

## **Introduction**

Have you ever wondered how people first become interested in the field of mental health, such as bipolar disorder, and feel the need to pursue that interest by researching it?

Is it that by reviewing approaches currently undertaken in the treatment of this complex mental illness that advocate a more comprehensive approach to improve and sustain benefits, although they still appear under-developed, that this interest first arises?

If a gap in the knowledge is evident, how best then to fill it?

This study explores the effectiveness of a comprehensive recovery-based group training, written and delivered by a person with bipolar disorder, that was offered to groups of people with the illness, in comparison with non-participating controls.

This case study approach has been informed by both a traditional research framework, taking into account prior research in the field of psycho-social interventions for people with bipolar disorder, and the lived understanding and personal experience of what is necessary to enable recovery from this illness.

The study provided promising evidence of the effectiveness of the “In-Sight” training: trends were noted in improvement for participants in comparison with trends in deterioration for controls in areas such as mood, symptoms, coping, empowerment and quality of life at the end of the six months study period for

both the pilot and main study groups. Participants also demonstrated trends in improved interpersonal skills, healthier lifestyle, balanced structure in their lives, and trends in development of their intellectual outlook and responsibility towards themselves.

The “In-Sight” training is proposed as a step towards enabling recovery for people with bipolar disorder. The promising evidence of its effectiveness, clarified through qualitative and quantitative methods, from both the participant and participating mental health professional perspective, indicates that by bringing together a range of different techniques and lived understanding of this illness, this hybrid might usefully advance service provision by giving those with the illness the skills they need and use in their recovery from it.

It is not enough to distinguish a gap; it is what you fill it with, and how you fill it, and more importantly, why you started to fill it in the first place, that count.

# **1 Literature Review**

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The purpose of this critical literature review is to explore current approaches to the management of bipolar disorder and to recommend that an holistic or whole-life perspective situated within a user-led group training be adopted to assist people to achieve greater recovery from this illness.

## **The illness and its impact upon people**

Mood disorders were identified by the World Health Organisation in its 1999 annual report as among the most common causes of morbidity, lost quality of life, lost productiveness and chronic impairment in developed countries. When burden of disease was measured by ‘disability adjusted life years’ (time lived with a disability), mood disorders were near the top of the list in high-income countries, number one in the Americas and number three in Europe (WHO 1999).

Epidemiological estimates (George, 1998; Weissman et al, 1998; Hilty, 1999) suggest that bipolar disorder affects 1% of the population; in the order of half a million individuals have bipolar disorder in the UK. Individuals suffering from this incurable illness may spend many months or even years of their lives dealing with the symptoms of mania, hypomania and depression (Fukuda et al., 1983).

In bipolar disorder, mood swings can oscillate between the extreme poles of mania with psychotic features likened to schizophrenia, being accompanied by thought disorder, hallucinations and delusions and the profound depths of

clinical depression. The nature of the disorder means that those leaving hospital not only experience functional impairment after discharge (Harrow et al., 1990) but also continue to suffer from a range of difficulties when trying to reintegrate their lives in the community: financial and employment problems (Targum, 1981), decreased work status and functioning (Soloman, 1995; Goldberg et al., 1995; Mason, 1998), relationship problems and increased likelihood of divorce or separation (Targum, 1981; Soloman, 1995), decreased social functioning (Goldberg et al., 1995; Soloman, 1995; Daly, 1997; George, 1998; Hilty et al., 1999) and family dysfunction (Goodwin & Jamison, 1990). Lifetime suicide risk has been estimated as high as 15% (Sheppard & Hill, 1996).

Co-morbidity between bipolar disorder and Axis I disorders is common. Zarate & Tohen (1997) summarised research examining simultaneously co-occurring disorders with bipolar disorder to indicate the presence of eating disorders (from 2 to 15%), alcohol and substance abuse (from 48 to 60%), panic disorder (from 7 to 16%) obsessive-compulsive disorder (from 8 to 13%), impulse control disorder (from 13 to 23%) and attention deficit hyperactivity disorder in 57% of adolescents hospitalised in one study; between 42 and 66% of people hospitalised for mania had a co-occurring Axis I disorder. Early onset bipolar disorder resulting in interrupted development rendering a 'dual vulnerability' (Kahn, 1990) leading to a concurrent diagnosis of a personality disorder (50%; Goodwin & Jamison, 1990) and high levels of expressed emotion in bipolar families leading to a poor prognosis of recovery (Priebe et al., 1989) have also been noted.

Contrary to historical emphasis and myth derived from the work of Kraepelin, the outcome for people with bipolar disorder is not a rosy one (Gitlin et al., 1995; Goldberg et al., 1995; Soloman et al., 1995). Now perceived as a life-long disorder with multiple episodes recurring for 80% to 90% or even 95% of those diagnosed with the illness (respectively Hilty et al., 1999; Tohen & Grundy,

1999; George, 1998). Relapse rates following hospitalisation for mania can be as high as 50% in the first year and 70% within the first five years (Perry et al., 1999).

It has been noted through previous research that bipolar disorder is a clearly a complex illness. It would appear that such complexity demands an even greater range of therapeutic interventions consolidated in one complete package than mono- or dual psychotherapies currently offer. This complexity impacts upon all areas of an individual's life in a long-term and in an all-pervading manner to the extent where each episode indicates a person's inability to maintain good health due to an increased stress reaction and the prognosis of an accelerating illness over time (Mondimore, 1999).

Given the above, it is proposed that treating bipolar disorder therefore requires a multi-faceted or whole-life approach to address this complexity and support individuals in their recovery from it.

### **Current treatments for bipolar disorder**

Although pharmacological interventions are often the first line of treatment for bipolar disorder, these are insufficient to control fluctuations given extremely high relapse rates previously mentioned; three quarters of clients also experience residual symptoms between episodes even whilst on drug treatment (Keller et al., 1986; Gitlin, 1995; Kalbag et al., 1999).

Pharmacotherapy for depression is often a first reflex and can be beneficial in the short-term. However, treatment with antidepressants does not seem to affect the long-term outcome of client prognosis, once the treatment is stopped. There may be residual symptoms, and treatment by pharmacological means may

worsen the course of the depression. Cognitive-behavioural approaches can be effective in engendering complete recovery in the long-term (Fava, 2002).

Adjunctive psychotherapies for bipolar disorder are experiencing a certain success in comparison to pharmacotherapy alone, despite a historical emphasis of pharmacotherapy on its own for mania present until the early 1990s (Sachs, 2000). Not only does pharmacotherapy on its own not meet the needs of many bipolars (Prien & Rush, 1997), but therapies combining pharmacotherapy and psychotherapy generally receive approval from service users (Seligman, 1995), have received approval from experts concerning treatment for depression (American Psychiatric Association, 1993; Gregory et al., 2001) and, on the whole, the different combined pharmaco-psychotherapeutic approaches for bipolar disorder tend to point towards improved outcomes for this group (Jindal & Thase, 2003).

Although high relapse rates for clients with mania are influenced by stressful life events (Johnson & Roberts, 1995), high levels of expressed emotion (Butzlaff & Hooley, 1998), marital discord (Miklowitz, 1998) and lack of social support (Johnson & Winett, 1999), different psychotherapies have sought to address these destabilizing factors, each with improved client outcomes:

### **psycho-educational interventions**

One of the main aims of psycho-education is to improve adherence to medication, as non-adherence is one of the causes of relapse (Lingham & Scott, 2002). Peet & Harvey (1991) randomly assigned 30 patients attending a lithium clinic to receive a videotape lecture, a handout and one home visit compared to 30 waiting-list controls. Measured by standardised questionnaires at pre- and six weeks post-intervention on their knowledge of lithium, participants in the education group showed significant increases in their knowledge and attitudes

towards lithium and their medication adherence either self-reported or noted through plasma lithium levels.

Group psycho-educational programmes such as those undertaken by Colom et al. (2003a) comprised aspects which individually had shown efficacy: detection of prodromes and illness awareness, lifestyle regularity and medication adherence. Group training participants received 21 90-minute sessions of psycho-education compared with controls who attended non-structured group meetings. At two years post-therapy, it was beneficial in preventing manic, depressive or mixed episodes, which contrasted with Perry et al. (1999) and Lam & Wong's work (1998) that suggested benefits for manic but not depressive symptomology. Colom et al. (2003a) found that psycho-education was more helpful than simply the supportive role of the group. Colom et al. (2003b) later found that this psycho-educational programme, whilst enhancing medication adherence, represented more than that and pointed towards a "tripod model" comprising lifestyle regularity, prodromal detection and prompt medication, and finally medication adherence.

Colom et al. (2005a) proposed that there was a synergistic triple action in that whilst the educational component of the therapy would illicit changes these might not lead to optimum lithium levels. However, a secondary outcome would improve medication adherence thus resulting in less variation in lithium levels. It was also found that group psycho-education may benefit bipolar participants with a co-morbid personality disorder (Colom et al., 2004; Colom & Lam, 2005).

