hope – people who experience mental health difficulties get well stay well and go on to meet their life dreams and goals

Personal Responsibility – It's up to you, with the assistance of others to take action and do what needs to be done to keep yourself well

Education – learning all you can about what you are experiencing so you can make good decisions about all aspects of your life

Self Advocacy – effectively reaching out to others so that you can get what it is that you need, want and deserve to support your wellness and recovery.

Support – while working toward your wellness is up to you, receiving support from others, and giving support to others will help you feel better and enhance the quality of your life⁶

The Scottish Recovery Network provides training for WRAP facilitators who themselves have already been trained in and developed their own WRAP⁷. It is recommended that WRAP training is done in a group setting⁸ but the idea is for each individual to develop their own recovery plan or WRAP, based on their personal circumstances, experience and aspirations.

Each WRAP training session consists of the following elements.

- Wellness toolbox
- Daily maintenance plan
- Identification of triggers and associated action plan
- Identification of early warning signs and associated action plan.
- Identification of signs that things are breaking down and associated action plan
- Crisis planning
- Post crisis planning

These elements seem self explanatory in relation to service users. The point about this study is to explore how they are used with carers.

Discussion

The WRAP brand was explicitly aimed at service users although as a self-management tool it might be useful to others who are going through crises or who feel that they have lost control of their lives. The language of recovery is optimistic and based on the fundamental belief that human beings do not thrive unless they have self-determination. It remains a controversial concept. Proponents of recovery might come across as zealots who are underplaying barriers to self-determination. These barriers include serious mental distress or psychosis, stigma, discrimination and massive cuts in public services. The criticisms have to be balanced with the knowledge that the new recovery concept was developed *by* service users *for* service users who were fed up with the *disempowering* effect of the more traditional personal tragedy model of mental illness.

⁶ <http://copelandcenter.com/what-is-wrap/>

⁷ <http://www.scottishrecovery.net/WRAP/about-wrap-training.html>

⁸ <http://www.scottishrecovery.net/WRAP/about-wrap-training.html>

4 DELIVERING WRAP TO CARERS

This chapter explains the background to Edinburgh Carers' Council decision to offer WRAP to carers, describes the thinking behind it and how it fits in with the work that Edinburgh Carers' Council does.

How did it start?

The initial inspiration for offering WRAP training to carers came from listening to a service user talking about her own recovery, achieved despite years of hospitalisation. Now a WRAP trainer herself, this woman was living proof that there could be life after a mental health diagnosis.

Linda MacLeod was impressed by the recovery story and so decided to ask the woman to come along and talk to carers at Edinburgh Carers' Council.

I thought well, I like this idea of recovery, living well, with or without mental illness. It's so positive, it's so hopeful, it's so like, not medicalised. It's just so empowering I think for service users.

The WRAP training she envisaged for carers involved a crucial switch from focussing on the wellness of service users to the wellness of carers. This was in itself a challenge. One of the WRAP facilitators explained how important it was that carers understood before the training started that it was for them and not for the people they were caring for.

This is *not* a tool for them then to go on and do it to the person they are caring for. They're coming to the training for their needs, for them and I think for carers to actually take that time out to do something for themselves, that is so powerful because most carers don't think about themselves.

Linda was keen to explain that getting carers to focus on their own needs was not about driving a wedge between carer and service user but about learning how to manage relationships better.

[It's] not about separating carers and service users. I'm really much more about the whole relationship, the behaviours that they're experiencing, how they can manage that, how they can set boundaries for themselves and that's where the whole idea of WRAP came in because I've seen that many carers have been impacted greatly by their caring role.

How WRAP fits with the work Edinburgh Carers' Council does.

Edinburgh Carers' Council's overall purpose is to provide the practical support and empowerment that carers need in their caring roles. This includes the provision of information; individual and collective advocacy, training opportunities and the promotion of self-advocacy through confidence building. WRAP fits into Edinburgh Carers' Council's training and awareness programme, providing an opportunity for carers to think about their situation and relationships, develop the tools and strategies they need to cope and the confidence and self knowledge to express their needs effectively.

Carers will normally approach Edinburgh Carers' Council because they are having problems accessing the right kinds of services for the person they are caring for. Not everyone who is told about the WRAP training will see its significance to them or be able to make sense of the WRAP concept.

It can be quite difficult, trying to explain the idea of recovery and WRAP to someone -who isn't familiar with it at all because it can be quite an intangible thing for people to grasp...even talking about wellness, it's not actually a term we use as a society. (Andrea, Edinburgh Carers' Council, Development Worker)

Within the field of mental health, the recovery concept is not universally accepted. 'Recovery' might be seen as the most recent buzz word. Years of personal experience had made both services users and carers sceptical.

..there was a lot of suspicion originally around recovery because I think for some service users it was seen as really very positive and a new way of going and they wanted to see it embedded in all services but for others who'd maybe been ill for years and years, they just thought it was a kind of fanciful bit of hype ..and for carers, as well, when you're telling someone who's caring in a devastating situation about things like hope and this and that, they get pretty hacked off or they did. (Ruth, Edinburgh Carers' Council, Co-ordinator)

The formula that worked

Because of negative attitudes to the idea of recovery Ruth had expected some cynicism about the use of the recovery model with carers. However, carers signed up for the training and continue to do so. The popularity of WRAP training with carers compared to other things that Edinburgh Carers' Council has tried suggests that WRAP has something to offer carers that other supports lacked.

.. the reason we carried on with it was really because of the feedback we got each time we advertise a training. It's been booked up immediately whereas other things we'd run in the past and still sometimes try to run, you maybe get three people

signed up for it and then only one comes at the end of the day so we felt we'd found something that really was meaning something to people and that's why we've carried on with it...WRAP's been the formula that's worked. (Ruth, Edinburgh Carers' Council, Coordinator)

When working with carers to look options of support, more and more I find carers are wanting something more specific, something more focused than a generic support group. (Andrea, Development Worker)

In some cases it is an issue of timing. Carers might not be ready for the group, too fragile or too caught up in the business of caring to attend training. For some carers, WRAP would never be right. Not everyone would find it useful and WRAP should never be presented as if it was the solution to everyone's problems.

That's not to say WRAP is the be all and end all and you'd never promote it like that. WRAP can't be seen as the next Mr and Mrs fix it. For some people WRAP works really well, it's something they can relate to but for other people, it's just not for them and that needs to be respected as well. It would be really wrong to enforce it. It's about offering choice, it's about, this is just one tool of many (WRAP facilitator)

This was important because the recovery model has to be self-directed.

The WRAP for Carers Format, Edinburgh Carers' Council style

There are two main elements to the way that Edinburgh Carers' Council delivers WRAP for carers. These are a) the training and b) the on-going group.

Training WRAP training is carried out by a trained WRAP facilitator. Carers are introduced to the key concepts and main elements of WRAP as developed by Mary Ellen Copeland. More recently training has lasted for 6 weeks with a two hourly session per week. Earlier courses lasted eight weeks and four weeks⁹. The current thinking is that the course should last for at least 6 weeks because that allows group members time to get to know each other. A week between sessions allows carers time to reflect on what they have done to look after themselves. Delivering WRAP training for carers was new, so there were inevitably some teething problems but overall feedback from carers has been positive. Training is discussed in detail in Chapter 7.

⁹ It seems to have been due to availability of the trainer more than a deliberate decision that four weeks would suffice

The On-Going group When the training comes to an end, carers are provided with the opportunity to attend monthly WRAP Group meetings, facilitated by Linda MacLeod¹⁰.

This is a significant innovation which is explored further in Chapter 8. Carers are formally invited each month by way of an invitation card. Groups seem to have their own 'shelf life' as some members drop away but individual members who feel they want the continued support of a group are accommodated by arranging planned mergers. Groups are consulted before any merger takes place. In total there are 26 carers who are regularly attending WRAP Groups.

Facilitating WRAP

One of the main recommendations of an evaluation of wellness planning carried out for the Scottish Recovery Network (Pratt, 2010) was that

Training facilitators who are committed to the principles of recovery is important. Also the ability of facilitators to share their own experiences was highly valued and may be an essential part of the success of the training (p.3)

Edinburgh Carers' Council has bought in trained WRAP facilitators who have experience as service users to carry out each of their WRAP training courses with carers. The recovery experiences of service users can be inspirational because it gives carers hope that their own loved ones can recover. The most recent facilitator also had experience as a carer and became a trainer after doing the WRAP for carers training. There is no reason to think that carers' WRAP stories would be any less inspirational than service user's stories and a carer facilitator may well be able to draw on 'insider' experience to make training more relevant to carers. But without a doubt, in this study, carers' accounts suggest that the story of recovery they heard on the first day of the WRAP training had a powerful impact on them and this seems to have been as important to the success of the WRAP training with carers as it has been with service users.

Linda, Edinburgh Carers' Council's development worker co-facilitated WRAP training. She not only supported the trained facilitator and provided refreshments but also took part in the group as a member of the group. Linda continues to facilitate the on-going WRAP Groups. A trained psychotherapist, Linda draws on a number of theoretical approaches to Group Process and Dynamics¹¹.

¹⁰ Linda is not a trained WRAP facilitator but follows the same format used in WRAP workshops of asking participants how they are and what they have done to look after themselves.

¹¹ In particular, she cites Tuckman (1965) who describes four stages of group development involving the initial formation of the group where people are waiting to see what they and others are going to do in the group (Forming), the establishment of roles, power differentials and boundaries (Storming); the establishment of a

Linda explains that it is not necessary to be a trained psychotherapist to understand how groups work but feels that her experience of group work is helpful. She sees her role as follows.

It's about encouraging [the carers] to use their WRAP tools within the safety and containment of the space they're in.

Edinburgh Carers' Council's view is that a) Linda's presence has provided continuity throughout carers' WRAP experience and b) her professional knowledge of carers' issues has helped her to provide appropriate support. Carers were very positive about Linda's involvement and her on-going facilitation of the WRAP Groups.

Tea and Nice Biscuits

Refreshments are provided throughout the training and at monthly group meetings. Because the point of initiative is to encourage carers to think about their own wellbeing and to try and have a break from caring, Linda takes on the carer role by insisting on making the tea/coffee herself and providing 'nice biscuits or nice sandwiches'. She explains it as follows.

..my way of getting carers to think about allowing someone else to care for them, is I will always make the teas and coffees or I try to and I try to get nice biscuits or nice sandwiches for the evening group because I want to offer some kind of nurturing to carers to get them to start thinking about nurturing and taking care of themselves and I know it might seem like a simple thing...

Carers seem to appreciate this. In one of the focus group discussion, there was a humorous exchange. *Moderator: Why do you think this group is still together? Participant 1: The sandwiches are quite important. Participant 2: He just comes for the sandwiches.*

Funding

Originally, a small amount of funding was received from the 'See me' fund. It is now part of the service level agreement but as such, not ring-fenced in terms of staff hours. It is estimated that the cost to Edinburgh Carers' Council of running WRAP for carers has been £7260 per based on 30 carers undertaking WRAP and WRAP Groups over a 2 year period. This includes 8 hours a week of the Development worker post Linda provides. This works out at £242 per carer. In 2008 it was estimated that the work of informal carers saved the state around £5 billion. Given these savings a yearly investment of £121 per carer per year would seem to be good value for money.

group culture (Norming) and the final stage which involves the group getting on with the task of the group (Performing).

5 WHAT DOES WRAP MEAN TO CARERS?

This chapter begins the process of understanding how WRAP works with carers by exploring what WRAP means to carers who took part in this study.

Timing

For anyone who had not had contact with carers' organisations before, a WRAP advertisement might bring them in the door. George had been referred to a mental health event and came across Edinburgh Carers' Council stall. Up until that point he had not come across anything for carers like him..

..it was because it was for carers. There was nothing else I'd ever seen for carers and it was relevant to the illness of [the person I am caring for]

Unlike George, Marsha had already been receiving help from Edinburgh Carers' Council when the opportunity to do WRAP came up. Quite simply, she took that opportunity because it was on offer.

It was just up for grabs here...it's because I'd been around and involved... I mean there's the newsletter they send out, it is very good and always tells you what's coming up. I'm the kind of person if there's something up and it looks interesting then I'll go.

Marsha already had some idea of what WRAP was because she had already been at a talk about it. Carers may well have come across WRAP before they signed up for the WRAP training. The chances are, if they did, they heard about it as a recovery tool for service users.

I always thought it was for service users or clients or whatever...it was confusing to me. It came across to me like it was all about the person that you were supporting (Christine)

One of the WRAP facilitators described how in her experience, carers are likely to come to WRAP training when they are struggling to cope.

When people come to the training they're coming at a very low point. They need something, they can't see what they need but they know they need something. They need things to change (WRAP facilitator)

This was echoed in interviews with carers in this study. The offer of training seemed to have come at just the right time for them because they were struggling to deal with the mental distress of a loved one or worried about a loved one's high risk behaviour or they themselves were suffering from mental distress. In other words, the offer of WRAP training came when they were at some sort of crisis point.

With the WRAP thing coming up we thought well, we'll just give that a try and it came at a very good time because we were struggling (Martin)

A newsletter came out and I saw this and it just, so much of my life is serendipitous and it just came at the right time and it sounded like the right thing to do (Sophia)

..and in that very month when I was going through this crisis that's when they were talking about starting the WRAP training..it was the perfect time for me to get involved. (Mary)

It came at the right time because I had a very distressing episode (Sharon)

Arguably the WRAP is all about service users avoiding crisis or laying down plans so that crises can be managed effectively. It is not always clear what crisis means to carers. Christine already knew about WRAP and until Edinburgh Carers' Council laid on WRAP training for carers, she hadn't been able to grasp the relevance of it to her. There was something about this course that made sense.

I didn't see the full implications for myself and it was only when ..I was not in a good way and the Carers' Council has said, we're running another six weeks course..and all of a sudden, the light bulbs came on, because we were not allowed to think of the person we cared for, this was about me.

Carers might sign up for WRAP simply because it was there or in sheer desperation but what mattered was what they made of it once they got there. It had to make sense or it is unlikely they would stick with it.

Making sense of WRAP

Carers had different understandings of what WRAP provided. For some it was simply about learning how to cope in challenging circumstances. The support of others in the group was crucial to that because it ended the isolation carers might have been feeling up until that point.

.. I desperately felt I needed something, a lifeline to hang onto. I felt on my own at that point and I thought this was maybe a way of getting involved and building a strategy to help me cope (Sophia)

You know I learned a lot from the others, their kindness, their patience, seeing how other people cope (Marsha)

For Mary the WRAP training came at a time when she was going through “a big crisis”. WRAP provided her with an opportunity to step back a little, see her situation differently and adjust her reactions to what was going on in her life.

I know how helpful it was because I was going through a big crisis and that kind of gave me the tools that I was needing to have a bit more perspective on how to go ahead, so perspective is a major thing, change in perspective, seeing that you are supported first of all and you’ve got tools to start using rather than panicking because that was what I was doing before, I was just panicking (Mary)

Given the traumatic events which might have led to carers seeking help and the isolation they may have felt up to this point, meeting other people who have had similar experiences can provide a release for pent up emotions. A story of recovery can give a renewed sense of hope.