### **cognitive-behavioural therapy (CBT)**

CBT encourages clients to correct their negative thinking patterns by a combination of behavioural activation and cognitive restructuring to enhance

engagement with their environment and has achieved benefits with manic symptomology (Perry et al., 1999; Lam & Wong, 1997, 1999). The use of behavioural coping strategies and early medication intervention resulted in fewer manic relapses and use of behavioural with consideration also accorded to cognitive strategies results in few depressive relapses (Lam, 2001).

Lam and Wong (1997) found that individuals suffering from bipolar disorder can usually detect the symptoms of approaching illness (prodromes). They found that a patient's level of social functioning was related to their level of insight and to how well they coped with the prodromes of mania and whether they could detect warning signs of depression. In their conclusion, they state that 'the research suggests that it is worth exploring ways of teaching patients to monitor their moods and to promote insight and good strategies for coping with their prodromes'. In 1999, Lam and Wong, with the cooperation and based upon the observations of members of the Manic Depression Fellowship, constructed and validated the Coping Inventory for Prodromes of Mania. MDF members identified six common warning signs of mania: reduced sleep, increased activity, over-talkativeness, euphoria, racing thoughts and irritability. Further idiosyncratic symptoms (individual relapse signature) were also identified. This Coping Inventory comprised four sub-scales of coping strategies for dealing with mania: stimulant reduction, problem-directed coping, seeking professional help and denial or blame. They found that the use of adaptive coping strategies (the first three) and decreased maladaptive strategies (denial or blame) were related to a higher degree of social functioning. Further, that the ability to seek professional assistance and reduce activity levels at an early stage is adaptive since this may prevent escalation of symptoms to an uncontrollable level. However, stimulation reduction strategies, in comparison with others, were not found to be readily deployed by people with the diagnosis and might usefully, albeit with difficulty, be integrated into psychosocial education interventions. Problem-directed coping with prodromes was not as beneficial to social

functioning as stimulant reduction or seeking professional help. Denial or blame, previously identified as a salient coping strategy for manic depressives, was confirmed as maladaptive in that it alienated an individual's social network and tended to increase the severity of the problem.

Perry et al. (1999) employed expert-taught individual instruction in the recognition of prodromes. NHS referred patients received between 7 and 12 sessions of one hour each. Referrals were taught to identify prodromes for both mania and depression separately and then they produced and rehearsed an action plan to carry out when symptom recognition had taken place. This plan consisted solely of contacting a preferred mental health professional whose contact numbers were carried by the patient at all times. Perry et al. (1999) found that in comparison with the control group, experimental group participants benefited from improvements in the length of time to first manic relapse, although not to first depressive relapse. The experimental group received significantly more antidepressants than controls pointing to increased awareness of symptoms but lack of skills to cope with them. Social functioning in the experimental group was improved probably due to increased confidence in coping with relapse. Employment stability also appeared to improve in the experimental group. They concluded that rather than the non-specific effects of support from an empathic therapist, a specific treatment effect was recommended for people with bipolar disorder.

In comparison with Perry et al. (1999), Scott et al. (2001) randomly allocated 29 patients to 25 individual sessions of cognitive therapy lasting 6 months covering psycho-education, cognitive and behavioural approaches to illness management, dysfunctional thoughts and beliefs, barriers to treatment adherence and anti-relapse techniques and belief chaining. Scott found that, compared to 29 controls, the therapy was effective in reducing depressive symptoms but not as effective in the reduction of manic symptoms. Fewer hospitalisations were

noted during the measurement period of 12 months following the end of the therapy. Although post-intervention improvements in global functioning were noted, these did not persist to this later measurement period. Scott noted that co-morbidity and an individually-tailored therapy to meet the needs of this heterogeneous client group as mood fluctuations required different elements of the therapy at different times meant that it was “not appropriate clinical territory for novice therapists” (p 466).

Lam et al. (2003) randomised 103 bipolar I patients to either a 14 session and two booster session therapy over six months or a control group. Therapy addressed the need for combined pharmacotherapy and psychotherapy, cognitive behavioural skills, mood monitoring and management, the importance of sleep and routine and unrealistic striving behaviours. At 12 months post-therapy, the intervention group had fewer episodes and hospitalisations and higher social functioning. There was also better coping demonstrated with manic symptoms. However, improved coping with depressive symptoms at six months did not persist at 12 months, which was consistent with their earlier pilot study (Lam et al., 2000). They concluded it was more difficult to teach bipolar patients to recognize and cope with their depressive prodromes than it was for manic prodromes. They also noted that highly driven and extreme goal attainment beliefs, identified as a vulnerability factor, had decreased at six months post-intervention although were not distinguishable from the controls at 12 months. The conclusion was that these attitudes were highly valued and hence hard to change. In their two-year follow-up study, Lam et al. (2005b) concluded that the differences in effect were significant for depression but not for mania, similar to that found by Soloman (1995), and that some form of booster therapy was needed to maintain the significant effects noted at six months post-therapy.

### **interpersonal and social rhythm therapy (IPSRT)**

IPSRT is a combination of two distinct therapies (interpersonal and social rhythm) and encourages clients to understand and renegotiate the social context linked to disordered mood and to recognize and modify the impact of interpersonal events on their social and circadian rhythms to achieve control over these and engender greater mood stability. After taking an initial history of the patient's illness, an interpersonal inventory is established in which the social network is clarified and a core interpersonal area identified. This usually covers grief from loss including the loss of the 'healthy self' (Frank et al., 1994), interpersonal disputes (on-going conflicts with significant others), role transitions (disruptions in a patient's work or social venues) and interpersonal deficits (in social skills). Tracking social routines and sleep-wake habits enables patients to identify disruptions and to correct these and identify how relationships affect and have been affected by the illness and to improve these. It has benefited clients with depressive symptomology (Frank et al., 1997, 1999, 2000).

### **family-focused therapy (FFT)**

FFT is delivered in 21 sessions over nine months and consists in five stages. From the assessment taken of the most recent episode and an evaluation of family members' attitudes towards one another (expressed emotion), the third phase is psycho-educational. Skills training to decrease family stressors and increase the protective milieu of the family and finally communication enhancement through role-play and exercises conclude the therapy. FFT has benefited clients with depressive symptomology (Miklowitz et al., 1996; Miklowitz & Simoneau, 2000). High expressed emotion (critical, hostile or emotionally over-involved attitudes) from either the patient's spouse or parents

results in the discharged patient more likely to experience a relapse in the nine to twelve months in comparison to low emotionally expressive families (Miklowitz, et al., 1996).

Since bipolar disorder is clearly a complex illness, it would follow that a complex therapy is needed to treat it successfully. Craighead et al. (2002) in the conclusion of their paper state that “the overall pattern of findings from these studies (on CBT, IPSRT and FFT demonstrating effects with either depressive or manic symptoms) ... may suggest the wisdom of combining CBT with interpersonally oriented or family/marital psycho-educational interventions (first cited in Craighead & Craighead, 2001).

### **group therapies**

Often combining different types of intervention, group therapies have resulted in improved social functioning and lower relapse rates (Sharkir et al., 1979; Kripke & Robinson, 1985; Cerbonne, 1992).

The Life Goals programme (Bauer & McBride, 1996; Bauer et al., 1998; Bauer & McBride, 2003) combining illness management skills with improving social and occupational function resulted in clients’ greater knowledge of the illness and almost half of the originally enrolled clients achieved at least one self-designated functional status goal within a mean time period of nine months. Divided into a highly structured psycho-educational group intervention of six weekly sessions, followed by a more flexible behaviour-oriented group psychotherapy of one-year duration, this represented a mixed approach.

De Andre et al. (2006) delivered a French version of the Life Goals programme and found that the group therapy was well received by participants and their medication adherence and relapse prevention had improved. Half the

participants achieved their goals completely, the other half partially. After one year in the second goals part of the therapy, depression scores had reduced significantly although no significance was found in scores for mania. No control group was used in comparison.

### **theoretical approaches to self-management**

In self-determination theory, the basic psychological needs for autonomy, competence and relatedness are seen as essential to personality growth and well-being (Ryan, 1998). Cowen (1994) underlined the link between empowerment and the acquisition of skills to cope effectively with life stressors and the improved psychological wellness of an individual. Hoffman (1978) demonstrated how an individual's locus of control and self-esteem are linked. Bandura's Self-Efficacy theory shows that acquirable skills can be progressively mastered, with monitoring and feedback, to increase an individual's subjective confidence in managing stressful situations by their awareness and adaptive action (1982, 1986, 1999).