I can remember just feeling wonderful because I was with a group of people who understood where I was coming from and I just cried, I remember the very first time because it was just the [WRAP facilitator’s] voice and the fact that she had been through mental health herself and to watch her leading this group was just amazing and so it was just perfect for me (Sharon)

The delivery of WRAP to carers, focussing attention on their needs as opposed to the needs of service users, is an acknowledgement that carers have rights and perhaps redresses an imbalance in terms of how relationships of care are generally viewed, not just by service providers but by carers themselves. In the WRAP training programme, this is presented as the Personal Bill of Rights. Martin saw this as key to the relevance of WRAP for carers.

In my view, the personal Bill of Rights is crucial to the whole concept. Carers are generally programmed to believe that they have no rights. This Bill of Rights gives them the belief that they have rights. This should be the starting point for any re-write of the WRAP programme.

What’s in a Name?

Although in many ways it was self evident that carers have to be well themselves in order to be able to keep on caring, when it was pointed out to them that they not only needed but *deserved* to keep well, it was revelatory. However, some of the carers in this study queried the usefulness of the recovery concept.

[WRAP] is the wrong name for a start....wellness recovery action plan is not really what carers need. Carers need a wellness plan for themselves. They're not actually recovering. They are trying to survive and not go to pieces. [Discussion Group]

There were suggestions for alternative names which made more sense for carers e.g. Wellness Action Plan. *Survival* of the caring experience is important in its own right. It suggests the danger of something going wrong in the future: the danger of "going to pieces" and not being able to care anymore. The 'R' In WRAP is dropped and what you are left with is a preventative measure or intervention so that carers do not get to the stage where they can no longer cope.

Discussion

WRAP training seemed to be filling a gap in provision for carers generally. That there was anything that helped carers to cope in challenging circumstances was to be welcomed and seemed to be an acknowledgement at last that carers have rights too. Being introduced to other carers who were having similar experiences was important to all the carers in this study. Learning that recovery is possible by listening to a WRAP facilitator's own powerful recovery story was inspirational. However, that story was the recovery story of a service user. The training that Edinburgh Carers' Council was providing was specifically aimed at helping carers develop their own WRAPs. Carers have an emotional and practical interest in the recovery of the person they care for but as evidenced in this chapter, not all carers accept that they need recovery. The meaning of recovery to carers is the subject of the next chapter.

6 DO CARERS NEED RECOVERY?

My perception is that we really, really need to explore what does recovery mean for carers? What does wellness mean for carers? Because I think that it's wrong to make the assumption that recovery means the same thing for everyone [and] if we don't explore that thoroughly enough then we're not on the same page (WRAP facilitator)¹²

The significance of the recovery concept to carers was explored in interviews and discussions. This is important in an evaluation of the delivery of WRAP to carers because WRAP as developed by Mary Ellen Copeland is ostensibly a recovery programme. The Scottish Recovery Network website explains that "recovery is a unique and individual experience and while there may be common themes and experiences, no two people's recovery journeys will be identical"¹³. This allows for some flexibility and could be interpreted to mean that carers can make of recovery what they will. But this may not be enough. Not all of the carers in this study were comfortable with the idea that carers needed recovery at all or that the positive experiences they gained through WRAP amounted to recovery. Yet WRAP without recovery seems to be like an ambulance that doesn't move. Recovery is the very point of WRAP. This chapter is all about what the 'R' in WRAP means for carers.

"It's a nice word"

When carers first encounter 'WRAP' it is likely to be as something which could help the people they care for with *their* recovery. However, carers may hold out little hope that the person they care for *will* ever recover. Marsha found it difficult to see the relevance of the recovery concept to either her or the person she cared for "because they're never going to get better". WRAP helped carers to cope or survive on a day-to-day basis but when confronted with the reality of living with or loving or feeling responsible for someone with a mental health condition, the idea of recovery might seem like a cruel illusion.

I'm coping, I'm coping with a day at a time and feeling okay about it and I mean grief is always with you and it'll never go away and so how *can* you recover? I mean it makes a nice word [laughing] WRAP. But I mean you're still broken, they will never be well, will never do what they were supposed to. They've lost a lot and it's not right. So I think recovery is not the right word, it's control.

¹² In feedback after reading a draft report, the WRAP facilitator asked me to emphasise that a great deal of time was spent during the training workshops exploring what recovery meant to individuals within the group to help make sense of WRAP.

¹³ <http://www.scottishrecovery.net/What-is-Recovery/what-is-recovery.html>

For anybody, we're all up and down and round about, out and in and out and we're all just keeping a lid on one way or another

This highlights the relationship between the mental well-being of the carer and that of the person for whom they care. It is important not to gloss over the feeling of loss that carers feel. The idea of a WRAP that keeps you warm and cosy might evaporate in the face of the truth about mental illness. This understanding of recovery as complete recovery or absence of symptoms goes hand in hand with the continuing dominance of the personal tragedy model of disability and the challenges of coping with mental ill-health in the face of discrimination and strained public services. The reality of coping with too few resources came to the fore elsewhere in this interview. The carer spoke of her frustration that the professionals who were supposed to be providing care weren't actually providing it. A lack of alternative care makes it more difficult for informal carers to stop feeling responsible and more likely that they will neglect their own needs. Marsha recognised it as a resource issue.

So they're overworked as well. I tend to say people are overworked rather than they're not doing their job properly because when there is so much on top of you...

Although recovery did not make much sense to Marsha, WRAP did. She described it as "an essence that comes round you...like the duvet". The word itself 'WRAP' has a potency while breaking it down into its constituent parts might expose weaknesses.

George also thought that 'recovery' was irrelevant to him as a carer although he acknowledged that it was meaningful for carers who were also service users.

This is where I thought the WRAP thing fell down a little bit because actually the wellness concept is important for the carer. And I know there are some carers who have mental health problems themselves and there'll be a recovery issue but for a carer just as such, recovery's not really the issue, it's wellness. Some of the stuff about recovery *could* be relevant to some people, but it wasn't necessarily relevant *as such* to a carer.

It was important to George to express his view on recovery. On the other hand, he was emphatic that this conceptual weakness did not outweigh the positive benefits to carers of a) thinking about their own wellbeing and b) being reminded to schedule in "me-time". He also acknowledged that he might himself show signs of being stressed and "a bit run down" and that this might be attributable to his role as carer although there was no way of proving the link.

It's difficult to show causation but there might be little things where no doubt, the stress at home has been a factor.

It was possible that 'recovery' was too strong a word and too readily associated with service users to be useful to everyone. However, evidence from this study suggests that there were a number of circumstances in which carers do need to recover. Three such meanings have been identified in this study. They are:

- ✓ Recuperation
- ✓ Revival
- ✓ Renewal

This is not an exclusive list nor are these necessarily mutually exclusive. In some cases they might even be seen to amount to the same thing.

Recovery as Recuperation

In some cases, carers are struggling with their own ill-health which may or may not be associated with their caring responsibilities. Their own health problems may have pre-dated their caring responsibilities. Carers may even feel that this has contributed to the mental illness of the person they care for.

In cases where the carer has acknowledged their own mental ill-health then recovery and wellness might be no different for them than for the person they care for. However, as a carer, they might still feel guilty about taking time out. WRAP could help by identifying the need for recuperation *and* give carers permission to attend to it.

Well for me [recovery] is taking time out and obviously because it's usually depression or anxiety, it's not feeling guilty about taking that time out. It's the fact of realising that I need that time out". (Christine)

The need for time out to recuperate is an important aspect of recovery and as much an issue for carers as it is for service users. The need to recuperate fits comfortably into both the traditional and new models of recovery. If carers don't have that opportunity to recover or charge their batteries then it might make it harder to cope not just with the big things e.g. the hospitalisation of a loved one, they might also be too worn down to deal with the little day-to-day problems that everyone has to face.

And then you've got the quieter time. How do you deal when wee gentle things come up that could knock you back into needing to recover again? How do you stop it getting to that? (Group Discussion)

The process by which carers achieved recuperation could be linked to and run in parallel with that of the person they were caring for

For me [she describes the sudden onset of serious mental health challenges of the person she cares for] that's been quite devastating and so I *do* feel that it's a process of recovery back to some sort of sense of normality (Group Discussion)

In the case of service users it might be taking time out from paid employment, taking time off work. For carers guilt might be relieved by acknowledging that caring though unpaid, is work and it is very hard work.

I learned that health care professionals get trained to deal with an hour session with somebody they're looking after because it will take it out of them. They will balance their time because they can't be spending all their time with ill people. And just the revelation that spending half an hour of close proximity with somebody, how much that takes out of you. It seems like common sense I suppose but it was actually a revelation.. the extent to which even low level depression can be really quite emotionally draining on somebody who is the carer was quite an important insight. (George)

..you know how counsellors unburden themselves, they go to their own effective counselling, I find [the WRAP Group] a great place to unburden myself, just an outlet, let off a bit of steam because I've had times when three, four, five, nights on the trot I've been doing two hour counselling sessions, post-midnight. Now I'm the sort of person who likes to be in bed at ten o'clock so it's been quite challenging and you don't have any of this opportunity to release. I mean how many counsellors do two hour counselling sessions repeatedly [laughs]? You know you don't do it. (Sophia)

This was not about being selfish. Carers *deserved* and *needed* time out to recover.

Recovery as Revival

Martin handed me some written thoughts about WRAP training. In it he discusses the name and the possibility that recovery *is*, after all relevant to carers.

I am personally not that keen on the name – Wellness Recovery Action Plan (WRAP). But it is well established, and it could equally refer to carers. After all they deserve “wellness” and they definitely need an “action plan”. Perhaps they also need to “recover” – possibly to recover their own identity. So perhaps we should retain the acronym WRAP.

It was as if Martin was thinking out-loud and playing around with the idea of recovery as something that could have a meaning, albeit a rather esoteric or mysterious meaning beyond the conventional medical understanding of the term as complete or symptom free recovery.

For carers, the identity of carer can be all-consuming and they can lose sight of what is important for them as individuals. This point was made very powerfully in group discussions and interviews

I feel like I’m, phaw, recovering the person I was. How am I going to recover because I feel physically, mentally, I’m catching up but physically I feel beaten and mentally I feel beaten and I think how am I going to find a life amongst this, you know? (Group Discussion)

It came at just the right time because I was so traumatised by where I was that I had lost who *I* was. We were all focussed on the person we were caring for so that allowed me to have the space to sit round with a group of people and just explore where *I* had gone. And that’s really where we started and I suddenly over time did WRAP and then in the support group, found out that I still existed, you know in this equation (Sharon)

And all of a sudden I realised who *am* I any more? Which was the question. So I mean that must have been over two years ago and that just changed everything in my mind (Christine)

This meaning of recovery has elements of recuperation in it but it seems to be more than that. It is almost as if the self has died and recovery involves bringing it back to life.

Recovery in the sense of recovering your sense of self or identity has been found to be important within the field of mental health (Brown and Kandirikirira, 2007). Here was clear evidence that it was *as* important for carers.

Recovery as Renewal

In some cases it might be about recovering something that had been lost but it might also be the case that by confronting the situation they were in and admitting that they had lost a sense of self, carers might start to uncover *new* selves, new potential.

WRAP gave me a focus to start looking at what do I enjoy anymore, what am I? I'm a carer. So it was finding a new identity and from that I went on and did things that I hadn't done in twenty five years and I started actually thinking about my own life and what I could do and also admitted to the stress I was under at the time. (Christine)

This idea of renewal or recovering a new self was typified by the recovery stories of those who had gone on to become WRAP facilitators.

It's the passion and belief in what I'm doing. I really believe that the work I do has the potential to make a difference and if it makes a difference even just for a handful of people then it's been worthwhile.... The training gives me meaning and purpose. It's something I believe in. I didn't have *any* meaning and purpose really apart from being a patient. (WRAP facilitator)

Mary described how her life had been turned around by doing WRAP training. Mary had actively committed herself to being a carer for the foreseeable future. WRAP had helped her to confront her own mental health issues and realise the things she had to do to keep herself well. This in turn had helped her to build a more positive relationship with her son and at the same time build a new personal identity for herself.

What I am trying to do is introduce more and more into my life so that I'm not just a carer but I am maybe going to write a book. I have something to say about it. It's just an idea but what I *am* doing, I'm reading a lot, I'm writing, I'm gathering things together and then something will come out of it

In the same way that a service user is not defined by their mental health diagnosis, Mary was not defined by her role as carer. Being a carer was neither a personal tragedy or life sentence but had provided her with an opportunity to see herself in a completely new light.

Discussion

In these conversations about 'recovery' and its relevance to carers, a number of issues emerged which helped to explain the value of WRAP with or without the 'R'. Carers might need to make a clear distinction between the needs of the carer and the person being cared for. This is important in the context of a programme which is supposed to be aimed at carers' needs as opposed to the needs of the person they are caring for. Given the culture of hopelessness that tends to surround mental health diagnoses, it is not surprising that carers internalise that hopelessness *on behalf of* the person they care for. They may also lose hope for themselves.

On the other hand, those who want to keep the 'R' may have reasons which are not so very different. It is *because* the 'crises' that service users go through do not take place in isolation but impact on those who feel in some way responsible. If carers' well-being is compromised, it can weaken their ability to deal with even the smallest of issues that arise and so the need to prepare for recovery can be a constant in a carer's life.

Carers had no problem understanding the value of the training they had received and whether or not they accepted the recovery concept might seem irrelevant. On the other hand, by not exploring different meanings of recovery, it leaves the way open for carers to question the relevance of WRAP for them and might even put some carers off coming along in the first place. Identity issues matter to carers as well as to service users. There were some inspiring stories told in this study about how carers might recover a sense of self and perhaps more importantly discover new things about themselves. Retelling carers' stories of recovery might help future carers to understand the significance of WRAP for them as well as for the people they care for.

The idea of recovery itself was controversial but the concepts upon which it was based didn't appear to be problematic. The extent to which carers identified and were inspired by the key recovery concepts is the subject of the next chapter.

7 THE KEY CONCEPTS OF RECOVERY

In Chapter 5 it was found that while some carers embraced the idea of recovery, others struggled with understanding its significance. In this chapter, the key concepts of recovery are explored.. Each of the five concepts are interconnected and overlap but for the sake of clarity, they are dealt with here individually.

Hope

.. when you see people coming to the training, desperate and within a few hours being able to get support from the group, suddenly you can see that maybe things *might* be a bit different for them, that potential in their face, it's just wonderful, money can't buy that.. (WRAP facilitator)

Evidence from other studies suggests that hope is seen as crucial to recovery by service users (Leete 1989, Perry and Gilbody, 2009). Right back at the beginning of training, it was the recovery story of a service user that inspired hope in carers. It showed them that "recovery can happen" (Group Discussion). A carer's hopes and dreams might be neither more nor less than the hope that the person they care for recovers. In difficult times, the role of carer was all consuming.