### **Bipolar disorder: a complex illness requiring a combined therapy**

It is now commonly accepted that "bipolar disorder is a complex disorder" (Lam & Wong, 2005). It is influenced by and impacts upon all areas of an individual's life. Hence "it needs an intervention to be multi-faceted" (Lam & Wong, 2005 in 'conclusions') to aid individuals in their recovery from it.

A reading of recent literature indicates that whether it is therapy derived from multi-level model-driven theories (Jones, 2005) or existing therapies that are combined which result in increasing positive outcomes for bipolar participants (Miklowitz et al., 2003) or the growing number of user-led recovery-based programmes (Davidson, 2005), the tendency of research appears to move slowly

towards integration. This integration is warranted with bipolar disorder in order to theoretically “encapsulate its complexity” (Jones et al., 2005, p. 29) and fully address the “multi-faceted needs of the individual”. (George, 1998, p. 151).

However, research has mainly focused on the comparative benefits of various therapies rather than take these forward towards even greater integration through adopting a more holistic approach to address these complex needs. Group psycho-education (Bauer & McBride, 1998, 2001; Colom et al., 2003), cognitive behavioural therapy (Lam et al., 2003; Lam et al., 2005b), group CBT (Palmer et al., 1995; Patelis-Siotis et al., 2001); group psychoanalytic psychotherapy (Retzer et al., 1991; Cerbonne et al., 1992; Hallensleben 1994; Kanas & Cox, 1998); family focused therapy (Miklowitz et al., 2000; Rea et al., 2003), interpersonal and social rhythm therapy (Frank et al., 1994; Frank et al., 1999; Frank, 2001; Frank 2003; Frank & Swartz 2004) integrated family and individual interpersonal and social rhythm therapy (IFIT, Miklowitz et al., 2003) although sharing similar therapeutic components appear to compete for effectiveness rather than combine their benefits.

STEP-BD, which purports to be the “largest trial of psychosocial interventions ever conducted in bipolar disorder”, (Thase et al., 2003 p. 514) will compare the utility of CBT, family therapy and IPSRT and various pharmaco-therapies without integrating these therapies into one combined holistic therapeutic package.

In trying to establish “which component in a multi-component package was responsible for the treatment effects” whether impacting upon time to relapse for mania or depression, it might be preferable to focus on the fundamental need for “a full package” (Lam, 2005b in ‘conclusions’) which combines these different interventions to enable full recovery from a complex, fluctuating and worsening disorder. Colom & Lam (2005) pointed out that whilst it could not

be established whether every individual element in psycho-education was indispensable for successful outcomes, it was this “combination” that had shown good prophylactic success.

It may be preferable to focus on evaluating clinical and functional outcomes across treatment modalities rather than conduct “horse races” between the different modalities (Bauer, 2001) when each therapy has something beneficial to offer.

Since the different therapies are beneficial in their various ways, it would seem appropriate to combine these benefits to address this complex disorder more fully. For example, Lam et al.’s work (2005a) on dysfunctional assumptions and beliefs held by this group pointed to high goal attainment, anti-dependency on others and striving for achievement. In working towards establishing this ‘package’, it may be wise to incorporate strategies that would situate realistic goals within a firm structure of balance and routine to guard against schedule and sleep disruption that may ensue from extreme goal focus. Enabling bipolars to develop their communication and assertiveness skills towards developing a social circle to reduce isolation and challenge overly self-reliant beliefs might also aid in their renegotiation of expressed emotion in their family.

Rather than “studies... proceeding independently” (p. 183 Miklowitz et al., 2003), competing for treatment success in what is a complex illness requiring a multi-dimensional and integrated approach, might it not be more logical to take this integration one step further and focus on the summation effect of additive effects of these integrated treatments to enhance greater recovery, i.e. that  $0.5 + 0.5$  may only equal 0.8 but this has been achieved (Keller, 2000) and not that 0.2 remains unaccounted for?.

In current therapies, there is overlap, so why not overlap in the maths? In most therapies, common themes are present: medication adherence and symptom reduction, psycho-education and illness management. Some therapies have a secondary aim to improve social and occupational function, some deal with internal and subjective (intrapsychic) themes thought to influence psychosocial function and quality of life (Bauer et al., 1998). However, IPSRT, FFT, CBT and that found in the group Life Goals Programme all aim to promote the client's understanding and treatment of bipolar disorder, medication adherence, contingency planning for symptom management, modulation of environmental stressors and responses to these, skills development to enhance environmental and interpersonal coping and improvement of functional outcome, either directly or indirectly.

Patelis-Siotis et al., (2001) found that group CBT improved participants' psychosocial functioning without this being attributed to symptomatic improvements. Whether this improvement is due to the practising of the 'behavioural activation' component or through group support, it is known that perceived increased social support is linked to greater recovery and preventative against relapse (Johnson, 2003). Integrating this social component into the integrated "package" would serve several functions.

Seen as a complex disorder, with research conclusions pointing towards a multi-dimensional integrated 'package', these recommendations still fall short of an holistic approach to the treatment of bipolar disorder.

### **Integrated psychotherapies: further but not far enough**

If poly-pharmacotherapy is accepted in the treatment of bipolar disorder then equally poly-therapy might also be considered as a new type of psychotherapeutic intervention that was called for in The National Institute of

Mental Health's recommendations in 1990 (Prien & Potter, 1990). The pattern of findings of successful combinations of pharmacotherapy and combined psychotherapies for bipolar disorder suggests that further integrations, leading to a "multi-modal" combined treatment model, are indicated (George, 1998). If we accept that a combination of medication and psychotherapy are "not only compatible but also may be synergistic" (Craighead & Miklowitz, 2000 p. 58) might we also hypothesize that combinations of various psychotherapies likewise result in greater and more long-term benefits?

Sandra George (1998) advocated an integrated treatment approach for people with the diagnosis based upon the concept of recovery. Her findings were based on certain treatment interventions for people with schizophrenia and bipolar disorder and drew upon similarities between these mental illnesses. Although separate interventions in the areas of psycho-education, family therapy, psychological therapy and group therapy had been found helpful, these individual psychosocial approaches were found wanting. The results of each psychosocial approach, each applied to specific problem areas of bipolar disorder, could be optimised by pulling them together into an integrated intervention designed to address the multi-faceted needs of the individual in a multi-modal approach. In such a way, biological, environmental, social and psychological aspects could be addressed. George advocated certain key elements: psycho-education for the individual and the family, a focus on relapse prevention, cognitive therapy strategies and solidarity of group support. In order to implement this integrated approach, she recommended harnessing multi-disciplinary professional skills and the involvement of professional groups and service users in establishing this collaborative treatment model.

Gournay and Ritter suggested multidimensional interventions bringing together a variety of approaches to decrease vulnerability (1996). As previously noted, Craighead & Craighead (2002) recommended that drawing the benefits from

several different psychotherapies would be a wise strategy to adopt. A Rehabilitation model (Dion and Pollack, 1992) integrated a range of treatment strategies including didactic modules about the illness, goal-setting, skills development and planning for rehabilitation.

Bauer (2001) proposed a Collaborative Practice Model comprised of developing patients' management skills and supporting provider capability and availability in order to engage patients in timely joint decision-making regarding bipolar disorder. This organisation of a new system of care was aimed at reducing the efficacy-effectiveness gap and represented a step towards a multi-faceted collaborative approach that could be manualised. It has shown improvements in process and intermediate outcome variables for this illness.

Simon et al. (2005) developed a multi-component care programme including elements from the Life Goals Programme, such as initial assessment and care planning, monthly telephone monitoring, medication monitoring, coordination with the treatment team and a structured group psycho-educational programme provided by a nurse care manager, in comparison with controls receiving usual care. At one year post-therapy, significant decreases were found for mania whilst depression scores, although not showing significance between groups, did demonstrate a decline over time.

In this vein, the Integrated Family and Individual Therapy (IFIT; Miklowitz et al., 2003) synthesized family psycho-educational sessions with individual interpersonal and social rhythm therapy. Thirty participants received 25 sessions of individual therapy, held fortnightly, alternating with 25 sessions of family therapy compared to 70 controls from a previous study that received standard community care. The results indicated benefits in depressive symptomatology, but impacted less upon manic symptoms.