When it was bad, you couldn't think of anything else. It sort of took over your life (Martin)

WRAP provided an opportunity to carers to concentrate on their own hopes and dreams separately. It could be a liberating experience and could happen at any stage of life. And in the same way that you could have a life even without full recovery or an absence of symptoms, so carers could continue to care and yet still have a life of their own. It was also a question of rights: a right to your own future.

WRAP's about moving forward, no matter what age, you can still move forward as an individual even though you may have this particular role. Being a carer does take up a lot of role and is incredibly stressful but as an individual, you deserve your own role, whatever that might be. (WRAP facilitator who is also a carer)

Knowing that you had a right to a future was empowering and energising.

I think that what [WRAP] did for me, it made me more positive, much more confident. I mean it kind of made me more secure in myself..It did empower me because it kind of reinforced all those kind of wobbly parts. (Mary)

WRAP was also about giving me back control of myself and of my time and of my choice, that I *had* choices, that I still had choices, that they hadn't just all, you know, this was life and that's it. (Christine)

The idea of movement as opposed to stasis was important. By focusing on their own hopes and dreams for a change, carers might even start to believe that the concept of recovery had a meaning for them.

[If it wasn't for WRAP], I don't think I would have moved out of paralysis really. I possibly would have had counselling. I think I would have probably been on anti-depressants and everything because it was really pretty awful and that wouldn't have solved anything. This has been a much more positive, active recovery (Sharon)

The sense of empowerment that accompanied hope meant that you were no longer "the victim of circumstances".

I can do something about it, you know and what to do, you know, even if it takes small steps, you break it down, you chunk it down and you've got a grasp of the situation. Power in the good sense, you know, empowering yourself, you're not oh poor me, I can't do anything about this (Mary)

Hope and empowerment are symbiotic – they feed each other and they are underpinned by *personal responsibility* which is the second of the key recovery principles.

Personal Responsibility

In the training materials that carers were given there is a reminder that every individual has the knowledge they need to identify their own needs and wants and that each individual must

take personal responsibility for [their] own wellness and life. Sometimes this means taking back control that you have lost in the past.

This is equally applicable to both service users and carers. Caring for someone could mean periods of 24 hour care, especially if there was a danger of self-harm or at the very least it meant being on call and ready to respond at a moment's notice.

The study revealed that a major issue for carers is *boundaries*. Guilt or fear might ensure that carers never say no to a request even though they might be struggling to cope and/or have health issues themselves. WRAP reminded carers of the importance of looking after themselves and most importantly, not feeling guilty about it.

I never thought about it in terms like that. I was thinking, what am I actually doing to look after myself? Nothing. I just feel guilty if I say no to something. So I don't say no and then I'd feel guilty. I always, always felt guilty. If I worked too hard then I'd have to take time off and I'd feel guilty (Christine)

Carers who have been used to taking personal responsibility for others but perhaps *not* for themselves may find it difficult to let go.

..you look at personal responsibility and you know that carers have to look at, well, what decisions am I making for myself? And they might struggle to identify those but they're very quick at actually identifying all the decisions they are making for the person they care for (WRAP facilitator)

Personal Responsibility is a tricky concept for two reasons.

1. It seems to exemplify criticisms of the recovery model that it puts too much emphasis on self help and individual responsibility and so risks underplaying very real constraints which service users and carers might face when they try to take control of their lives.
2. It might make carers feel that they are or have been personally responsible for holding back the recovery of the person they care for.

In the story of recovery that had been so inspirational it seemed that a key factor in recovery had been the recognition by a carer that for the sake of her own health, she would have to step back and do less. By taking a step back carers allow the person they care for to start taking responsibility for themselves. Saying no once in a while is not just good for carers but might also be good for the people they care for.

Now that was very pertinent to what was going on with us because [the person we cared for] just *wasn't* taking any responsibility at all, that's how we knew that he needed to have somebody independent...and I could see what she was doing now you know, with her life and she was very good (Sharon)

My aim is to help [the person I am caring for] back to independence. If I can't do that I have failed because ultimately I am not going to be here forever. (Sophia)

The risk of underplaying constraints on personal responsibility is reduced if it is understood that taking personal responsibility is about taking control of and owning one's own decisions but definitely not about managing alone. In periods of mental distress or crises, service users may be unable to act autonomously. By planning for crises and making advanced statements service users retain a measure of control and personal responsibility, How much personal responsibility a carer takes on is clearly a matter of negotiation. When service users are unable to take responsibility for themselves, it is not that they are behaving *irresponsibly*, it is more likely that they lack the resources to take responsibility or have spent so long in the role of dependent that they have become used to relying on someone else. This was explained very well by a WRAP facilitator as part of her recovery story.

I'd been totally and utterly dependent on other people to fix me, to support me, to mollycoddle me but after all the years and all the therapies, I didn't actually *have* the resources to be self determined, to take personal responsibility (WRAP facilitator)

In the same way, carers might have spent so long caring that it had affected their sense of self. Guilty feelings that you are responsible can be exacerbated if a loved one blames you for their mental health problems. You might know deep down inside that you are not to blame and that can cause feelings of resentment yet not remove the guilt. Guilt was a powerful emotion and rather than blaming carers for taking too much responsibility on themselves WRAP could help carers to shift the way they thought about their role. In taking less responsibility for others, they not only facilitate others' recovery, they also start to take personal responsibility or, in other words, take back control over their own lives.

.. many of us have people we're looking after who tend to blame you for everything but there's a sort of reinforcement of the fact that it's not really my fault whatever the other person says and that it's okay to sit back and let things happen rather than be the one that tries to prevent things going wrong (Martin)

You know I've never been really good on personal responsibility [laughs] ..because somehow or another, I can be responsible for others. That's the thing with the carers, you know, I'll take on responsibility, helping other people and just end up a wreck. And actually I do have responsibility to look after myself. I can't expect everybody else to keep on putting [me] back together again...because it's not the same thing as being irresponsible" (Christine)

Carers in this study found the idea that they had been taking *too much* responsibility on their shoulders, a liberating experience. It *allowed* them to start taking care of themselves for a change without feeling guilty.

Conversely, a carer might make an active choice to focus on getting a loved one better. It is important that the choice to do so is also respected and acknowledged.

I had to kind of take a big decision: my work is going to be to help [him] and that's my priority which means that I couldn't really go out and get a job. In my case it would be almost impossible to be able to have a job. I had to make a commitment so it means my career's got nowhere. But on the other hand, I have made a choice about it and my work is all towards getting him better and better (Mary)

Making a decision to spend more rather than less time caring does not mean taking on more responsibility for that person. Consideration of the concept of personal responsibility can lead to an understanding that being a carer is not the same as being personally responsible for another person's life or decisions.

Education

In the WRAP training materials, participants are urged to “Learn all about yourself so you can make good decisions about you”.

Education is a social or a collective activity. Carers learned a lot from each other through discussion in the groups. They learned about what was possible and about their own potential.

Because hearing all those other people, you're learning by experience or from example..we have some great conversations and he said something and we had quite a discussion about it and I thought, I don't know if I could have done that five years ago. (Marsha)

Sharing ideas and having them taken seriously made you feel better about yourself.

It's good if there are suggestions popping up or whatever and they're accepted and it makes you feel good that, oh I have got something to offer, I'm not just a waste of space. (Group Discussion)

The fact that a carer might at any time feel they were a “waste of space” was a testimony to the incredibly disempowering effect of being a carer who feels they are unable to fix the person they care for, unable to make them ‘better’. However, this feeling of helplessness is reduced by the recognition that each individual holds the key to their own recovery. Through WRAP carers learned that recovery did not come from *telling* people what they should or should not do but about sharing ideas and supporting each other's decisions. Up until they came across WRAP, they might have spent a lot of their time trying to fix everything. In one of the group discussions, Linda explained that this was part of the group's original ‘comfort agreement’ . Over time carers came to realise their role wasn't to be ‘Mr or Mrs Fix it’.

At a very early stage you set a comfort agreement so it's not about fixing but in a funny way that is the hardest thing. As a group you're listening to other's stories and you're able to bear hearing other people's stories and the urge as a carer is to want to fix it but in the process of the WRAP Group you're taking care of yourself so it's like you can offer something to someone but you're not feeling quite so much that you have to fix it.

This came back to the idea of personal responsibility. Most of us resist being told how to run our lives and we are each of us best placed to decide what is and what is not in our best interests¹⁴. Through consideration of the recovery concepts, carers came to understand that there was only one person they could fix.

I think that's something I've learnt because I was always one for speaking my mind in most [laughing] situations but it would be very direct thinking that everybody would take my advice but of course they don't, do they? And they don't want it really but now I don't do that so much. I've started looking at me first and realising that if I sort me out then that's enough. (Group Discussion)

I've learned a lot, especially I've learned how not to interfere, not to control and to like learn how to step back and be silent when it's important to be silent instead of just being reactive and responding. (Mary)

Self awareness could lead to the negotiation of an improved relationship between carers and service user.

Relationships can be very difficult because we don't really understand the dynamic and the nature of how we are controlling or trying to control and so in that sense, I've done tremendously well and [the person I care for] consequently is doing the same because when he sees that I'm not so controlling then he's not so controlling (Mary)

Self Advocacy

It is easy to see how the self advocacy concept might translate to carers who often report that they are not listened to and marginalised by service providers. The perceptions of Edinburgh Carers' Council staff is that through WRAP, carers become more confident and are more able to self advocate and hence place less reliance on advocacy services by

- focussing on their own wellbeing
- increasing self knowledge
- taking a fresh look at care relationships by "looking at their own situation in relation to other carers' situations"
- being able to explore tensions in a relationship and be able to set boundaries

¹⁴ The exception is when we lose capacity altogether e.g. in cases of dementia or psychosis, This is the point about advanced statements and the crisis planning in the WRAP training materials. The point is to take personal responsibility for laying down plans which can be put into operation by people that are trusted to respect decisions made when a person *has* capacity.

- positive reinforcement within the group

There were two ways in which self advocacy might be important to carers.

1. In relation to service providers
2. In personal relationships

Meeting with others who were “in the same boat” made carers feel less isolated in dealing with professionals. Challenging professional attitudes to carers was also an issue that projects like Edinburgh Carers’ Council might do on their behalf.

.. we’ve all experienced the same rubbish care from the mental health services so we’re all in agreement about that, you feel less alone. If Carers’ organisations as a whole could put a bit more pressure on the mental health teams to give carers more of a role, that’s something that could be done. ...I think we’ve all felt we’re struggling against the system and nobody could care less but when it’s discussed in a group and we find that we’re all having similar problems, that gives you a certain strength (Martin)

Carers in this study tended to be confident enough to speak to professionals even if they were unhappy with the response and this probably reflects the make-up of the groups and/or those carers who agreed to take part in the research. But in any case, a focus on dealing with professionals was likely to plunge carers back into thinking about service users’ needs and not their own. In other words, dealing with professionals was often about advocating *on behalf of* the person you were caring for whereas self-advocacy was about voicing your own needs.

The thing that I would spend a fair amount of time exploring with them, how do you have a voice, not your voice to say what the person you’re caring for needs but your voice about your needs. (WRAP facilitator)

Where the idea of self-advocacy really came into its own was in relation to personal relationships. This is where carers really struggled to make their voices heard or to express their own needs. WRAP seemed to be able to help them to confront personal relationship issues.

Sharing care with other family members might expose relationship weaknesses which up till now carers had not had to confront. WRAP provided them with the confidence to advocate on their own behalf within the family.

I’m much more active when I feel well and just recently I’ve found a voice... I’ve been working extremely hard on that and if it hadn’t been for WRAP, and it’s a process, you know, I wouldn’t have found that voice.

And the voice is participating within my extended family and I certainly didn't have that before. Everything was passive but inside me, it was locked. So I think WRAP certainly helped to unstick me (Sharon)

Confronting a problematic relationship might be part of a wellness action plan and for Sharon it gave another meaning to the concept of recovery.

What the caring situation has brought to a head is how poor our relationship is because we both have to care and have to relate and that's been something for me, part of me has had to recover from my poor relationship.

Most importantly, familiarity with the concept of self advocacy could help a carer to renegotiate their relationship with the person they cared for. For example Marsha spoke about an insight she had gained from coming to carers' meetings. When someone close to you was making you feel unhappy you could just say to them "do you know how that makes me feel?" The responsibility is shifted back on to the person doing the hurting.

The message of self advocacy was based on the idea that human beings have a responsibility to themselves. It fitted well with other WRAP issues e.g. a) carers have rights b) they are responsible for their own lives and c) that if they didn't look after their own needs they might not be able to continue caring.

Support

And the WRAP has given me the tools to keep myself well and then the ability to share some of this burden in between times because I've needed to (Sophia)

A strong support system is seen as vital to the recovery and continued wellbeing of service users. For carers, the key issue is how to separate their own need for support from their obvious concern to get the right type of support for those they care for. Carers' own support systems might have become depleted either because caring leaves little time for socialising or because of perceptions about mental health which made it difficult to share with others.

Many carers don't actually have that many supporters for themselves. There's a lot of stigma and discrimination. As a whole people withdraw a lot so I just think there has to be a fair amount of sensitivity and exploring with carers what would make an effective supporter for you, not for the person you're caring for. How do you rekindle those connections that sometimes have been lost. (WRAP facilitator)

Carers in this study spoke about the problem relying on friends for support. Friends might shy away or carers might withdraw, fearing that they were overburdening friends and hence undermining friendships. Also friends might not understand and so the help on offer might be less than helpful.

You can only go on about your problem for so long, you can't *keep* going on. [At the WRAP Group] you can actually say how you feel without any come back. Because most people, if you say you've got this problem, they'll all want to well, why don't you do this and why don't you do that. (Martin)

Well I have to say that because it's been so traumatic, you know talking with friends, I got to the stage I just don't talk about it. .. I started off telling everybody because I'm quite open about talking to people but they were asking the most, they just had no idea what it's been like. And you just gradually stop. So that is how I find WRAP very comforting here in this room, this cosy little room and just talk. (Sharon)

A carer might anticipate negative reactions from others. What they needed was non-judgemental support. Behaviour which might be seen as out of the ordinary or abnormal to others was not out of the ordinary in the safety of the WRAP Group. A carer might anticipate negative reactions from others. In the WRAP Group they found acceptance and that in turn might make it easier to accept the person they cared for, as they are.

I think being able to accept [the person you care for] in all [their] peculiar guises is down to having come together with other people through the WRAP. Finding out that well, actually his son's downright peculiar and her daughter is a bit odd and oh yeah, I recognise that one and you know, that sort of thing and knowing that you're not alone and that you don't have to agonise about that. So that's been quite important to realise that you're on an extreme end of the spectrum but it's normal within that bit [laughs]. (Sophia)

The WRAP training and group provided more positive and self affirming support.

Before I didn't have a support group. I now have a support group that I build around me, that from time-to-time, quite regularly I actually go along to. That reminds me that I am important. I think it reminds me, helps me to sort of rationalise and accept something that I might find a bit of a strain and it's somewhere where I can actually talk about things which are perhaps getting me down. Those things are really quite important. (George)

There was potential for carers to be inspired and encouraged in the WRAP Groups as they perceived changes taking place in each other.