More recently, in Germany, Bernhard et al. (2006) integrated 14 90-minute sessions of cognitive-psychoeducational group therapy for bipolar patients with two four-hour group workshops for their family members. Delivered by two expert psychologists in bipolar disorder, supplemented by a psychiatrist for the sessions on medication, the psycho-educational component, although in a restricted form, in comparison with Colom et al.'s work (2003a, 2003b, 2005a) integrated cognitive restructuring and behavioural activation for depressed mood. Social rhythm and goals were also integrated into the bipolar therapy. Families received information on communication and problem-solving, strengthening their own resources and coping with suicidal behaviour, together with illness management techniques. Patients reported finding the therapy informative, having increased their knowledge of the illness and being able to cope better immediately following the therapy; however, no mood rating nor other scale was employed post-therapy, nor at a later follow-up stage. Handouts were given out at the end of each session, rather than participants engaging in structured and personal exercises applying the material. Only half of the relatives completed post-therapy questionnaires, reporting feeling better informed and a reduction in problems related to their family member's symptoms. One year later, only a third of these respondents completed questionnaires, which showed significance levels for lower expressed emotion and a reduction in their own depression levels, which may point towards only the satisfied families completing these questionnaires. No control group was used and most of the patients recruited started the therapy immediately following an acute episode possibly attributing the therapeutic benefits to regaining their normal euthymic mood after this episode. It was recommended by Bernhard et al. (2006) to recruit from bipolar patients who were at least three months euthymic.

Despite this more recent move towards greater integration of therapies, current multi-dimensional combined therapies still fall short of what is needed for

living an optimal life with the illness as research attention is still drawn towards “racing different horses” (Bauer, 2001).

As with the Bernhard et al. (2006) study, efforts are being made to integrate psycho-education and cognitive-behavioural elements together with a structured approach for family members, but it is advocated that a more comprehensive holistic approach for people with bipolar disorder is needed for full recovery from the illness. Rather than working from the start-point of delivering piece-meal therapies and then combining these as if putting together a jigsaw, or the theoretical start-point that is slow in building a multi-level model, a holistic approach addressing a person’s whole life is needed.

The illness impacts on all areas of life hence a comprehensive and combined therapy is needed for recovery. In “our quest to provide the best possible symptom relief to our patients in the quickest possible time, it makes intuitive sense to combine both (psychotherapy and pharmacotherapy) treatment modalities” (Jindal & Thase, 2003). As Colom & Lam (2005) pointed out psycho-education has the ability to deliver both class ‘A’ (effective in itself as a mood stabiliser) and class ‘B’ (effective through increasing medication adherence) and hence they concluded “we are obliged not to withhold this excellent treatment from our patients” (p. 364).

It has been noted that we might usefully draw from the expertise of those who ‘know about’ bipolar disorder in advocating poly-pharmacotherapies and pursuing poly-psychotherapies in the treatment of this complex illness. Likewise, in establishing this necessary ‘package’, might it also be proposed that we combine the professional expertise with the first-hand knowledge of those Experts by Experience who ‘know the illness itself’?

This lived experience of bipolar disorder, and psychiatric illnesses in general, advocates adopting a holistic or whole-life approach to enable recovery.

### **Holistic recovery is not simply illness management**

Anthony (1993) described recovery as a “deeply personal, unique process of changing one’s attitudes, values, feelings, goals, and/or roles... a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. Recovery involved the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness”.

Recovery is often misinterpreted as ‘cure’, the process of recovering often wrongly assimilated with a successful endpoint not the journey (Repper & Perkins, 2003) and the result associated with the benefits of illness management alone resulting in professionals regarding the maintaining of a stable condition as synonymous with recovery (Coleman, 1999).

Having lost a sense of self, power, meaning and hope, recovery is about regaining control over one’s life and renewed self-belief (Repper & Perkins, 2003). In therapeutic approaches, it is also important to include non-specific treatment effects such as “maximising patient hope (as it) may also be important in enhancing functioning” (Morris et al., 2005, in ‘discussion’). Hope is the bedrock present in recovery approaches (Copeland, 1992, 2002) underlining the importance of “creating provider-patient partnerships that maximize non-specific treatment mechanisms such as hope” as impacting positively on functioning (Morris et al., 2005, in ‘discussion’).

Williams and Collins (1999) in their work with people with schizophrenia, found that the struggle for control was a central theme, affecting the management of symptoms, self-image, feelings of social competence and

dealing with others' expectations. Patients pointed to recovery through a period of internal and external reorganisation of the self. Davidson (1999) in his review of this work, underlined the confirmation of previous studies that this research represented and advocated these 'non-specific factors' as a guide for disorder-specific treatments. He noted that recovery from psychotic experiences involved making sense of the experience in ways that allowed individuals to preserve or reconstruct a sense of efficacy and control and to re-establish meaningful connections to others. Long-term recovery involved progressing from a passive victim of the illness to a more active agent in order to master its various secondary negative effects, including the ongoing vulnerability to relapse.

It is about a search for meaning from what is often a 'spirit-breaking' occurrence (Deegan, 1990). Drayton, Birchwood and Trower (1998) developed a recovery style questionnaire from McGlashan et al.'s work (1975) and explored the relationship between 'integration' coping style (integrating distressing life events) and 'sealing over' coping style (denial or refusal to draw any lessons from the distressing experience), depression and early childhood attachment. They found that the majority of the 'sealers' were moderately to severely depressed, compared to half of the 'integrators' who were mildly depressed. No 'integrators' experienced moderate to severe depression. More 'sealers' made more negative self-evaluations than the 'integrators' and also perceived their parents to be less caring than the 'integrators'.

The search for personal meaning, development of self-confidence, and of the self beyond the illness, of enjoyment and of a sense of well-being, hope and optimism are all part of the process (Mueser et al., 2002). Whilst mental health professionals may view complete recovery as a return to a pre-morbid state of functioning, service users view recovery more as positive social engagement despite still possibly experiencing symptoms (Warner, 1994).

Like the ‘turning point’ which marks the start of the journey on the road to recovery, often enabled by a significant other in a supportive role (Allott et al., 2002), there can be no return to the state of mind or the self pre-illness, only a forward movement. The Recovery Advisory Group’s model of recovery (Ralph, 1999) postulates a process of six stages towards regaining wholeness or well-being: anguish, awakening, insight, action plan, determination to become well and well-being/empowerment. In measuring improvements in recovery, also associated with empowerment, Rogers et al. (1997) encompassed five themes of self-efficacy/self-esteem, power, community activism, righteous anger and optimism or control over the future (c.f. Outcome measures in the Methodology and Appendices).

However, in terms of the concept of taking back control over one’s life and in learning to manage the illness and personal growth, there is an overlap with illness management techniques. Illness management, as defined by Mueser et al. (2002), is seen as “the practice of medicine of professionals teaching persons with medical diseases and their families about the disease in order to improve adherence to recommended treatments and to manage or relieve persistent symptoms and treatment side effects” (p1273). Further, as previously noted, some psychotherapies focus on improving self-efficacy and enable people to pursue their goals thus overlapping with recovery ideals that enhance accomplishments and personal meaning and enable people with mental illness to spend more time formulating personal recovery goals than having their lives disrupted by episodes of illness that detract from these (Mueser et al., 2002).

In the five foundations of recovery cited by Copeland (2002), who has a diagnosis of bipolar disorder, personal responsibility is also cited. Repper & Perkins (2003) point to “recovery not being a professional intervention, like

medication or therapy, and mental health workers do not hold the key .. recovery is possible without professional intervention”. (p. 47).

Similarly, the distinction made between illness management and recovery often resides in the power differential between professionally-based and peer-based teaching in the concept of where responsibility for the health of the individual lies and from the point of view of imparting personal experience of ‘self’ management lessons (Mueser et al., 2002). Recovery is more the demand for a new approach to services than a separation from them, whereby empowering service users to engage in this self-determination towards their own wellness is not seen as disempowering professionals, rather a more effective use of their power. Thus recovery can be seen as a paradigm shift, not towards how a limited amount of power is distributed, but how the differing nature of it may be more effectively deployed (Allott et al., 2002).

Although illness management and recovery are related, one does not equate with the other. Given the complexity of bipolar disorder, the recommendations to pursue poly-pharmaceutical and poly-therapeutical interventions to treat it successfully, and the more encompassing definition of recovery, this restrictive definition of illness management does not offer the ideals nor hope to achieve the optimal outcome of all that recovery entails. Nor does it measure up to what governmental organisations recommend for the future direction of mental health services.

### **Recovery is a ‘Whole Life’ approach**

As *The Journey to Recovery – The Government’s Vision for Mental Health Care* (DoH, 2001) pointed out, “services of the future will talk as much about recovery as they do about symptoms and illness... The mental health system must support people in.. whatever they think is critical to their own recovery” (p

22, emphasis in the original). Likewise, if recovery is the ideal direction to enhance mental well-being and health, “hand in hand with improvements to services, a change in attitude must take place” (p. 23, DoH, 2001). Hypothetically this change in attitude may include the therapeutic approaches that have hitherto been historically emphasised i.e. illness management which is beneficial but, as noted, insufficient to achieve the direction of recovery that is advocated for the future of mental health services, nor for the future of those with mental illness.

The National Institute for Mental Health in England’s (NIMHE) Guiding Statement on Recovery, taken from the work by Woodbridge, Kim & Fulford (2004), indicates that promoting recovery is one of the Ten Essential Shared Capabilities for mental health practice. Tackling mental health problems with ‘hope and optimism, to work towards a valued lifestyle within and beyond the limits of any mental health problem’ is advocated, as is “enabling self-empowerment and self-determination” (appendix D, p. 15). A second shared essential capability is that of user-centred care in that “meaningful goals.. primarily from the perspective of service users and their families” are achieved (appendix D, p. 16). These capabilities are situated within a multi-disciplinary approach to providing the best possible user-centred care (appendix B, p. 10). Thus it is the service user, the person diagnosed with mental ill health, that takes charge of the direction of travel that he/she needs to optimise his/her meaningful life, over and above the limits of any mental health problem whose symptoms might abate through illness management alone.

The Whole Life Programme, commenced in 2003 and led by NIMHE’s Eastern development centre, currently has 11 development sites in the UK piloting a holistic approach to mental health. Linked to other European pilot sites, it advocates a five-pronged approach to ensuring that local service delivery is able more closely to reflect the needs and objectives of service users in all their

multiple dimensions and provide a more person-centred, holistic and empowering response. From a whole life vision uniting mental health systems by a clear and meaningful set of shared values, this leads onto operationalising these values and principles (derived from the work of Woodbridge & Fulford, 2004), developing an holistic service that enables practitioners to creatively apply these values, engage with service users on a whole persons approach to enhancing their recovery and a whole systems approach whereby local services respond more adequately and integrate with the wider local community (Rix, 2006, personal communication).

Whilst research into bipolar disorder indicates that a multi-dimensional approach must incorporate different therapies specific to the management of bipolar disorder in order to combine the benefits of these, a recovery approach advocates fundamental cross-mental illness values which would develop this multi-dimensionality further into a true holistic approach to enhancing the entire life of the person with mental ill health.

### **Paucity of service users' experience and research into bipolar disorder**

The Government White Paper 'Saving Lives: Our Healthier Nation' introduced the concept of an Expert Patient Programme. The NHS Plan announced the further development of an expert patients programme to build on such experience and to bring it into the mainstream of NHS and related services. Professor Liam Donaldson, the Government's Chief Medical Officer, stated in the Expert Patient report to ministers that:

4.1 'The Expert Patients Programme holds out the promise of thousands of confident and more informed patients and large numbers of lay people involved in evidence-based self-management programmes of one kind or another. However, in order to achieve this, there will need to be a major shift in cultural

attitudes, and this in turn will depend in part on convincing patients and professionals of the value of this approach’.

He went on to say that ‘there is as yet little exploration of the potential of self-efficacy evaluations of UK patient education interventions’.

Given these positive benefits derived from self-management training in physical and mental illnesses and self-affirming theoretical approaches, the government is currently exploring the effectiveness of user-led self-management training programmes in a wide variety of health fields through their establishment of the Expert Patient Task Force (1999). There is a willingness to incorporate user-led initiatives into mainstream interventions (e.g. Department of Health 2001. Williamson C. (1992). However, the Task Force noted that randomised controlled trials exploring user-led initiatives are lacking in the area of mental health, and specifically those employing user-established outcome measures. Others have noted that “self-management strategies need to be more formal and robust” for serious mental illnesses (Davidson, 2005).

Whilst it is now accepted that service users’ experience of services can be used to improve mental health knowledge (Whittingham & Parsons, 1999) and that the involvement of service users, through their understanding of their experiences and needs, is central to offering better NHS services (Sang, 1999), research on users’ experiences remains limited (Scott, 1995; Hill & Sheppard, 1996; Hill et al., 1996; Birchwood, 1998; George, 1998). Pollack (1996) remarked that ‘changes in the understanding of the self-management of people with bipolar disorder are pivotal to the development of strategies that may reduce relapse’.

In the UK, the first user-led research into self-management in bipolar disorder, and the first in the area of mental health, was undertaken by the Manic

Depression Fellowship/The Bipolar Organisation during 1998/2000 (Harris, 2001, personal communication) although a formal published evaluation is unavailable. As an illness management training, it aimed to teach its member participants to recognize triggers and warning signs of the illness, to monitor their mood and to plan for crises. Self-report measures demonstrated improvement in participants' lives; however, the programme content excluded many CBT and IPSRT techniques, social and lifestyle components were not developed and information on expressed emotion was lacking. Geographically remote training venues and intensive course length of two/three days were not conducive to integration of the training into participants' lives, optimisation of the knowledge base or continued group cohesion and support after the training had finished. The well-educated member sample was not representative.

In contrast, Baker (2002) provided an insight into coping techniques commonly used by members of the Mood Swings Network which were also supported by earlier research as being useful coping strategies: support groups (Ah-Mane, 1999), healthy lifestyle (Currey, 1995; Mason, 1998), lifestyle balance (Mondimore, 1999). Interestingly, only 25% of the coping strategies used by bipolars in the Network study involved medication and services, with the remaining 75% being essentially non-medical (family/friends, support groups, positive thinking, exercise, sleep, education, mood monitoring, routine, work, hobbies, understanding the illness, talking, space, self-management, good food, socialising and faith, in order of importance).

The Wellness Recovery Action Plan developed by Copeland (1992, 2002) presented a generic (ie. non-bipolar specific) group programme over 40 hours in which, although planning elements for well-being and in case of illness were extensive, detailed healthy lifestyle elements, IPSRT and CBT techniques were not incorporated. Illness specific components for bipolar disorder, previously noted as vital, were lacking. Only 44% of participants completed pre- and

immediate post-course self-report questionnaires, with no longer-term follow-up or follow-up on drop-outs. There lacked an external evaluation to confirm that client perception of improvements had translated into veritable positive change and a control group was absent. Based on five key concepts of hope, personal responsibility, self-advocacy, education and support, mental health user participants reported improved knowledge about the illness, use of coping and wellness skills and advanced planning. The programme was delivered to groups of generic service users, their family and friends, and service providers. Two people facilitated the group, one of whom, not Copeland herself, had personal experience of mental ill health.

Drawing from the above service user-led research work, and from the previously noted necessity to create a “full treatment package” to address the complexity of bipolar disorder, tending to verge also towards a more comprehensive view enabling self-determination within a whole life approach, would it not be possible to hypothesise that these benefits, drawn together, would enhance successful treatment outcomes i.e. a person’s recovery? (c.f. Straughan & Buckenham, 2006 (A) and Straughan in press (B), in the section on Publications). Further, that situated within an on-going self-help group format for maintenance this holistic approach might continue to support this recovery?

### **Helping oneself to health on the cheap**

Putting ‘experiential knowledge’ in a socially supportive environment (Borkman, 1990) to good use can enable group members to be more understood, less isolated, have greater empowerment and greater coping strategies (Helgeson & Gottlieb, 2000). Sharing similar experiences to enhance wellness and problem-centred coping (Ah-Mane, 1998) harnesses the needs of service users who participate in mutually supportive self-help groups to aid

their recovery. It also appeals to a currently cash-strapped NHS by way of providing an effective and cost-effective service not otherwise offered by professionals.

Although it is not the purpose of this review to detail economic benefit, it is worth mentioning that the cost-effectiveness of self-management interventions in such areas as asthma (Liljas and Lahdensuo, 1997) and of management programmes in mental health (Hu and Jerrell, 1998) points towards the potential cost-effectiveness of other self-management programmes, in this case in bipolar disorder. The current Expert Patients Programme for generic enduring physical illnesses is the most recent example, set to be widely available in the UK during the next few years. In France, the government considered that self-help groups offer such great benefit that 300 are to be created with each group receiving regular annual funding (c.f. (C) Straughan, 2006 in the section on Publications). Huxley et al. (2000) found that cost-effective psychotherapeutic interventions in bipolar disorder can achieve important gains in terms of increased clinical stability and reduced hospitalisation as well as other functional and psychosocial benefits.

Besides representing an inexpensive option in the current financial mental health climate, any concerns that self-help may interfere with treatment or provide inappropriate advice (Chinman et al., 2002; Salzer et al., 2001) must be reviewed: self-help engenders more positive gain than negative effects. The group is seen as bringing social support where an individual is without family or peer support and group therapies seen as cost-effective (Bauer, 1998).

If the intrinsic nature of the self-help provided – that of an holistic user-led therapy specific to bipolar disorder situated within a self-help group format – were offered and if this integration were to draw from professionally proven therapies, then it would not be interference nor ill advice that would result,

rather congruence with ‘treatment’ as an integral part of the illness management component in the recovery training. However, whilst 25% of an individual’s whole life towards recovery might incorporate current ‘treatment’ (ie. medication and services) per se, the greater part i.e. 75% does not.

Following on from the multiplicity of therapies and the recommendations to establish ‘full treatment packages’, together with a more holistic recovery direction towards regaining good mental health, it would appear hypothetically sound to integrate this additional larger percentage of ‘treatment’ not currently offered yet used and needed in recovery, despite a few concerns that no longer apply.