We're kind of like sharing things that we've learnt and we're, basically going round and talking about the things that we've been doing, that we've been in *control* of for once and we're not reacting in ways as we have been before and our ways are changing so I mean, it's not a big group [and] we encourage [each other] because we find the positive in there, 'but you've never said that before' that you've done that.

It's not like giving advice but it's giving suggestions of what you found to be useful and then someone else will say, oh I'll try that, that might work..the whole time it's kind of patting ourselves on the back with these amazing things ..it's that continuous support: it's always positive feedback. (Christine)

In theory other family members could provide support but in practice you might also be supporting them. Carers often have more than one caring relationship e.g. they might be caring for an elderly parent as well as daughter or son. Caring for someone who is ill is often in addition to meeting the needs of others.

You're always the one who looks after somebody else even in a marital relationship, somehow you're always the carer...It was always the fact, that was always my role and with friends as well, I was the one who listened to the problems and tried to help out. (Christine)

Family relationships too could be put under tremendous strain. One woman in the group discussion talked about her efforts to support other members of the family who were struggling to cope and might feel neglected. At the same time as she was looking after a seriously ill person, she was also trying to make sure others in the family didn't feel left out. She was keeping the family together.

Trying to make them still feel important and loved and needed, that's really hard.

There might be disagreement about how best to respond when someone in the family is showing signs of mental distress or there are concerns about risk taking behaviour. Disagreements can be exacerbated when you know something is wrong but you don't know what it is.

..it tore us apart..because everybody had different ideas about how best to deal with [the situation] and there was no clear diagnosis (Martin)

The opportunity to talk through relationship issues at WRAP Group meetings seemed to help make more sense of them.

It's taken quite a while so we [the family] are all pulling together now (Sharon)

One good source of support might be a partner, even an ex partner could be supportive. If you shared care, there was a shared interest in the recovery of a loved one. However, being a carer could put a strain on a new relationship. The support the WRAP Group provided might take some of the pressure off other relationships.

If you're trying to establish a relationship with somebody else for example, you don't want to be going on and on about all your problems. But you have to talk about it to *somebody* so here is a safe place to do that. (Group Discussion)

WRAP Group meetings were spaces to think about what supports you needed and what supports you already had. For example, some of the carers I spoke to found their faith and their Church community a great source of strength. Some had moved on from WRAP to seek further professional help e.g. counselling. These supports were part of the resources you needed to cope. It might be a question of recognizing and valuing existing supports and, just as important, knowing when to ask for help.

When the anxiety is reaching certain levels, I know I must now ask for help, I must now pick up the phone and phone the doctor and also tell my family. I never used to do that. I used to reach the stage where I was nearly flat out before I could do it where now I will still wait an awful long time before I say something but I will say [to a close relative], listen, I'm really going through a rough time and she'll come round and speak to me and just admitting it to friends, because [before] it was always a sign of weakness. (Christine)

Group meetings might also provide the opportunity to pursue other avenues of support. At each meeting carers were encouraged to talk about how they had been looking after themselves. It was an opportunity to share support ideas.

Discussion

What is required is a service delivery system that acknowledges the disabled person's requirements, that places choice and control by them at the centre of good quality service provision and that respects their rights to exercise choice and control in all matters. This does not mean, however, that carers have to be made invisible, or their rights ignored, in order to produce the latter situation. Carers have rights also (Harris and Roulstone, 2011, p 121).

'Recovery' is an intriguing idea which has been seen to liberate service users from the personal tragedy or 'life sentence' view of mental health. It doesn't necessarily translate comfortably for carers. However, the established concepts that underpin Recovery do apply to carers and in this respect a number of parallels can be drawn between the needs of carers and the needs of service users. The concept of hope challenges the personal tragedy or life sentence model of *being a carer* as much as it challenges the traditional model of

mental illness. Carers have a need to take control of their lives – take personal responsibility - and through developing self awareness they can come to appreciate the personal resources which will not only enable them to cope and thus continue to be able to care but also the resources they have to build a meaningful and satisfying life for themselves. Of course they also need to be able to identify and make use of the supports they have in place. Carers are urged through the WRAP programme to recognise that they have rights and start attending to their own needs. Moreover, a person's independence can be severely compromised if someone else is constantly trying to make decisions for them. This can lead to relationship damage as the person being cared for struggles against what seems like the oppressive behaviour of the carer. It can become a tug of war over the decision-making process. Because of the emphasis on personal responsibility in WRAP, carers can feel more able to step back and let the person they are caring for make their own decisions and allow them to make mistakes too.

There is evidence in this study that WRAP can help carers to renegotiate relationships of care and to acknowledge and even confront other relationship problems. This is self advocacy. For carers in this study self-advocacy seemed more important in terms of personal relationship negotiations than it did in terms of negotiations with service providers. Self advocacy combined with new understandings of personal responsibility had the potential to improve relationships between service user and carer. This has nothing to do with abandoning the role of carer and everything to do with learning new ways of relating based on the idea of interdependency.

8 WRAP TRAINING

This section is focussed on what can be learned about the WRAP training methods and materials. The training was found to be helpful to carers in a number of important ways. However, the materials that were used in those initial training sessions had been designed with service users in mind and carers struggled to see the relevance of certain parts of the WRAP 'brand'. The shift from focussing on the well-being of the person they care about to focussing on themselves is the most challenging but significant aspect of the WRAP training for carers and that raises important questions about how some of the trickier parts of the training could be handled with this group.

The Brand

'WRAP' is a brand with a registered trademark. This has implications for the way that WRAP is delivered. 'Guidelines for use and distribution of copyrighted materials' warn the reader of the following:

All rights are reserved by the author. Any copying, translation or inclusion in other materials for distribution must be approved in advance, in writing.¹⁵

On the Copeland Centre website, the reader is told that the system can be "adapted for use with other conditions"¹⁶. Although there is a known association between being a carer and ill health (NHS Lothian, 2008), not all carers are ill, have a 'condition' or see themselves as in need of recovery. Furthermore it might appear self-evident that the key to carers' wellbeing lies in the recovery of those they care for. This presents a problem for WRAP facilitators. How can the 'brand' be delivered in such a way that it encourages carers to think about their own needs, if in fact the materials are aimed at meeting the needs of service users?

I think it's really important when looking at the format of WRAP that we remember that WRAP was created by a group of people led by Mary Ellen Copeland who all had severe and enduring mental health problems.... I have to be very mindful about how I present it as a WRAP workshop because there's copyright but for me that's not enough. I need to interpret it in a way that makes sense. I have to be faithful to the materials but then I have to think about how is this going to be meaningful to carers. (WRAP Facilitator)

¹⁵ <http://mentalhealthrecovery.com/aboutwrap.php>

¹⁶ <http://copelandcenter.com/what-is-wrap/>

Participants in this study acknowledged that the system had been designed with service users in mind and that they had been the subjects of a very valuable experiment to see how it might work with carers.

I know that it was the first group and they were learning (Sharon)

Personally I think it was a mistake to just pick up one that was meant for people with mental illness and try and get the carers to do it but you've got to start somewhere. I understand that. (Martin)

There were quite a number of things where I felt that it was irrelevant, things like talking about when you're unwell and you know, it was clearly aimed at service users and yeah, I know I get unwell but I didn't need to think about what sort of treatment I would accept [but] we were led to believe that it *had* to be produced exactly as it is. (Group Discussion)

The original WRAP trainer acknowledged there were weaknesses with those first courses. WRAP training itself was "evolving" and delivering WRAP for carers was a work in progress.

When I first delivered WRAP for carers a number of years ago, I was still working it out myself, well, how does this actually work and I think that's probably where I'm at although I now do a fair bit of work with carers.

However, the evidence in this study was overwhelmingly that carers saw the benefits of WRAP training irrespective of any issues they might have with some of the training materials. One carer was worried that the study might overemphasise the negatives and thus give a totally false impression about the value of the training.

I'm worried that [your study] could misrepresent it and say there were problems with it. That's not true at all, it was extremely good. (George)

The Group Dynamic

As the training had taken place over two years previously, carers in this study were a bit fuzzy on the detail. However, there were two things they remembered well. One was the WRAP facilitator's recovery story, covered elsewhere in this report. The other was how important it was to meet with other carers.

There is general agreement that WRAP is best delivered to groups rather than to individuals. As one WRAP facilitator explained “there is something very powerful about that group experience”.¹⁷ This was largely confirmed in the interviews and in group discussions with carers¹⁸. It might have been the first time that carers had ever met up with others with similar experiences to themselves and who shared an understanding of what it was to *be* a carer.

..it was wonderful to speak with other people who knew what you were going through. [Sophia]

It was also one reason why carers might quite happily overlook some of the weaknesses in the programme.

Discussing and sharing things...that’s where you get the profound things...and to have other people who are going through the same thing to talk to. (George)

On the other hand this was not just a support group. Within the group carers were encouraged to develop their own individual WRAP with the *structured* support of other group members.

.. one of those things I particularly remember was the bit where people were actually talking about their own support networks and realising where there were shortcomings or where it either wasn’t there or wasn’t quite the right quality or fit for what they actually needed. And that was a profound bit which came out because you were looking together as carers at particular issues rather than just free discussion. You were all looking together at the *same* issue that you face and that’s something you get from a structured programme like a WRAP that you won’t get from just a group where everybody just goes round and talks about their issues. (Group Discussion)

¹⁷ It is possible to deliver WRAP to individuals and in some circumstances that might be unavoidable. Not everyone responds well to being in a group and circumstances at any given time might make individual WRAP delivery more appropriate. In some cases it might be necessary to start working with an individual on their WRAP as a prerequisite for introducing them to a group at a later time when they are ready..

¹⁸ However, it is important to remember that these were all carers who had found the WRAP training and on-going group helpful and so they are a far from representative sample. Nevertheless some of their insights might help to make clear *why* WRAP works well with groups.

The Methods

Two carers showed me their training folders which helped them to remember what they liked. Some remembered it as being a little confusing but the following descriptions from carers reinforces the message that the training was also an enjoyable and/or helpful experience.

The method was very well delivered by a trained WRAP facilitator. ..we had a little game at the beginning. We were throwing a ball to each other, calling the name so we could remember everybody's name so it was like socialising at the beginning and then we would briefly tell our experience in the last week... so everybody could share with everybody else in the group and then she would actually go to the board and start talking on certain topics. Every week was a different one and she would explain it very clearly and then she would probably talk about her own experience because she delivered it through her own perspective because she's obviously been through the whole experience herself. We had all the papers, the print outs and then we would share again, ask questions and we had something to bring home and then start focussing on for the rest of the week. (Sharon)

We cut up magazines and made a sort of collage just as we thought about all the things we take pleasure in and actually thinking through what it is that I take pleasure in is probably quite important because it could even be something daft like, downloading a podcast or a radio programme, things that seem almost quite mundane or going out to the pub with a couple of particular friends for a couple of hours and some people might actually consider them as ways of idling or wasting time but in actual fact if you sit down and think, wait a minute, that's actually me, the little things I take pleasure in ...and almost being quite disciplined in making sure you do all those things. (George)

These bits were quite good. We all found this extremely difficult to fill in, what gives you hope...What takes that hope away? .What can you do to nurture hope?..That was painful but that was good. (Martin)

The role of facilitator was important. Her role was to help carers to maintain a focus on their own well-being.

It was very helpful because really for me I was probably in as bad a state as [the person I was caring for]. I do remember I wanted to talk about him the entire time but I wasn't allowed to do that and that was a good thing really because I think I had forgotten that it was me who needed assistance. (Group Discussion)

One of the carers had since gone on to become a trainer herself. She spoke about how visual activities could help to maintain that focus.

it's almost like when people are doing activities, they don't know why, they enjoy doing the activities and then afterwards they realise that actually the activity was really about something so I mean personally I feel that, the visual and whatever sort of creative activities whether it be you know rolling big dice, doing collages, doing dot to dots, the thing is there is a point to it although it's enjoyable I think it's because if you do things with colours and graphics and activities it takes people away out of themselves. Then they're not sitting there, especially for carers, thinking about the person they care for, for once *they're* in the moment and they are there with themselves in that moment with everybody else so it's much more difficult to be thinking if you're doing something with your hands, I mean that's the way I see it.

Not everyone liked writing things down¹⁹. Some, not all, seemed to feel intimidated, unsure whether what they were writing was correct. One of the groups decided not to write anything down. That was their decision as a group and the facilitator respected it.

Carers described how hard some aspects of the training were because they involved confronting who you were in order to see how you could make changes in your life. Issues were beginning to emerge which otherwise might have remained hidden .

This was extremely difficult, we all found it difficult. Who are you? Describe yourself. I'm a well organised person who feels it's much easier to look after other people than to look after myself, It's really hard putting myself first. What are my roles? How do these roles impact on my identity? They all reduce it. Although it was painful, it was actually helpful (Martin)

There were a couple of moments which were actually quite profound. There was one bit where actually at least three people were actually quite emotional so you got the sense we were really getting at things that were really quite important, where people were having a real sort of moment of, you know, epiphany, understanding or something (George)

This was the start of a process which was initially difficult but ultimately rewarding.

¹⁹ Some groups members clearly saw the benefit of writing

The Materials

Looking through the original folders, it was clear why some, though not all, carers might find some pages irrelevant to them. There were references to ill health and in the later stages of the programme, references to mental incapacity. For example, under 'Triggers' was written the following:

External events or circumstances may make you feel like you are getting ill.

In Appendix 13, under the title *When things are breaking down or getting worse*, was written:

You may begin to feel even worse – very uncomfortable, like the situation is serious – and even dangerous – but you are still able to take some action *on your own behalf*

On the other hand, the relevance to carers of other elements of the training were obvious. These tended to be the ones that coincided with the key principles of recovery.

Martin showed the interviewer his WRAP folder. He had used a clip to draw together all those aspects of the training that he felt were irrelevant for carers. These included all references to mental health recovery and medication. Triggers, warning signs, supports and crisis planning were all seen by him as parts of WRAP which service users might find helpful but which are irrelevant for carers. However, that did not mean that Martin found the training unhelpful. On the contrary, the following aspects of the training made perfect sense to him as a carer.

- The Personal Bill of Rights,
- Hope
- Personal Responsibility
- The Wellness Tool Box
- The Daily Maintenance list and Plan
- Change
- Identity
- An anonymous poem entitled 'Listen' which was about the importance of not trying to fix things for somebody else or tell them how to act or feel

In the following sections, elements of the training are looked at in more detail, starting with their intended significance to service users and then, using evidence from this study, examining what possible meaning they could have for carers.

Training Elements

Wellness Toolbox The wellness tool box was probably the aspect of the training which was most easily transferable to carers. Right at the start of the programme, participants are encouraged to think about the things that make them feel good. These are conceptualised as wellness tools in a box which can be opened as and when when required e.g. when someone isn't coping very well or is feeling a bit low.