Support groups have been noted as beneficial. They “may be helpful to confront denial often seen in early phases of bipolar disorder. Patients who have come to terms with their own denial are very adept at confronting patients in denial and often provide more credible explanations about the illness than clinicians employing technical terms and jargon” (Dion & Pollack, 1992, p. 91). The group format for therapy enables more patients to be treated at one time and allows them to benefit from the non-specific effects of a sharing in a group experience (Yalom, 1975). George (1998, p. 153) noted that the “group provides the means by which self-management strategies can be reinforced and new ones developed” and together with encouraging contact with others it represents “an available network of contacts to members who can, if they wish, use (this) in times of crisis”.

Yanos et al. (2001) examined the relationship between participation in consumer-run services in comparison with traditional mental health services. In terms of recovery (defined as good community adjustment) among individuals diagnosed as having a serious mental illness (including bipolar disorder), self-help attendees achieved better overall social functioning scores than non-

attendees. This was mediated by the use of more problem-centred coping strategies in attendees. Psychosocial variables such as hopefulness/self-efficacy and education, which were also important predictors of social functioning, were found to exert an independent effect. Yanos et al. findings “supported the view that mental health services that aim to help people to learn how to cope effectively with symptoms, become more hopeful and gain a greater sense of self-efficacy may increase an individual’s chances of obtaining a positive outcome” (p. 499).

The Expert Patient Programme, launched in England by the Department of Health in 2001, targets chronic disease management in general. Whilst it may be viewed as a tool to further the wider recovery approach for mental health services and enable shared learning across diagnoses, it does not provide vital illness-specific therapy nor establish the foundation upon which self-help is based on commonality of experience (Davidson, 2005). Whilst the uptake from individuals with serious mental illnesses has been poor, ‘expert patients’ facilitate these short self-help group interventions.

### **Harnessing the Para-Professional experience**

Hossack & Wall (2005) argue that para-professionals (defined as service users providing therapeutic services) in mental health services, like service users in general despite the National Service Framework specifying their involvement in mental health services, remain an “untapped, undervalued and underused” (Webb et al., 2000; Rose, 2001) resource pool, whilst the health service is “understaffed and overworked” (Hossack & Wall, 2005 p. 134).

The effectiveness of the para-professional in mental health interventions is clear (Schortinghuis & Frohman, 1974; Karlsruther, 1976). Through “already having lived the experience” (Gartner, 1979, p. 119) para-professionals are able to help

others; through the process of modelling successful change, para-professionals provide motivation and hope to other service users (Atkins & Christensen, 2001). Para-professionals' shared understanding and ability to communicate in a common language with their clients enables trusting relationships to build and provides a model of success for others to follow (Abdul-Quader, 1992). Para-professionals are able to enhance their own prestige and further their own recovery by being positively rewarded and confirmed in this para-professional role (Lee, 1986) and, like a snowball effect, if perceived as revered by others, further positive effects on their status, self-esteem and quality of life result (Wilson & Leary, 1980). In modelling 'good lives' for others, they effectively live better ones themselves (Ward & Brown, 2003).

Interestingly, although many para-professionals lack formal training, studies have concluded that para-professionals and professionals "are equally effective in therapeutic terms" (Hossack & Wall, 2005). It might therefore be advisable to focus on areas where the para-professional was preferable to the professional (Christensen & Jacobson, 1994). Further, the added value that high-cost training brings to the therapeutic relationship might also be questioned (Atkins & Christensen, 2001). An excellent therapeutic alliance, seen as the cornerstone of ensuring good treatment outcomes, might be further enhanced by the commonality of experience between participant and para-professional bipolar therapist, the latter serving as a model (Aitkens & Christensen, 2001).

Illustrating both the effectiveness of para-professionals and the effectiveness of self-help, Bright, Baker & Neimayer's (1999) randomised controlled trial compared the efficacy of group CBT and mutual support groups for depression, both professionally and para-professionally led. The study showed that, from both a subjective (participant) and objective (clinical) point of view, outcomes improved. As support groups were seen to be just as effective as CBT groups and para-professional leaders were just as effective as professional therapists,

would it not also make “intuitive sense” to harness the benefits derived from employing para-professionals to advancing mainstream mental health services?

### **Academic Consumer Researchers: Bridging the knowledge gap**

Krumm & Becker (2006) indicate that the lack of research knowledge and skills of mental health service users involved in research may be problematic. However, Faulkner & Thomas (2002) pointed to the “marriage of two types of expertise (being) the essential ingredient of the best mental health care: expertise by experience and expertise by profession” (p.3). Academic consumer researchers, known as ACRs in Australia, hence represent this ideal “marriage” or “ideal cross-cultural travel guide” who could bridge this gap (c.f. (D) Straughan, accepted for press, in “Influencing Change: User or Researcher? Elitism in Research” in the section on Publications).

Likewise, Griffiths et al. (2004) indicate that the dichotomy between “professional researchers”, defined as individuals with research and/or health qualifications and experience in the field of health research, and “consumer researchers”, defined as people with little or no formal training and experience in conducting research, merges in ACRs (quoted from Ochocka et al., 2002, p. 380). The unique advantages of merging these two sources of knowledge of the academic and of the lived experience to inform research results in a unique insight. This unique insight is able to address the questions of most concern to service users and thus contribute to better mental health outcomes (Griffiths et al., 2004).

## **User-research: Adjunct, alternative or advancement of mainstream services?**

The net weight of evidence from the literature review is clear. We have seen that bipolar disorder is a complex and complicated illness. Poly-pharmacy, multi-level models and professionally-based integrated psychotherapeutic approaches are advocated although slow to establish themselves to treat this complexity. Meanwhile, an holistic recovery-oriented direction is employed in many generic user-led approaches and the values enshrined in recovery and whole life are those required by government although appear absent in practice. Recovery is much more than illness management; para-professional therapists are equally effective as professionally-trained ones and group self-help just as effective as CBT. Academic consumer researchers offer a distinct advantage in conducting research. It would appear that research tendency, user need and government policy converge in advocating a more comprehensive approach to recovery from bipolar disorder, which is currently lacking.

In summary, it can be proposed that by integrating the benefits of para-professional experiential knowledge within a self-help group format, by drawing from current professionally-derived integrated techniques specific to bipolar disorder and placing these in a wider didactic and robust manualised training rooted in the ideals of recovery and whole life might optimise treatment outcomes.

“In-Sight”, the mental health service user-led lifestyle development group training for people with bipolar disorder is proposed to fill this current gap in knowledge and practice.

This approach might not only improve outcomes of time to relapse, hospitalisation frequency, medication adherence and functioning, but also

encourage a healthy lifestyle, self-development and self-actualisation with and despite the illness. At the same time, it might also promote the usefulness of research conducted by those 'experts by experience' who also consider they have a worthy contribution to make in exploring what might be useful knowledge in the treatment of this disorder.

This may represent a step closer towards establishing an Expert Patients Programme for bipolar disorder in the UK and towards a new psychotherapeutic intervention to supplement pharmacological approaches called for in the American National Institute for Mental Health's 1990 report (Prien & Potter).

## **2 Writing the Training**

**- a personal view**

## **2 Writing the Training**

### **– a personal view**

This section outlines, from a personal standpoint, why and how the “In-Sight” training was written and researched.

For additional information, it may be useful to refer to Chapter 13 “Influencing Change: User or Researcher? Elitism in Research” I authored in the book, This is Survivor Research, collating a variety of service user-research experiences, supported by the Mental Health Foundation (in press). It may also be useful to refer to the testimony of “Helen” I authored in User and Carer Experiences of bipolar disorder, NICE Guidelines (in press). Both are in the section on Publications (D) and (E).

#### **Start point: personal journey not research question**

It was from the basis of personal experience of two manic episodes with psychotic features and the need to inform myself of the illness and how to cope with it, that the idea of developing a group training for people like myself, with bipolar disorder, first started.

I had been living in France, where I had called home for 13 years, but realised that the psychiatric institutions and the treatment metered out to “les malades” (the ill ones) would not help me get better. I returned to England, and my

family, and a completely blank slate, having to rebuild my life where once the bottom had dropped out of it.

A purely selfish enterprise at first, to read up on published literature to help cope with the illness and to follow the user-led self-management training established by The Manic Depression Fellowship/The Bipolar Organisation eight years ago. Purely selfish again, and a cheaper option to three years of personal counselling, to retrain to honours degree in psychology. Pure curiosity to become a volunteer group facilitator in a day centre for people with enduring mental health problems to see if my experiences might make a difference to the lives of clients who attended.