The metaphor of the tool box worked well with carers because as well as being easy to understand it also helped to focus carers' attention on *their* own needs or those things that made them feel good. Coping tools seemed to be exactly what they needed most in order to be able to carry on caring and not fall to pieces, especially if the whole family relied on them. Here are some of the things carers in this study said about the wellness tool box

The most valuable thing I think I got is the idea of the tool-box. I cherish that and keep adding things to it and making sure that I'm good to myself (Sophia)

The wellness toolbox was the thing that was actually quite useful and we each did our own one, they were all different (Martin)

I think it really has sharpened up my tools and given me a broader range of tools, um to help keep well, help me cope, help me, help the other members of the family cope (Sophia)

Although carers might, through sharing with others, discover tools that they had never thought about before, in most cases, they already had the tools. People used phrases like "it's not rocket science" or "it was common sense".

I learned [to focus] on tools that I probably was already using in my life... nothing was really completely *new* for me because I was already trying to help myself in every possible way but what WRAP did was made me focus more on the tools that they offered like I care, I'm important, you know. You start caring for yourself first. And then you understand that's the only way because then you can care for other people. But if you're not caring for yourself, you're just like panicking (Mary)

The true value of the toolbox analogy was that it encouraged carers to

- a) recognise that they already have the resources to cope – after all they have been coping in extremely challenging circumstances.
- b) recognise the importance of using these wellbeing tools for their own sake but also for the person they were caring for

- c) not feel guilty about pursuing the things that give them pleasure and make them feel well.

The tool box wasn't simply about doing things you enjoyed. It was about having a life worth living. Sophia spoke about the importance of the tool box to her. Inside it were what carers needed to keep mind and body going. It was sustenance.

I don't think I would have coped anywhere near as well without it. It's like having vitamins, you know, you need them, it just keeps you trundling along [laughing] (Sophia)

The Daily Maintenance Plan This involved three sections.

1. What am I like when I feel well?
2. A daily list of things which an individual needs to do to keep well. It can be the simplest of things such as getting dressed in the morning or going outside even if it's just to the corner shop or it can be something which helps maintains your physical health such as drinking enough water or having three nutritional meals per day
3. Optional extras which although not necessary for well being can help to reduce stress or enhance recovery e.g. meeting with friends or signing up for a class

As with the toolbox, it did not *necessarily* mean doing anything different although it might be. It was about making sure that you thought about what you needed to do to keep well or, as made sense to a lot of carers, in order to cope.

For me personally it would be the daily maintenance and the options: to give myself credit at the end of the day for one thing done because sometimes I can't do a lot. But now I do a list and it's quite an extensive list but it's ticking off something and the fact that even if I'm really having a bad day but I will clean the cat litter or something really small, it would be something that I would normally do but this time I take notice of it and I say well at least I did that today. (Christina)

I remember writing lists of things that we would like to do every day or *should* do every day and then every week and every month. One thing I remember particularly that Trained WRAP facilitator said which I thought was so sensible, it was a nice way of explaining it, there's sometimes things that jolly well have to be done and you don't let them get on top of you like paying bills, well she was suggesting a set time that you do your bills every two weeks or whatever but I thought that was, there was something about that, that got to *me* as, you know, you're not daft for trying to keep

on top of things because once they do, you know, like if your house is a mess and it upsets you, get it cleaned, you'll feel better. (Group Discussion)

..having things that you take pleasure in, that you almost timetable in things to do on a reasonably regular basis in terms of looking after yourself, so what some people might call me-time, you know, making sure you eat properly and regularly that you get enough sleep and you get some regular exercise and that sort of thing wasn't that revelatory to me but it was useful to be reminded of it and useful to think of what routines we actually have whereby we get enough to eat and sleep and enough exercise and what are the sorts of things we take pleasure in. How might we sort of schedule a life (George)

Carers who had been used to thinking more about how they managed other people's lives might find it a challenge to think about their own maintenance. In the quotation below Martin speaks about his daily maintenance plan.

Then the daily plan was quite a good thing, get up... that was quite useful, I found that useful and this was, again, this was very difficult, how easy would it be to change? I will need to change the habits of a lifetime because I've always been a person who looks after other people, sadly. What would I need to do? You know, usual story, lose weight, drink less, allow other people to take responsibility for themselves, stop jumping to fix other people's problems,

Flexibility and individuality were key to this section working because everyone's daily maintenance plan would be different. There is no right or wrong way to keep well. What for some might be part of the daily maintenance plan could for others be an optional extra. For example, a carer might feel that in order to maintain mental wellbeing they had to make sure they get dressed every day because to lie about in pyjamas all day was a sign for them that they weren't coping. For another carer who always got up, got dressed and did everything to order every day, a break with routine, like deciding to lie around the house in their dressing gown once in a while could be an optional extra. Also what for one person might be part of a daily maintenance plan would for someone else be one of the tools in their wellness tool box. The tool-box and the daily maintenance plan seem to be more important for what they represent than for the detail. They are creative ways of addressing quality of life issues.

Identification of triggers and associated action plan Triggers are those external events which happen in life from time-to-time and which an individual can come to realise provoke a reaction in them which if not responded to appropriately can make them ill. The trick is to recognise what these are and then plan for them so that they don't catch you out.

This was the stage of the training at which carers might start to question relevance. Very little was said in interviews about triggers. If carers themselves had experienced mental distress or thought that the strain of being a carer might be too much to bear in the future, then this part of the training was self evident but without that context, it needed further thought. However, although triggers were not mentioned explicitly, there were descriptions in the interviews of relationship events which caused carers stress, sleepless nights, dented their confidence or sense of self or caused them to react in unhelpful ways.

Identification of early warning signs and associated action plan Early warning signs are those internal reactions to certain situations or triggers e.g. an individual might start to make unhealthy decisions in relation to alcohol or might start to behave recklessly in terms of spending money. By learning to recognise these signs, an individual can have a plan in place which will help them to get back on track. One of the WRAP facilitators explained their meaning in a way that would make sense for either service users or carers.

Early warning signs [are] signs of internal, subtle signs of change that indicate things aren't quite right...you maybe find things more challenging, it's more of an effort to get out of bed, you're finding things, chores, things you used to enjoy. Maybe you're not sleeping.
(WRAP facilitator)

Up until they were introduced to WRAP, carers were probably used to looking for 'early warning signs' that the people they were caring for were getting unwell but it was equally applicable to them, especially where wellbeing included being able to cope. Examples could be provided in the training that shifted the focus away from service users onto carers themselves.

By giving different examples and different ways of describing what you mean, you usually connect with the group and then they bombard you with, 'oh, I see what you mean, see what you mean, see what you mean (WRAP facilitator)

Early warning signs were mentioned as important in one interview with a carer who was also a service user. However, although not mentioned explicitly, carers had begun to explore through discussion with others, more constructive responses to difficult relationship issues and confrontations.

Identification of signs that things are breaking down and associated action plan The idea behind this stage of the programme is that things may deteriorate to the point where you are close to crisis point but it might still be possible for you to take action to avoid that crisis e.g. phone someone you trust, make an appointment to see a doctor or take a break from work.

In the training and the on-going group, carers were encouraged to look for their own early warning signs that things were not going well for them. It was a support (a crutch) but it was more active than that. If all your resources are spent trying to help someone else, you could easily neglect your own well-being and perhaps not even notice the signs that things were also breaking down for you. Things could get to crisis point before you realised that anything was wrong.

What [the WRAP] has done is given me the sort of crutches or the plan what to do if you feel something's not right, to recognise, I think that's important, to recognise when things aren't right because sometimes you can be in a *terrible* state and not even realise it because you're in such [laughing] a bad state (Marsha)

..and I've got to have all these plans in place so that, if I start feeling depressed I know what to do next, you know, bringing the focus on me rather than I've got to care for somebody else (Mary)

Crisis planning Once a person's mental state has deteriorated beyond a certain point, it might not be possible for them to act in their own best interests. Planning in advance for crisis means making sure you have supports in place and that others know how to act on your behalf. This can really only be done when a person is well enough to make decisions which will influence future care. By agreeing with others what should and should not happen in times of crises, you retain a measure of control²⁰.

²⁰This is the point of an 'advance statement' as cited in the Mental Health (Care and Treatment) (Scotland) Act 2003 Information on advance statements can be found On the Scottish Government website at <http://www.scotland.gov.uk/Publications/2004/10/20017/44081#1>

Suggestions are made on what should be included in your crisis plan e.g. at what point you need help i.e. what symptoms might indicate that you are at crisis point and what decisions should be made on your behalf e.g. contacting your GP or mental health services; preferred treatment and care and the sorts of things that are likely to be helpful and things that are likely to be unhelpful. Clearly you need to have the supports in place so part of the plan might include identifying appropriate people whom you can trust to act in your best interests.

Crisis planning was part of the WRAP brand but it was “awkward” for carers.

I think Crisis Planning is covered because Crisis Plan is part of WRAP and must be covered, you know, it *is* part of WRAP but I think crisis is just so different for every person that I think the only way to handle the crisis part is just to basically go through the sections, and say ‘this is a crisis plan’ (WRAP facilitator)

It was crucial to clarify what ‘crisis’ means, particularly in relation to carers. More specifically, it was important to clarify whose crisis it was that carers were planning for? There was not universal agreement about this. For example, the WRAP facilitator who had also been a carer saw no problem in acknowledging that service users’ crises are also crises for their carers.

In a way if the person that you are caring for is going through a crisis, you are going through a crisis as well, at the same time or after, you know, because you’re just on reaction so I mean I think [you develop] your WRAP plan up to there but your crisis is particularly about the list of supporters that you have to support you even if it is [the person you care for who] is in crisis..because you can’t really separate the two.

The other WRAP facilitator in this study made a strong case for a much clearer distinction between the crisis that the person you were caring for was going through and the crisis that carers themselves might experience. This was important because otherwise the focus would shift back onto service users. She wanted to make the distinction between being in crisis and feeling the impact of the crisis.

they [carers] would be agitated but *they* wouldn’t be in crisis at this point...the crisis would maybe come afterwards..and that’s actually important because we need to keep going along the lines of separating being a carer and the person you care for and unless there’s a facilitator making it *clear* about that then we’re encouraging people’s identities to be muddled again.

Although crisis in the recovery model is usually associated with a loss of control or agency, a broader definition which might include something less than complete incapacity or the need to be hospitalised, might make more sense for carers

I think that for a lot of people [pause] not everyone, crisis is about when you're not making good decisions that are impacting on your capacity to keep on working towards your goals, be it getting to work or whatever it is. I don't mean airy fairy goals, I'm just meaning short-term goals. That for me would be a crisis. (WRAP Facilitator)

It might be possible and even beneficial to separate the crisis that a service user goes through from the crisis a carer goes through but they were still not unrelated. The crisis a service user goes through can be a trigger for carers, plunging them into their own crisis sooner or later. The service user's crisis becomes "the external thing" which can lead to a carer becoming unwell themselves or less able to cope with even the smallest of issues or which might lead to them becoming "paralysed" in the way that earlier Sharon spoke about in her interview.

Post Crisis Planning Planning for the immediate aftermath or when you start to feel better can help in the recovery process and avert a relapse like thinking about how you might feel after the crisis has past; planning what should happen after you are discharged from hospital; how you will cope with feelings of remorse or the consequences of your actions during crisis and thinking about the steps you might take on the road to recovery e.g. easing yourself back into work slowly, perhaps working one day a week at first. In these first training sessions, the fact that the materials are clearly speaking about service users means it was more difficult to see how it applied to carers. In some ways it might be easier just to leave crisis/post crisis planning out of the picture altogether and yet there were very good reasons to keep it in. Linda explained.

It's the aftermath of the crises and its effect on you. That's where WRAP could be adapted for carers more. Carers are brilliant at crises, it's just they're not so good at taking care of themselves and nurturing themselves afterwards.

Carers were likely to feature in a service user's crisis and 'post crisis planning' and this was one justification for including discussion of it in the training.

If everybody had worked on a WRAP, things like advanced statements would probably come up because it's part of the planning process but also there were a lot of issues around people becoming named persons by default rather than by being chosen by the person to be the named person and things like that would be

overcome as well, that hurdle and all those feelings of guilt that sometimes carers have that they've had to in their named person role, say, yeah I agree that this person, you know, needs hospital for treatment and it might be against their will and I think part of all that kind of conversation does or could come in to WRAP. (Andrea, Development Worker)

This raised the possibility of introducing WRAP or the underlying principles of WRAP into the process of engagement between carers and mental health services.

If there was an open dialogue about people's health and looking at it positively, talked about with professionals and with carers alike, maybe those things could be avoided (Andrea, Development Worker)

So there was an argument for making WRAP training more widely available so that everyone, service users, carers and health professionals were all using the same language. A discussion of what was or was not a crisis could be useful to carers and it seemed a waste if it was relegated to the clipped bits, marked 'irrelevant' at the back of the folder.

Discussion

Whatever reservations carers had about some of the material included in their WRAP training packs, there was no doubt that they found the training useful to them as carers. They gained inspiration from the WRAP facilitator's story of recovery but that was not the end of the story. If it had been it would have remained all about service users and not about carers. The training was also valued for the insights carers gained from each other and from activities in which they were encouraged to focus on their own wellbeing and not feel guilty about it. The wellness tool box and daily maintenance elements of the training were useful to carers for that reason and carers could make sense of their inclusion in their packs.

Triggers and early warning signs made sense to carers with experience of mental distress or ill health but tended not to feature in carers' accounts of the value of the training. However, carers' narratives suggested that through their WRAP experience, they were learning to recognise those things – notably relationship events - that triggered unhelpful responses or required careful handling to avoid further deterioration in their interactions or in the way they were feeling. As a result of doing the WRAP training, some of the carers were now better able to recognise when things were not right or breaking down for them. They had not only learned the value of support, they were actively seeking it out.

The need to divert the focus away from service users means being very clear about what crisis and post crisis planning can mean for carers. There is a danger that (1) carers will take these parts of the training as an invitation to slip back into focusing on the person they care for or (2) they will switch off altogether, thinking, this has nothing to do with me. On the other hand, the crisis planning part of the WRAP programme is essential to it and to remove it is to deliver something less than a WRAP. Carers are usually an important part of service users' crisis and post crisis planning and it might make sense to flag this up by way of introduction to these elements of WRAP. At the very least there should probably be some discussion about how carers experience crisis and whether or not it is helpful to them to see the crisis that service users go through as *their* crisis. Being clear about whose crisis it is should probably include a reiteration of the principle of personal responsibility because arguably the most important issue for carers is that they do not feel personally responsible for somebody else's crisis or personally responsible for fixing somebody's else's crisis. Making an explicit distinction between the crisis carers are going through and the crisis service users go through could help to avoid confusion at this stage of the WRAP training.

9 KEEPING IT GOING

This chapter looks at perspectives on the continuation of the WRAP Group after the training had come to an end.

Developing the Group

The on-going group had always been part of the plan.

I always had the idea that they would be made aware, quite early on that the training would be delivered but it would continue with a WRAP Group ... we would use the same ways of asking them what they had done to take care of themselves (Linda)

Carers in this study appreciated the importance of the WRAP Group.

I know that my group, you know, the people that go there wouldn't miss it, you know it's like, this is in my diary I won't miss this for *anything* (Christine)

The idea of keeping the group together after the training came to an end was one of the things that made this WRAP training different from other WRAP training.

When I've talked to carers or service users who've gone on the WRAP trainings where you have your two days., it's too much too quickly. They can't see how it fits with their life. Well, actually they've gone away and forgotten about it by the next week. I think you do need some sort of facilitation for people to be able to put their WRAP into practice. (Ruth, Edinburgh Carers' Council, Co-ordinator)

This was confirmed by carers themselves who recognised the difference between WRAP and other training they had done in the past.

The one thing I found was essential with doing the WRAP with the carers group was that we got together afterwards and then just carried on instead of a number of half days and then off you go (Christine)

I'm the kind of person, if there's something up and it looks interesting then I'll go. But you do get a wee bit fed up going to things and you think, what was that? But these things seep in and I think that's the thing about long-term things.

It takes time to seep in....it was the knowledge it was carrying on, that was the thing.. If it hadn't it would have eventually just been another one. I know it would have been. (Marsha)

And part of the ethos of the support group is that each person reports briefly on what's happened to them since the last time and then Linda usually says, what have you done to take care of yourself and most of us come up with something or other, not always, but to keep, keep being reminded that you must look after yourself is very important (George)

For these carers the on-going group was the special ingredient for success. There were four reasons why it was so important. Firstly, there was the continued support from other carers (peers). Secondly, it provided a safe space to talk about what it was like to be a carer. Thirdly, carers needed to be reminded to look after themselves. Finally, one off training sessions were much less likely to have a lasting impact.

I think one of the really big things is going to the WRAP Group meetings. I do wonder how useful the WRAP would have been without it. I mean we've not gone back over the WRAP training particularly, we've mentioned bits of it from time-to-time. The one thing that does come up is, and what have you done for yourself this month? And you know that just reminds you, yeah, be good to yourself. That's really chrysalised it all and set it in concrete for me (Sophia)

It's a progressive thing and if it had just stopped, probably my recovery or wellness would have stopped then whereas having the support group has enabled us to have a place to talk about the emotional side of being a carer. (Sharon)

..an on-going group is desperately important because if you don't have an on-going group, it's actually not much better than seeing a really good documentary about the subject..forgetting it or half remembering it (George)

In the following extract from a group discussion, carers speak about one of the reasons why they think this group is still together. It illustrates the process whereby carers encourage each other and collectively make sense of what is going on.

1st Voice: Not so much me but most people have had terrible experiences with the so-called mental health services.

[murmur of approval]

1st Voice: It's the only place we've ever been where anybody takes you seriously or gives you a voice

2nd Voice: That's true.

[voices of approval]

3rd Voice: Or gives you a voice because sometimes you just do not get..

1st Voice: Yes. Carers seem to be the *last* people anybody wants to listen to.

[voices of agreement]

3rd Voice: So we talk to ourselves [laughing]. We talk to ourselves.

The humour is also important. At both the group discussions there was a great deal of humour. This researcher sees it as an expression of resilience and the group was important because it was helping to maintain and build resilience.

“This is Our Time”

The monthly get-togethers were an opportunity for carers to focus on themselves which might be difficult to do the rest of the time.

It's really, really important because it's our time, you know, this is our time to talk about, to feel good about ourselves and what we've, what we've accomplished, what we've been doing for ourselves and to hell with somebody else, you know, it's really important ..you need other people to bang off (Christine)

It was very helpful to have a forum, even after the actual WRAP thing, it was the support group meeting regularly which was actually helpful (Martin)

Mental health service users are not ill all of the time. That means that being a 'carer' isn't the same as caring for someone who is *always* ill. Group participants share the knowledge of the *less* obvious ways in which they need support *and* time out.

I'm caring for someone who is in many ways able and some of the other people are caring for people who can look after themselves so that necessity to look after yourself to quite that extent is not so immediately relevant but to be able to talk about the ways in which it *is* a strain and actually how you cope with specific episodes or periods is quite helpful (George)

Carers often don't recognise their own resilience. Carers received encouragement from others in the group. They were “great”. They were “strong”. They were “coping”. And perhaps most important of all, they were making positive changes in their lives.

it's kind of like a cell, it's almost like a peer support... we'll say, well why do you feel guilty about that... so we're kind of confronting each other along the terms of WRAP, the whole time..and pointing out the fact that well, you may not see it in yourself, you need someone else to point it out that you wouldn't have done *that* six months

ago. And then you turn round to somebody else and say, you wouldn't have done *that* six months ago, would you? So it's a kind of reaffirmation from your equals, your peers, that you've gone through this process and people are blossoming (Christine)

This 'peer' support was special in at least two ways

- a) It came from people that had experienced similar although not identical issues and who all identified themselves as carers with all that entails.
- b) It allowed them to be themselves and to talk freely about their feelings about their situation and their relationships without being judged.

Inspiration and reinforcement of self and self-confidence seemed to come from group recognition that far from failing, carers actually have strengths.

It's given me a forum here. I can interact with people who are, they're not the same but we all have components of similar issues and I think most people in the group are actually, are amazing in fact, amazingly strong (Martin)

A Safe Space

..you're hearing other people's inner thoughts and feelings that they might not be able to talk about anywhere else so it's really nice when people can *share* that within the group and you know that it's confidential, you know it's not going anywhere, that people actually are there with you, you're not alone. And then you can go away feeling, I hope, a little bit lighter. (Linda)

The on-going group was a place where trust had developed to the point where carers could speak freely. The carers in this study were carrying around complex feelings, including anger, resentment and guilt. The group provided a safe space where carers could talk about these feelings and say things that were difficult to express in other contexts.

we've built up a relationship between ourselves of trust and understanding and it's very, very useful, that is. (Sophia)

I think the natural reaction is frustration and anger sometimes and sometimes what WRAP is doing, it's actually holding those feelings within the group, other people sharing, well actually, I've felt like that as well and that peer support within the WRAP Group is, you know, so powerful (WRAP facilitator)

I think that fact that being in the group or attending the WRAP training made me feel that it is quite *reasonable* to have the feelings I *do* have, angry feelings and whatnot, that it's really not my fault. (Martin)

In the following extract the group discuss the importance of a common understanding and where what might be odd or unacceptable to others is accepted and understood in the safety of the group. They could also trust each other not to make the sort of unhelpful suggestions which they were used to hearing in the 'outside' world.

Voice 1 Well, you said earlier on, you can't talk about this to most people. You can for a wee while but after ten minutes they're all fed up so this is a venue where you can actually say how you're *really* feeling and there's no pressure because out in the rest of the world everybody's got ideas of who you are and what you're supposed and you're not supposed to feel like and all that stuff but in here there's none of that.

Voice 2 Some of the things we encounter are so bizarre

Voice 3 I think that's right.

Voice 2 In most other people's lives.

Voice 3 Absolutely. They cannae relate with this.

Voice 2 Yeah, you know, if you shared half the things that go on.

Voice 1 They didn't do that!

Voice 2 Yeah.

Voice 1 Why didn't you tell him just to do this, this, and this?

Voice 2 Well, because [laughs]..

Voice 3 Right and everybody [in the group], they sort of understand your language

It has already been noted that the group can help to reinforce carers' confidence that they are doing a great job but at the same time it is hard playing the hero all the time. It was just as important to have a safe space where you could admit that you were struggling and know that you wouldn't be judged. Others often felt the same way.

I think the idea that you have to look after yourself otherwise you're no good to anybody else is quite important and easy to forget. The sense that without actually not caring for your loved one or not loving them any less, the chance where you can in a non-judgemental way talk about the way in which it can be rather difficult and do that without feeling guilty or bad. (George)

Mary describes her experience of the group as a sort of shared humanity which reduces the feeling of isolation and makes coping a lot easier.

I mean from a human point of view, it's just so nice to share. You get much more, I don't know, much more understanding, much more compassion, you feel that you can cope much better. You know, you can go home and feel like, okay, there's so many people like me and it helps tremendously.

Sharon describes how being able to talk to others and offload reinvigorated her so that she was able to get on with other things in her life. The process started in the training when she was encouraged to start to think about and, most importantly, express what she was feeling.

And I remember that started because I was talking about myself. I started being able to have the energy, you know, it's like you know, if you talk about what's in your brain, your mind, it's put on the table, it gives you space in your mind to start doing other things.

Education

One of the things that we do here at Edinburgh Carers' Council is offer people opportunities to increase their own mental health and wellbeing and to look at their own situation perhaps from a different angle...and to me one of the advantages of coming and joining a WRAP Group would be first of all that they would be meeting other carers and looking at their own situation in relation to other people's situations because I think people do like to do that very often. (Ruth, Edinburgh Carers' Council, Co-ordinator)

The link with the WRAP training is maintained by focussing on carers' wellbeing and although as a rule they do not go back over the key principles and training elements, these underpin the format and facilitation of the meetings. Everybody got their turn.

Everybody having their allotted time stops you being selfish because a lot of these things, there's always one person who keeps asking questions and stops the flow. That's not allowed to happen. Each person has their private moment and that is major and I hadn't thought of that until just now (Marsha)

Carers themselves saw the on-going groups as a learning experience. They learned self awareness: new ways of thinking about themselves.

Voice 1: It's awareness isn't it?

Voice 2 : You can't see yourself but when you looked and did the bit of work it made you see who you were, you know whether [laughing] we liked it or not ..

[laughter from the rest of the group]

...but it was, that's quite good. It's about who we are

Voice 3: Yes.

Voice 2 It was learning. It was good. (Group discussion)

Much of the learning came from each other. By listening to each other's stories and then having a discussion, carers learned more than they would have done in one-to-one counselling sessions

... that made *you* realise, it's other people opening up makes *you* realise and they vocalise things that, oh, that's right or whatever (Marsha)

there are a couple of quite profound things that you pick up, that came out of a group discussion that would never have come up from a really good one-to-one session...(George)

Linda and others in the group bring ideas to the meetings. One week Linda brought along a self-awareness tool using animal imagery devised by Professor Janet Treasure to get the carers to think about what sort of carer they were. This was a helpful way for them to think about how they related to the person they cared for. The group talked about how much they enjoyed this in the group discussion

1st Voice: ...Occasionally we have structured evenings. I think of the dolphins

2nd Voice: What kind of carer are you?

1st Voice: I loved that.

2nd Voice: A rhinoceros?

3rd Voice: That was lovely yeah

Moderator: Do you want to tell me a little bit about that because it sounds really interesting?

2nd Voice: Well it's what sort of person you are.

1st Voice: what sort of carer you are

2nd Voice: I was a kangaroo.

4th Voice: I was a jelly fish.

2nd voice: Endless love and endless therapy. I have her in my pouch [speaks quietly] to keep her safe

Moderator: So there was no right or wrong animal?

[Voices saying 'no']

2nd Voice: No but the idea was something like a dolphin where you..

4th Voice: where you nudge.

2nd Voice: You nudge and you show the way rather than pushing the person or protecting them or just going, yuh [laughs]

3rd Voice Being a bully.

[lots of laughter]

Although the focus was on caring for themselves it might help carers to look after the person they were caring for.

You get two for the price of one because we can then help the people we care for too. You learn some of the skills. I know certainly [the person I care for] has learned different skills from me that I learned (Group Discussion)

There might be a danger in this that carers might try to become a Mr and Mrs Fix it all over again but it was clear that WRAP wasn't something you could force on someone.

... it certainly can't be done to somebody (Carer/WRAP facilitator)

Although carers were not explicitly referring back to the training all the time, the key principles of recovery were implicit in much of what they said. They were now able to appreciate not only their own strengths and courage but also the strengths and courage of the person they cared for. This is illustrated in the following extract where one carer is encouraged in their appreciation of just how much the person she cared for was achieving on his own.

Voice 1 And then you hear what they've done and I think crikey. And I look at the [person I care for] and I think, you know, what have you done just to be where you are. It's *enormous* what they've had to do.

Voice 2 He's been doing amazing.

Moderator So is it helps you to understand how well the person you are caring for is doing? Is this what you are saying?

Voice 1 We., that's maybe true.

Moderator Or is it something else?

Voice 1: You appreciate the small things even more or understand how difficult it is but he does terrific.

Voice 2: And it gives hope when you hear of someone else's experience and where they're at, you think, it's such an inspiration

Voice 1 As long as it's not sweetie sweet.

Voice 2 No.

Voice 1 Because I hate those booklets that give out things about how so and so's done this. Well, I mean it may well be true but how ill was the person in the first place? If you've got a person who's seriously damaged and you know getting out of hospital's a major event. He's looking after himself and paying his own bills but with support. If you knew he was going to end up like this, you'd think, oh this is terrible, how awful but I'm saying now, how wonderful!

(Group Discussion)

This is a crucial point. Taking personal responsibility when you are recovering from a serious mental illness is hard. If recovery is promoted as if it *is* easy, it is more likely to undermine than create hope.

The WRAP Journey

Interviewer What do you think you have learned about WRAP?

Marsha I couldn't say except it's a long-term thing that happens to you.

(extract from Interview with Marsha)

Williams (2009) describes the recovery journey as "a long term and not a smooth road". The conceptualisation in much of the literature of recovery as a journey is helpful to carers as well as to service users. It is a positive metaphor. A journey has ups and downs but it can also be exciting and a time of discovery not only about the world around you but also about yourself. The limitation of the journey metaphor is that it might suggest an end point, an arrival. For carers as for service users there was no clear destination, it was the journey itself which mattered.

The process or journey started with the training where you began to recognise the importance of looking after yourself not just for your own sake but because you needed to be well in order to be able to keep on caring. The journey was continuing as the group became more and more comfortable with each other and then it just kept going, developing, opening up. (Sharon)

It's a sort of constant building block and the thing that seems to have underpinned the whole thing is that actually, the carer actually puts himself first because unless the carer puts themselves first and stays healthy and has a quality of life they're actually not any use to anybody else. (George)

The original WRAP Groups had been going for over two and a half years. In that time, carers had witnessed changes in themselves and in others in the group.

and people have come on amazing compared to remembering when you were in the WRAP class with them...they've made huge changes in their lives slowly and gradually but they've felt comfortable with doing them, that they are their own person sitting round the table. So I mean that's how it works, it's all based on WRAP and it's about the things that we're doing or involved in but also how our relationship is changed with the person we care for or something. It's just that constant reminder that there's four or five people round the table who have *really* changed, remarkably well and are actually following WRAP. (Christine)

There were two journeys: a group journey - the development of trust and a dynamic that worked and also an individual journey. There was no schedule. In the spirit of recovery, it had to be self-directed otherwise it wouldn't work. A WRAP facilitator has to be responsive and sensitive to the group itself but more importantly to the individual within the group. If the facilitation of WRAP becomes top-down, then the WRAP itself is undermined.

The one thing about WRAP is that it is flexible, totally flexible because otherwise it's meaningless to people.... it's not a one-fit scenario. Two people can suffer from the same mental illness, it still isn't a one-fit solution because everybody's symptoms are going to be differentIt's organic and it grows, it just grows and it is flexible to adapt to their own needs and the main thing is that it should be adaptable, it should be completely adaptable to each individual need so it cannot be prescriptive (Carer/WRAP facilitator)

The 'organic' and individual nature of the overall WRAP experience was illustrated by George's comparison between his own experience and learning a marshall art.