It was a case of “what happened?”, “why me?” and “how was I going to fix it?”. Some might say that I had my research questions there already. Whilst retraining and living, I started to construct a growing self-help library and a personal ‘handy reference guide’ as and when I needed to explore issues. I was also in recovery from my second episode and re-establishing a healthy way of life.

Parental values and high standards and expressed emotion are interesting topics but experienced first-hand when in recovery from psychosis led me to examine my own background and upbringing. Just when and how had I started on this road to a diagnosis of bipolar disorder? The bipolar opposites from criticalness and hostility to over protection by my mother, her desire for me to succeed and invest me with perfectionism to mirror her own reflection and heighten it, made me realise that a more balanced perspective would be needed from her in my own recovery and a change in attitude from myself.

Anger and blame were other subjects, both my own and hers, directed at each other which led me to increase my library on anger management besides dealing

with difficult parents as emotions ranged from guilt to blame and back to guilt for accounting for what had happened. How to no longer be the perfectionist and just be happy being good enough, was another topic for my library and philosophical musings as I sought to clarify what had led to the pressure I seemed to put myself under that had led to my first episode and my second, as this had remained unresolved.

Naturally, the mood recognition and mood management techniques were useful as I coped with a post-manic depression. I needed a structure, a plan, goals and direction and I needed to put this into action without going with the flow of a low mood. I knew that this would worsen it if I did nothing. From blank slate, I established a weekly diary and a sensible bedtime routine.

Into this weekly schedule, I established a healthy lifestyle, incorporating weight management at the local self-help weight group, resulting in a loss of four stone. Twice or thrice weekly vigorous exercise sessions enabled me to work off aggression and get back in touch with my physical self to consolidate the mental recovery. Abstinence from alcohol for one year was included in this as I realised that these 'crutches' of both food and alcohol were both symptomatic of stress and illness and precipitants of further episodes.

Weekly relaxation sessions leading to weekly meditation sessions were incorporated into my diary as were social sessions as I picked up my life again. I also allocated time to my faith, renewed since my second episode and this directed my search for meaning and gave me the courage to examine the close succession of traumatic life events that had happened in the year prior to my first episode and how these had become intermingled with the illness. The making sense of it, the re-arranging of it into some sort of sensible understanding and the grieving over it were all necessary to the moving forward despite, and now almost a decade later, because of it. Post-traumatic shock had

been diagnosed prior to my first episode. The threshold that separates wellness from illness had been crossed and I knew that a line had been drawn over which I must not push myself again if I were to remain well.

Volunteering at the day centre brought me into contact with clients with enduring mental health difficulties. Activities were arranged in groups and it appeared that clients benefited from more than the activity per se, rather their pleasure, their application and their learning were increased through this group activity. The social aspect was an important factor to enhance mood. My 'coming out' to clients and staff alike after one year's voluntary work enabled me to appreciate how stigma and discrimination towards me, through changes in how I was perceived, could be a powerful negative force in an environment that was considered to be more understanding and supportive.

Retraining gave me distance and aided me to adopt a more positive-thinking approach and helped me become more assertive. I realised how negative thoughts could lead to de-motivation and giving in to a low mood and perpetuated negativity. Likewise, positive thoughts could do the reverse. Lack of assertiveness had been an issue that had led to my episodes. It seemed that introverts are less happy than extroverts but this is only mediated by the assertiveness inherent in extroverts, as such this was a skill I could learn. It would also help to avoid a similar situation happening again.

### **From user to researcher: building the training**

As has been noted in the literature review, what is emerging is a commonality of direction towards a more encompassing approach to regaining mental health that is shared between the needs of service users with a diagnosis of a mental health problem and specifically bipolar disorder, the direction of government

policy and professionally-derived integrated psychotherapies to treat this complex illness.

From the perspective of someone with a diagnosis of bipolar disorder, adopting this more comprehensive approach makes sense as it was one that I adopted to recover. Other user-researchers and other service users confirm that a holistic approach to recovery is also one they adopt; whether with or without mental health problems, who just lives one aspect of their lives? We all live our whole lives. As previously mentioned the “In-Sight” user-led group training did not originate in theoretical or therapy research; it originated from having to rebuild my life with and despite the illness but the idea was progressed and refined through a traditional research stance which drew upon current techniques known to be useful in the management of the illness, as too the foundations of recovery were also incorporated.

The name for the training “In-Sight” was chosen as it both represented the professionally-gauged threshold which distinguishes mental health from mental ill health, and it offered participants practical strategies and tools that might enable their recovery from the illness which were within their reach.

The group training takes place over a 12-week period, of three hours each weekly session, with an additional three-hour group follow-up or booster session after four weeks. Here the course is presented as a course, like any other, delivered over one term, requiring regular attendance and commitment to learning.

A place of usual frequentation by clients is chosen (certainly a venue situated at a distance from a hospital environment and one that is conducive to learning) so that participants might integrate and employ these new skills and information into their lives more easily (Repper & Perkins, 2003).

The group format serves multiple purposes: not only does it provide a ready-made social circle for those clients who are isolated, it offers a forum for peer support and feedback and reduces intervention time and cost. (Bauer et al, 1998). The group format encourages recovery values (such as hopefulness, empowerment, self-esteem), promotes the group as an additional social circle outside the weekly sessions and reinforces active problem-centred coping (Corrigan et al, 1999; Rogers et al, 1997; Yanos et al, 2001). The self-help approach within the group format is one that, with the geographical proximity of other group members, it is hoped will continue after the course concludes so as to strengthen and ‘top up’ the knowledge base.

The training is user-led. The therapeutic alliance between the message giver and the message receiver was considered to be stronger through this commonality of experience and sharing of ‘self’ management. Trust considered as more quickly established; the message considered as more relevant given by a person who knows the illness, rather than one who just knows about it. Para-professionals considered just as effective as professionals in delivering training and both self-help and cognitive behavioural techniques considered as equally effective.

Information on medication and the illness are taught and, with reference to previous research indicating improved outcomes for clients who adhere to medication, this is presented as essential. Side-effects are discussed and compared to the disastrous effects of non-medication through motivational interviewing techniques.

Clients are taught to recognize their mood, cognitive and behavioural changes and situate themselves regularly on a Mood-Thoughts-Behaviour scale ranging from -5 for extreme lows through 0 for stability to +5 for extreme highs. The scale displays commonly reported prodromal symptoms for mania and

depression (sleep patterns, appetite/weight changes, activity levels, memory/concentration levels, socialisation, negative/positive thoughts, mood fluctuations). Each participant is encouraged to add to this knowledge base and individualize it to suit their own personal experiences.

Clients explore past stressful events (triggers) and construct a life events chart, combining mood fluctuations from the scale with events. If mood variations establish a pattern, or repetitive triggers are determined, a personal mood signature chart is constructed.

Coping strategies and relapse drills are didactic and evolved from the research in that best coping involving mental health professional contact and medication adjustment is advocated initially, followed by stimulation reduction and monitoring strategies for mania; for depression, behavioural strategies in combination with cognitive strategies are employed after help seeking behaviour.

Participants are taught to record daily their mood and hours slept, negative thoughts and events, their feelings, thoughts and actions connected with these and any resultant outcome or belief together with final mood. These recordings are used in the group sessions to illustrate behaviour-thought-mood association, identify any recurrent or obsessional thoughts and beliefs and as a basis for identifying maladapted coping towards improvement.

Participants are taught to challenge negative thoughts and adopt strategies decreasing environmental and relational stress. Positive thinking and maintaining optimism are also taught. Dealing with underlying anxiety and panic attacks are discussed.

Relaxation techniques - deep breathing, body relaxation and visualisation – are taught. Interpersonal deficits such as anger management, communication and assertiveness techniques are taught. Relationships are considered in relation to a ‘rewards and costs’ structure.

Themes such as past stressful events and grief are covered as participants tend to evoke these in relation to their lives in the present. Issues such as aggression and passivity, over-sensitivity to situations, high standards/perfectionism and relationship difficulties are discussed in the group. Emotional expression in families and its role in relapse are explained.

The necessity for balance and routine in daily living is explained in relation to mood stability. Each client establishes his/her usual ‘sleep quota’ and integrates this into daily routines.

Healthy lifestyle components are taught: healthy weight is determined, basic healthy eating is taught and diet programmes are encouraged to achieve weight loss. The benefits of regular exercise sessions are explained and clients are encouraged to engage in what were previously advocated as three 45-minute sessions of exercise per week, now revised to five 30-minute sessions following health guidelines. Basic physical health monitoring is taught and encouraged.

Participants are taught the importance of a reliable social circle and encouraged to develop theirs if this appears reduced. The importance of self-help group membership is encouraged. Meaningful activities are discussed and participants are encouraged to develop voluntary, leisure or educational opportunities as first steps towards employment opportunities. The importance of safe and comfortable accommodation is discussed. Financial and budgeting considerations are discussed and right to benefits outlined, with applications for

additional benefits supported. Positive support offered by spiritual groups is discussed.