You see the thing is it never felt to me like I'm going to be trained and I am now going to use these techniques like some sort of Samurai warrior or something. The starting thing was there was a little bit of teaching about, as a carer, here's some of the issues you're facing, here's some of the ways you might try and handle it, and then it sort of rolled into a support group. It wasn't as if I was actually being trained to be a particular person.

Things change. For different reasons the caring relationship might come to an end. However, the impact that caring has had does not necessarily end.

One woman worried that because her circumstances had changed she might no longer fit into the group but because of the effects on her own wellbeing of caring, she still felt she needed what the WRAP Group was providing.

[Caring] had a hell of an impact..[we] are still suffering with the impact and so I still *feel* as though I need support [Group Discussion]

However, the WRAP Group was also a forum for her to discuss alternative support. The group was about moving forward not staying in some static place. This was a process and it wasn't over yet.

I think it's growing, you know, I think it's really developing. I don't think it's stuck. I think it's developing and it's got a lot of life in it yet. (Group Discussion)

Developing the Groups Further

I think we *could* develop it any way we wanted to develop it. (Christine)

In terms of the future, the most important thing to all the carers in this study was that the groups carried on. The successful merger of groups where a group was struggling ensured that carers who wanted to carry on being supported in this way weren't disappointed. However, that didn't mean Edinburgh Carers' Council would be able to provide the support indefinitely.

I've really been building up a wee fear knowing that Linda might leave and people might move on and I think well, what's going to happen then? (Marsha)

In this day and age of cutbacks and also there was pressure on the health services before the current round of cutbacks and I think there's always been pressure on things like mental health. I've actually been surprised that there's actually resources for this sort of thing because I thought there wasn't any and I think it's quite important and I'm always scared that it actually might be underestimated how important it actually is. (George)

If Edinburgh Carers' Council were unable to continue to facilitate, the group might just find other ways to keep going – perhaps over coffee. This seemed to be more of a possibility because the group knew each other well and understood the importance of the format. However, some doubts were expressed about whether the groups could survive or work without a facilitator or structure.

[Linda] is a contact, a liaison, a conduit into the health thing and I think, the person, whether a social worker or a worker in mental health as part of the group is fundamentally important because of the insights and the professional pointing things out, someone who knows, who has knowledge (George)

If the structure was around WRAP then that could be seen as a WRAP peer group but if it's actually a group of peers coming together who happen to have done WRAP but you're talking about the weather, you're talking about coffee and it's not centred round WRAP then I really don't know what it is. If it's a WRAP Group then I would be saying there has to be some sort of structure. (WRAP facilitator)

This was also a question of funding. Funders would want to be clear what it was they were funding. The WRAP brand was recognisable. On the other hand, WRAP is only one way of conceptualising wellbeing and recovery. If, as seems to be the case it is the key principles of recovery that really work for carers then this could be the focus of future training. Andrea, Edinburgh Carers' Council's Development worker explained her vision which didn't stop at service users or carers.

How do you imbed recovery in society? If it was then all of these terms wouldn't be so alien to people and actually just people looking at their own wellbeing and health would be completely different as well. [People would] see it really positively and get where WRAP was coming from.

There were limits to how many groups could be funded. If every group which trained together stayed together, that would surely be unsustainable in the long-term. The idea of a timescale for people using their own WRAPs did not fit with the idea of an 'organic' process which had its own natural course. As it was there was a sort of natural attrition as individuals moved on or moved away or weren't quite ready for the group experience. However, in the future Edinburgh Carers' Council might be faced with difficult decisions regarding on-going WRAP Group support. It might mean limiting the number of training courses that could be offered.

Carers were asked how they would like to see the groups develop. For some it was simply a matter of carrying on as they were because there was still more to learn

I think we'll learn even more about ourselves as individuals in our caring role and about each other and I think we will learn more about how to care about ourselves because it's a shared experience...you know, I think it's growing, you know, it's really still developing (Group Participant)

I'd like to look at the tool box more and get all these tools out [laughing] and really work out how they work for us, well me as an individual and look at some of the dynamic stuff (Group Participant)

Interest was expressed in a refresher course. This interest was probably stimulated by the study itself because carers were being asked to think about what WRAP was and it was hard remembering what had happened in the training. That these carers were pioneers of the use of WRAP with carers was also significant. Much had been learned since those initial training sessions. A refresher course might be more tailored to carers' needs.

One way of spreading the word would be to encourage more interaction between carers who have already been through the WRAP and those who have not with scope to consider the positive impact carers' WRAP stories might have on others.

You see my great dream, I've been thinking about it for the past six or seven months, is peer support for carers. Some carers come in and they're in such a state and they could benefit so much by meeting other carers who've been through WRAP and who have a WRAP Group (Carer/WRAP facilitator)

Other suggestions were a web site forum so that carers could keep in touch whether they were in a group or not and in between times (Christine)

Since this study started Lothian Recovery Network has made changes in the way its funding is used. It will now be working in partnership with Health in Mind and CAPS (Consultation and Advocacy Promotion Service) on the training side of its work. This again will have implications for the WRAP brand. There remains the possibility that courses could be held which teach carers about the key principles of recovery and borrow insights from WRAP without necessarily claiming to be WRAP.

Discussion

All but one of the carers who participated in the study were still attending the groups but from what staff said, WRAP didn't appeal to everyone and not everyone who tried it stuck with it. The point of this research was not to show that the format worked for *all* carers but to gain insights from people for whom it did. A number of insights emerged in interviews and discussions about the value of providing on-going support to keep together the group that trained together. Four main issues have been identified.

- ✓ Carers in this study believe that the on-going group is a crucial part of the success of the WRAP initiative with carers
- ✓ The on-going group provides (peer) support and a safe space to talk openly about what it is like to be a carer. This helps carers to cope.

- ✓ There is a significant educative element, Extracts from group discussions illustrate the process by which carers collectively make sense of their own lives and their relationships. This seems to be paying off in terms of greater wellbeing and improved relationships.
- ✓ The group was helping individuals to recognise and build upon personal resilience
- ✓ The metaphor of the 'journey' is useful to carers as well as to service users. The journey is on-going because there are always more things we can learn about ourselves and how we relate to others.

Any future development depends on funding but it also depends on clarity of purpose. It is important to remember that this was a group of 'pioneer' carers. WRAP was originally developed for service users not carers. A refresher course, could be useful to carers individually. It might also help them to reflect on the extent to which the elements and principles of WRAP actually apply to carers. That could be useful to other carers. One role for Edinburgh Carers' Council could be to facilitate a sharing of ideas beyond the group itself by introducing those who had been through WRAP to those who hadn't yet or setting up a web forum for carers.

Some thought has to go into the sustainability of groups and there is probably still a conversation to be had about whether groups have a natural shelf life or whether they should be time-limited.

The idea of the WRAP Group which continues to meet after WRAP training has finished is a significant development of the WRAP concept. The evidence from this study suggests that it should probably be a standard feature *on offer* at the end of all WRAP training whether that is to carers, service users or other groups.

10 CONCLUSION: DISCUSSION OF FINDINGS

If I had a magic wand, I would love to see WRAP being accessible to all groups of people, for young people, for children and it was more readily available. But not just more readily available but more readily available and understood (WRAP facilitator)

This final chapter is an attempt at drawing together the findings of this study in such a way that it represents the collective story of Edinburgh Carers' Council's delivery of WRAP to carers without ironing out the contours of their individual responses.

The evaluation was partly to provide formal recognition for what had already been said informally and to gain insights into *how* a programme designed to support service users in their recovery had worked with carers. The knowledge gained could then be used by other organisations that support carers. In order to be useful the evaluation had to take account of the limitations of the programme and any issues that still needed to be addressed.

It was a small study, effectively a case study of the use of a recovery programme with carers. As such it cannot be used to make wild generalisations about what helps carers to feel well and about the extent to which the recovery model works with carers. Carers are individuals with individual stories to tell, individual needs and individual aspirations. Within this study there was significant variation in terms of what carers took from WRAP, how they understood recovery, how they chose to live their lives. Unless the differences are captured rather than ironed out, then the researcher does a disservice to carers.

There is no specific meaning that can be attached to the term carer and yet all the carers I spoke to did have some things in common. They had all approached Edinburgh Carers' Council for help at some time or another and felt some negative impact from caring. This was why they signed up to the WRAP training and agreed to participate in this study.

The Benefits

Narratives in this study provide insights into the positive benefits that a wellness recovery programme can provide for carers' mental well-being. These include:

- ✓ no longer feeling isolated and alone
- ✓ increased ability to cope
- ✓ knowledge that carers have rights
- ✓ increased confidence and self-esteem
- ✓ ability to vent emotions in a safe environment
- ✓ more energy

- ✓ less guilt
- ✓ improved relationships.

WRAP gave carers permission to start looking after themselves better, not just for themselves but also for the person they were caring for. There is a minimum level of health and wellbeing required without which caring for others becomes impossible. Thus looking after yourself and taking pleasure in life again are not acts of self-interest, they are essential. The metaphor of the cosy duvet which Marsha associates with the word WRAP constitutes a powerful evocation of something which could only ever be good for carers who have previously been struggling alone.

Carers often feel isolated and unsupported. They are used to focussing on the needs of others. The mutual support offered by being in a group of peers with similar problems and shared experiences appeared to be of key importance.

Recovery - a Contested Concept

This study held a mirror up to a concept which is already contested even within mental health services. In the study various views were given on whether or not carers actually needed recovery. For some it was obvious, particularly if the carer had themselves been a service user. But not all carers feel they have anything to recover from. For some carers, even if they recognise in themselves symptoms of stress from time-to-time, the word recovery is just too strong a word and too easily associated with service users who have different needs. In discussion it seemed that the word 'survival' was more resonant because it suggested that although carers were so far managing, coping and intact, WRAP could help them avoid or prevent collapse or an inability to care at some later date. Carers might be overwhelmed by the tragedy of mental illness and, in these circumstances, too much focus on 'recovery' might lead to the conclusion that WRAP is after all just "a nice word". These are reasonable perspectives on recovery and have to be considered if the use of WRAP is to be marketed to carers more widely.

Others in the study were able to make sense of their own recovery as:

- ✓ recuperation
- ✓ revival
- ✓ renewal

The first fits in with both the more traditional understanding of recovery as *complete or symptom free recovery* and the more recent transformative definition as *being able to live a meaningful and satisfying life with or without symptoms*.

All carers might understand the need to recuperate after a traumatic experience or a crisis; if they are exhausted by constant vigilance because of unpredictable/risk taking behaviour or the actual or perceived threat of suicide; if their relationship is stretched to breaking point. It is akin to bouncing back. Given carers' contribution to social care and the cost to the state when caring relationships break down or when carers themselves become ill and need services, an initiative which helps carers to recuperate is likely to be cost effective and appeal to funders.

The second and third meanings of recovery are closely linked to the idea of identity which features so extensively in the recovery literature and in service users' own accounts of their recovery experiences. The notion that a sense of self which has been compromised by the responsibilities and stresses of being a carer can actually be revived is a powerful one. The evidence from carers in this study suggests that carers have experienced such a revival as a result of the WRAP experience. The third meaning of recovery is more like the recovery of a precious metal which was always there but only just discovered or uncovered. It is the potential in us all to be more than we perhaps are: as exciting as our wildest dreams or as modest as the feeling of contentment which comes from discovering that you are, after all, a sociable person or take pleasure in drawing or singing or gardening. WRAP had helped carers in this study to uncover new selves, not only in terms of the way they thought about themselves but also how they related to others or tackled problematic relationships. It was the realisation of resources they didn't know they had.

Despite disagreement about the meaning and significance of recovery, the recovery concepts were not contentious. They were significant to carers in a number of ways.

- ✓ Carers needed hope and WRAP helped them to separate out their own hopes and dreams from that of the person they were caring for.
- ✓ Hope was closely related to the principle of personal responsibility. Once detached from the cul-de-sac of an idea that personal responsibility means managing alone, carers are free to provide a different sort of support, relieved of the responsibility of making decisions for anyone other than themselves.
- ✓ An understanding of the principle of personal responsibility has the potential to improve service user/carer relationships, ending the apparent tug of wills or frustration when one refuses to do what the other tells them is best.
- ✓ The education principle is an expression of the importance of self-knowledge to human thriving. Humans learn through social interaction. Carers often spoke about what they had learned in training and continued to learn in the on-going WRAP Group from each other and from the insights of facilitators.

- ✓ Carers struggle for recognition of their experience, knowledge and contribution. The support of other carers can make carers feel more confident in their dealings with mental health professionals.
- ✓ The principle of self advocacy seemed to be most significant in the context of personal relationships. This is not about pitting carers' rights against those of service users but about renegotiating relationships through mutual respect
- ✓ The principle of support reinforces the principle of personal responsibility. People are enabled to take personal responsibility with the right sort of support, one that is not judgemental or based on Mr or Mrs Fix it solutions.
- ✓ The on-going WRAP Group provided a safe place where carers were not judged or told what to do. Instead their confidence was reinforced, not least because they noticed and commented on the strengths and resilience they now recognised in each other. This was the right sort of support.

In order to feel the benefits of WRAP, carers do not have to accept that there is a single or a distinct set of meanings attached to recovery. However, exploring the meaning of recovery with carers in this study helped to make sense of the process by which carers' as well as service users' mental wellbeing is improved.

WRAP Process and Training

There was no single WRAP process. In the same way that every recovery journey is unique to the individual, each of the carers who took part in the WRAP programme experienced it in a unique way. This was most obvious in relation to the training. Each carer took something different away from it. One thought that the personal bill of rights was the lynchpin of the whole thing while another said it was the daily maintenance and the optional extras. The metaphor of the tool box came closest to having a universal appeal. Carers weren't necessarily discovering new tools but learning to appreciate and make use of existing knowledge about how they could keep well and cope.

Although carers thought some of the training materials were irrelevant to them, there was general agreement that participation had been a revelatory experience. The training materials could be adapted for carers without losing the key elements and concepts of the original WRAP as developed by Mary Ellen Copeland. Unless carers had experienced mental distress themselves, elements such as 'triggers' and 'early warning signs' seemed more about the mental health wellbeing of those they were caring for than their own. However, there was evidence in the narratives that certain relationship events did trigger responses which were not always helpful and that through WRAP carers were learning different ways of relating and reacting.

Dealing with Crisis

The crisis/post crisis management sections of the training require further thought. The point was well made that if carers do not separate out the experience of crisis they go through from the ones service users go through they are more likely to conflate their own recovery with that of the person they are caring for. However, a crucial aspect of WRAP is that it is not prescriptive. Moreover, an insistence that the hospitalisation or psychotic episode of service users is not simultaneously felt *as* crisis for carers might mean that carers never confront the meaning or significance of that experience. It may be easier to conceptualise the crisis as a single event which is experienced differently. Rather than ditching the crisis planning section altogether when delivering WRAP to carers, time could be spent exploring what crisis means to them; working out what they can do to look after themselves whilst at the same time providing the right sort of support to the person they are caring for.

Encouraging carers to think about their understanding of crisis and how they have managed in the past could help prepare the groundwork for agreements between service user and carer about how they might manage future crises and their aftermaths. This could further strengthen the relationship between carer and service user and reduce the perception that their interests are oppositional. It is consistent with the view that recovery must be self-directed to be successful.

The Inspiring Recovery Story

The WRAP facilitator's recovery narrative had a powerful impact on everyone who heard it. It inspired hope and was a reminder that carers can never wholly separate their own hopes for their own future from the hopes they have for their loved one's futures. One of the conclusions of this study is that the value of WRAP lies in recognising that carers' and service users' recovery are linked. By taking personal responsibility for their own wellbeing and *allowing* others to do the same, carers are contributing to the recovery of their loved ones not abandoning them to their fate. That is not to say that all will be well or that the recovery model is the answer to everything. Much of the problems service users face such as unemployment, a punitive benefits system and mental health services stretched to breaking point reduce the chances of recovery. WRAP and other recovery programmes cannot overcome these obstacles but perhaps they can help people to identify the things they can change as well as the things they can't.

Facilitation

Co-facilitation by a WRAP trained facilitator and a non WRAP trained member of Edinburgh Carers' Council's staff team seemed to work for carers. The latter went on to facilitate the

on-going groups after the training came to an end, providing continuity which may have been instrumental in keeping the groups going. Carers wanted facilitators who were trained and had either personal knowledge of recovery and/or professional knowledge of mental illness. Facilitators were not teachers but enablers and they were part of the group, sharing aspects of themselves which made groups less deferential and more self-directing.

There is potential for carers' stories to inspire other carers. Consideration should be given to whether or not carers could become trained WRAP facilitators and whether facilitation of WRAP for carers training could be strengthened when it incorporates the dual perspectives of service user and carer.

The On-going Group

Carers have continued to develop their individual WRAPs through the on-going meetings with other carers. These meetings are part of a process which starts with the formal WRAP training and are seen by carers in this study as crucial to the success of the WRAP programme.

The groups provide on-going peer support, a safe space for carers to talk about what it is like to be a carer and to offload; most importantly a time each month when carers are reminded about the importance of looking after themselves. The group develops a life of its own. Each group matures as mutual trust and understanding increase. Extracts from group discussions in this study illustrate how the group becomes a place where carers are able to construct a sense of who they are and make sense of their relationships through discussions with each other. Carers learn to appreciate their own personal resilience and to build on it.

Carers valued the support of the organisation and an experienced facilitator. To date Edinburgh carers' Council has managed to provide on-going group facilitation for all carers who want it. There has been a natural process of attrition as some carers no longer need the support or cannot manage along for whatever reason. Group mergers have seemed to work so far but more thought needs to be given to what would happen in the longer-term if resources cannot cope with demand.

The Future of WRAP for carers

There is a tendency to treat carers' needs and service users' needs as if they are dichotomous. This is a false dichotomy. A complete separation of those needs is not possible. Each individual experience of the relationship of care is unique but it is communicable. By talking about how they experience that relationship, carers take the first step towards taking control of their own lives and at the same time start to release

themselves from feelings of personal responsibility for the lives of others. This means thinking about how they might provide the right sort of support to others, one which does not undermine but actually enhances recovery.

WRAP can increase carers' confidence to identify and articulate their needs and the resources they need to cope with the challenges that caring places on them. These challenges should never be underestimated. WRAP is not a panacea.

It may be that copyright issues make it more difficult to deliver a tailor made WRAP to carers. If that is the case, then the author of this report can find no reason why future programmes should not advertise as programmes which are inspired by WRAP, make use of the concepts of recovery and make explicit the crucial connections between the wellbeing of carers and the wellbeing of those they care for.

It is hoped that this report will encourage funders to see the value of WRAP or recovery inspired initiatives to carers. Certainly the savings to the public purse of informal care work and the cost to the health service when carers themselves become unwell would appear to justify investment in an initiative with proven benefits to carers' wellbeing.

APPENDICES²¹

APPENDIX 1 Introductory Letter/Information Provided to Carers

WELLNESS RECOVERY ACTION PLANNING: AN EVALUATION STUDY

Researcher: Sue Kelly
Telephone 0131 554 7391
Mobile 07505393812
Email
suekelly_51@hotmail.co.uk

14 January 2011

Dear Participant,

FOCUS GROUP INVITATION

I would like to invite you to take part in a discussion about your WRAP Group. This event is part of a small study of the use and value of Wellness Recovery Action Planning (WRAP) with carers which Edinburgh Carers' Council has asked me to carry out.

The idea of 'recovery' is well established in the field of mental health but its use in supporting carers is a new idea. There is little known about how WRAP training can improve the lives of carers. You are a member of one of two original groups which took part in WRAP training and which continue to meet regularly. As such you are very well placed to help me to understand how WRAP works and what sort of changes it can make to carers' lives.

In the near future I will be asking members if they would like to tell me about their individual experiences of WRAP and WRAP training but to begin with I am focussing on the group experience. I want to know how important the continuing group experience is to the success of WRAP. In order to understand more about the group and how the group works a discussion group has been arranged to coincide with your next WRAP Group meeting.

I understand that Linda has already spoken to you about the study. I am attaching three more pieces of information. They are:

- A summary of my research plans, including assurances regarding confidentiality
- A short biographical note
- A guide to the focus group discussion planned for your next WRAP meeting

²¹ These appendices contain copies of Information provided to carers participating in this study. Similar information was provided to EDINBURGH CARERS' COUNCIL staff and WRAP facilitators.

If you have any further questions about this research, please do not hesitate to contact me. My contact details are at the top of this letter.

I look forward to meeting you.

Best wishes,

Sue Kelly

WRAP EVALUATION STUDY

The Aims and Objectives of the Study There is increasing recognition of the important role of carers in the recovery of people with mental health and other illnesses and disabilities. It is also recognised that caring can place an enormous burden on individuals and that their health both physical and mental can suffer as a result. Feedback from carers who have been through WRAP training suggests that it can increase well-being. However there is little documented knowledge of how it works with this group of people, how it differs from other supports carers receive, its potential and its limitations. The purpose of this research is to gain a better understanding of the process by which and the extent to which WRAP improves the life of carers and might act as a model for other organisations to use.

In addition to offering WRAP training, Edinburgh Carers' Council provides a space for WRAP Groups who continue to meet on a regular basis after the training comes to an end. This seems to be an important part of the WRAP for carers project and may be important in terms of the long-term value of WRAP.

This study therefore seeks to explore three aspects of WRAP as follows.

- The experience and perceived benefits of WRAP training
- The experiences of the on-going WRAP group process
- The on-going individual experiences of using WRAP

Methods that will be used in the study The researcher will work *with* participants, checking that she is getting things right as she goes along. The recovery model is based on an understanding that a one-size fits all approach does not work in. This is the basis for a person-centred approach in health and social care services and this approach will be adopted in the research itself. The main methods used will be individual interviews and group discussion. However, the researcher will also explore alternative ways in which individuals might contribute knowledge to the study e.g. through visual images or a short statement, story or poem. There will be no expectation that participants use these alternative methods. It will be up to each individual to decide whether they want to take part in the study and the form their participation will take.

Reporting on the Research Eventually, a report will be written about what has been learned about WRAP. Initially this will be produced in draft form and participants will be given the opportunity to comment or make suggestions for changes and additions. Any concerns will be taken on board in the redrafting of the document.

Assurances Confidentiality will be of the utmost importance in this study. Nothing disclosed will be shared in the reporting phase without permission and every effort will be made to ensure that individuals are not identifiable by anything written down. It will also be important for participants to respect each others' privacy and not repeat anything they hear in the discussion either about a group member or about persons who are being cared for.

WRAP EVALUATION STUDY NOTES ON THE RESEARCHER: SUE KELLY

I am a qualified and experienced researcher. I have a broad range of knowledge of social issues, based on 14 years providing welfare rights advice and training and a more recent career teaching within the School of Social and Political Science at Edinburgh University.

I myself am attending WRAP Group training because I am a carer myself. This is providing me with insights about the way WRAP works and I have my own ideas about the way my own WRAP Group is developing and working. However, this does not mean that I will be making any assumptions about your individual experience or how your group works, not least because every individual will have different experiences and groups will have developed differently and have different outcomes. There is no right or wrong way for groups to develop or operate and in the same way that each individual will have a different story to tell about their well-being or recovery, so also each group story will be different.

APPENDIX 2: Focus Group Guide for Participants

WRAP (FOCUS) DISCUSSION GROUP GUIDE

The purpose of this discussion group event is to help me to understand more about your WRAP Group. It will take the form of a discussion about your group and about the WRAP training you received *as a group*.

I will facilitate the discussion by asking questions and making sure that the discussion does not drift too far away from the point. However, the questions will be as broad and open as possible in order to allow you, as a group to take the discussion where you think it should go.

I want to emphasise very strongly that there are no right or wrong answers to the questions I will ask and I will not be looking for single group answers to emerge. However, I expect that because it is a group discussion, you will bounce ideas off each other. I believe that this bouncing of ideas off each other is an important way in which we learn and come to understand things in the world. So the idea of the focus group is to tap into this natural way of learning and understanding.

The discussion will be recorded by a digital recorder. At first that may seem strange and you might feel self-conscious. However, I usually find that people start to relax fairly quickly once the discussion gets underway and sometimes even forget the recorder is there. It might help to know that no-one will be listening to the recording apart from myself and that everything you say will be treated with the utmost respect.

Although I expect to learn a lot about your group experiences through the discussion, I also know that the discussion is simply a snapshot of what people think. You might change your mind about things after further reflection and there will be plenty of opportunity for you to tell me about any further reflections you might have after the event.

I hope that you will all feel that you want to join in the discussion but there will be no pressure to do so. If you feel that you have to leave the room for any reason then please just do so.

I will start with a brief introduction which will include

- a recap of what the study is all about and how information will be used
- a description of how the focus group will be conducted
- assurances that confidentiality and anonymity will be respected at all times
- a request for any questions you might have

I expect the discussion to last approximately half an hour. At the end of the discussion I will take a few minutes to explain what will happen next and invite you to take part in individual interviews or make some other contribution to the study. In total the event should last no longer than fifty minutes.

I have put together a list of the main questions I will be asking you. These questions will provide a sort of structure to the discussion but the structure is not fixed in stone. Depending on how the discussion goes, I may not need to ask them all or I might ask follow up questions so I can better understand what is being said.

Key Questions

- The Scottish Recovery Network describes WRAP as “a powerful tool for promoting wellness and recovery”. Its use with mental health service users is well established but how does it work with carers?
- It is often said that WRAP is delivered best in group settings? Can you explain why that might be?
- Can you tell me about this group?
- What do you remember about the WRAP training?
- Can you tell me about the role of the WRAP training facilitator?
- Why do you think the group is still together?
- What do you think will happen to this group in the future?
- Is there anything else I should know about the way this group works?

If you have any further questions about the focus group, please feel free to contact me. My contact details are as follows:

Telephone no.

Mobile no

suekelly_51@hotmail.co.uk

APPENDIX 3: Interview Guide for Carers

WRAP EVALUATION STUDY

Individual Interview Guide

Purpose of the Guide

You have very kindly agreed to take part in an interview at the following time and place

Time:

Date:

Place:

This guide has been written for you to make sure that you know what to expect at the interview and how the information you provide will be used.

Purpose of the Interview

The purpose of this interview is to learn more about your individual experience of WRAP. This will include an exploration of its positive effects and also its limitations. I will also ask you about what it is like to be a carer and about any other supports or help you receive because I think your answers to these questions will help me to understand the part that WRAP plays in helping to keep you well.

The nature of the Interview

Interview structure will be kept to a minimum to allow you to tell me anything you want to tell me about your own experience of WRAP. Questions will be as open as possible to allow you to choose what you tell me because you feel it is important to your understanding of WRAP.

The interview will be recorded on a digital recorder in order to make sure that I do not miss anything that might be important. I may take some notes if I hear something important that I want to come back to in the course of the interview.

I will begin the interview by going over some of the issues and assurances in this guide.

I will be happy to answer your questions at any time before, during or after the interview. If for whatever reason, you prefer not to answer a question, then please just say so and we will move on.

At the end of the interview I will ask you if there is anything else you want to tell me, giving you an opportunity to add anything or review something that has been already said.

I understand that this interview is a snapshot of how you feel at a certain time and how you are feeling on that day. Therefore, if you think of anything else after the interview which you feel you should have said or wish you had said something differently or want to withdraw something you said, then please contact me using the contact details below.

Interview Questions

Here is a list of the sort of questions I will be asking you in the interview. During the interview, I may ask other questions in order to help me understand what you are telling me or to follow up on an issue which seems to be important to you.

- How did you come to be involved in doing WRAP training?
- What does being a carer mean to you?
- Do you receive support and if so, how do you feel about the support you receive?
- Can you tell me about your experience of WRAP?
- What difference has WRAP made in your life?
- Is there anything else that Edinburgh Carers' Council could do in the future to help you to keep well?

Reporting on the WRAP Evaluation

A final report will be produced and you will receive a copy. Anything written based on what you have told me will be respectful and sensitive to you and the people you care for. I have my own ideas about what WRAP is all about and what the value of WRAP is but I will listen carefully to what you and others tell me and not write over your account with my own. I will reflect the diversity as well as the common themes in participants' accounts. Great care will be taken to ensure that confidentiality and anonymity are maintained.

A draft report will be provided for all participants and you will be given the opportunity to comment critically on the content and presentation. This will give you an opportunity to say if you think I have misrepresented anything you have said or suggest other things which have been missed.

The Safety and well-being of Participants

I am committed to ensuring the safety and well being of participants and will do everything possible to make sure that no harm comes to you as a result of taking part in this interview. Confidentiality and anonymity will be maintained at all times and material will be checked

before publication to make sure that no individual can be identified. This includes the person you care for as well as you, the carer.

Usually researchers employ a trusted person to transcribe recordings of interviews. If a transcriber is employed for this research, they will be employed on the basis that they can be trusted not to disclose anything which they hear and will have to sign a confidentiality agreement to that effect. Transcriptions will be held in a safe place with all names and identifying features removed. Recordings will be destroyed after the research is completed.

I also recognise the wider interests of carers. I will be mindful throughout of the responsibilities attached to representing the experiences of others and the impact that anything placed in the public domain may have on carers as a group.

I will bring along a consent form on the day for you to sign. However, this does not remove the need for care throughout and beyond the research process. Having signed the consent form you can still choose to opt out of the research at any time or withdraw your consent for any material to be used.

Change of Plan

Please feel free to contact me if you have any questions or concerns about the interview or if, for whatever reason, you want to change the date/time of the interview or cancel it altogether. You can reach me by email or telephone as follows:

Sue Kelly (Researcher)

suekelly_51@hotmail.co.uk

0131 270 6087

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