The importance of participants' mental health professional team is outlined with participants encouraged to maintain and/or establish assertive engagement. The dangers of abusing illicit drugs and over-use of alcohol is outlined and the dangers of suicidal thoughts discussed.

Each client chooses a specific goal. Techniques such as weighing up the pros and cons of a situation before deciding to change and goal-planning are taught with the aim of achieving this goal. Problem-solving techniques are taught.

Throughout the training, participants are encouraged to establish a weekly Well-Being Diary (the idea of the 'blank slate') in which elements of the above are incorporated: daily sleep quota, at least three weekly exercise sessions, weekly weight management and healthy eating group, socialization activities, meaningful activity sessions, including integrating steps towards achieving their chosen goal. Each client is given a personal diary or calendar, depending on what they prefer, to continue this after the training concludes.

The training concludes with each participant completing his/her Well-Being Action Plan and Self-Commitment which recaps their learning from stressful life events and symptoms of highs and lows, a check-list for best coping strategies, medication adjustment and healthy lifestyle components that each participant agrees to maintain as their own personal responsibility to themselves in the future. It outlines the nature of the support participants find beneficial in order to achieve best coping and continued stability. Participants are encouraged to share this plan with chosen family, friends and mental health professionals. Each participant is encouraged to complete an Advanced Directive of

acceptable and unacceptable care in the event of becoming unwell and to forward this to their professional team.

During the training, participants have the opportunity to attend a post-session meal each week in a local restaurant. Aimed at improving social skills and as a debrief for each session, it forms the basis for increasing the social circle and developing friendships, besides being a social reward for what has been three hours of study time. Often course material is continued as a basis for discussion and personal difficulties, which would not otherwise have arisen during the group, are highlighted. The informal nature of this period leads to greater group cohesion. A telephone wheel, containing all group members' contact numbers, is circulated and given to each group member to continue this group support in between the group sessions and after these have concluded.

Currently, a publishing house, leader in the field of mental health training and educational materials in the UK, has expressed an interest in publishing the "In-Sight" training.

### **Methodology, Measurement and ViewPoint**

First, came the course content, second came the methodology and how the training would be measured. Volunteering for the Manic Depression Fellowship/The Bipolar Organisation's research project as coordinator helped me construct my own research ideas whilst concurrently training for a Masters in Research Methods. I was building the 'what' of the training, knew the 'why' of it, had a fair idea of the 'what' of the outcomes I hoped would be derived, but the 'how' of doing it, the methodology and approach to take, needed further thought.

Initially, I had hoped to conduct my doctoral research examining the Manic Depression Fellowship's self-management training; however, as an illness management programme, I felt it lacked a more holistic view necessary to rebuild one's life. Rather than trying to establish the smallest effective illness management component to the training, it was the training as an eclectic whole I considered as important for recovery.

Measurement from a purely 'subjective' ie. participant perspective without referral to mental health professionals as to whether these reported states had actually translated into visible positives would not give a rounded view; self-report questionnaires analysed through statistical tests would leave untouched the in-depth qualitative methods that would bring out how the training might be effective, or not, and why, and how far. Intensive courses of two or three days in remote training venues did not appear to be congruent with making the knowledge learned one's own, nor with the time nor on-going support that were needed for issues to settle, be re-integrated and applied in the longer-term.

I decided to incorporate a variety of perspectives to ascertain if change had resulted from participating in the training, and compare these to controls. Self-reported states confirmed through both individual interviews and questionnaires and outward changes as reported by mental health professionals, completed by my understandings of participants' case histories from their medical notes and my own observations to pull the whole of the data together would, for me, point to whether there had been trends in benefit, which ones and how these had come about. Thus the idea of undertaking a rich case study, rounded up by these various perspectives, started to develop as the methodology necessary to evaluate such a comprehensive holistic recovery training.

For me, it was not sufficient for participants to report trends in benefits if these trends were not also confirmed by professionals; nor sufficient that

professionals reported observable changes if participants did not also report or were observed as having experienced trends in positive change. In this way, I felt that if through these different sources, like several spotlights from different viewpoints triangulated on trends in positive change, and compared to the trends in outcome in the non-participatory group, then that would demonstrate promising evidence of effectiveness (or tend to confirm promising evidence of ‘a fact’, as worded by Yin, 1994, p 93). If these trends of positive change were prolonged until the end of the six months study period that would mean the promising evidence of effectiveness was sustained. If, by repeating the main study in a similar way to the pilot study, this would also further establish the trends of promising evidence as to the training’s effectiveness. In addition to method and source triangulation, if an additional researcher verified the data, this too would further demonstrate promising evidence of effectiveness.

### **User or Researcher?**

I believe that we all start with our own experiences of a subject and that these then guide us in how we perceive that subject. Even if we have no personal experience of a subject, or experience derived through others, we have a view on it. Values and beliefs, whether expressed or not, are present in what we do and how we engage with a topic; even deep-rooted, they may possibly develop or change as that topic is explored. Because we do not express our values or beliefs or experiences does not mean that these are absent or have conveniently gone away during the length of a research study.

Recognising and using these values as a sounding board and being mindful of them may actually help to distance oneself, as far as this is ever possible, from the topic under investigation.

Research is research; announcing the user standpoint is merely politeness that otherwise would have to be possibly elucidated by a thorough reading of a researcher's work for this information.

Research undertaken by mental health service users should no longer be viewed as second-class research, assimilated with fluffy qualitative methodologies, but is at the pioneering edge of what is considered as moving the research paradigm, and mental health services, forward. Academic Consumer Researchers offer this unique insight as the “ideal travel guide” between the two cultures of academic research and intimate knowledge of the subject matter.

I refer you to the section on Publications for a more detailed personal view on these issues.

### **3 Methodology**

## **3 Methodology**

### **(A) DESIGN**

The study aimed to determine whether “In-Sight”, the user-led lifestyle development group training for people with bipolar disorder, provided promising evidence of effectiveness in enabling recovery compared to controls. It was considered from the Literature Review and from personal experience of the illness, that theoretically no single therapy was sufficient for recovery and hence an holistic and comprehensive training, user-led, and delivered in a group self-help format would theoretically pool benefits and enhance positive outcomes.

As mentioned in the section on Writing the Training – a Personal View, an overall case study approach was chosen as this afforded a comprehensive research strategy to explore and explain the effectiveness of the multi-faceted group training from many different sources of evidence, data collection methods and researcher perspectives. The holistic study design was therefore chosen to mirror the holistic nature of the training.

Whereas a randomised controlled trial reinforces the medical model, diminishes the voice of the participants and the facilitator and leaves untouched the social, cultural and political context of the research (McLeod, 2001), a case study approach was adopted as it allowed for multiple sources of evidence in a multi-method, converging and triangulating approach, benefiting from these prior theoretical propositions to guide data collection and analysis (Yin, 1994).

The case study approach incorporated two stages: the first exploratory or pilot study (to consider if the training provided promising evidence of effectiveness), the second explanatory or main study (to consider how and why this evidence of effectiveness occurred).

**The exploratory stage/pilot used a quasi-experimental design:**

Self-report measures and participant and mental health professional interviews were taken pre-training, the training intervention of ten weeks duration was delivered, and self-report measures and participant and mental health professional interviews were administered post-training. At six months post-training self-report questionnaires were administered. The exploratory stage had no control group.

**The explanatory stage/main study used an experimental design:**

Self-report measures and participant and mental health professional interviews were taken pre-training, the training intervention of twelve weeks duration was delivered, and self-report questionnaires and participant and mental health professional interviews were taken at both post-training and six months post-training programme. Participants were randomised to either the training group or control group.

Randomisation took place through allocation of numbers to study participants and selection of these numbers from number tables by a third party.

## **(B) STUDY SETTING**

The study setting for the pilot study of this research was a day centre in an urban town providing a therapeutic and social environment for approximately 180 people with a variety of enduring mental health difficulties. The day centre also offered a number of outreach projects.

The researcher had worked at the centre as a volunteer for a number of years prior to undertaking the study.

The day centre was located in the heart of the community, within easy reach of transport and situated at a distance from the local psychiatric unit. Approximately 12 staff were employed. It offered a range of activities from the purely occupational (craft, under 30's, cookery, etc) to the more therapeutic (art & drama therapy, self-development, basic living skills, anxiety management, confidence building, etc). The day centre also served as a drop in for registered clients.

It was chosen as a comfortable and constructive environment for clients to attend the training group. For the main study, a church hall used by the day centre in its activities was chosen to provide an environment conducive to learning which was independent from mental health services.

## **(C) PARTICIPANTS**

### **Inclusion criteria at screening and baseline:**

1/ Study participants with DSM-IV criteria for bipolar disorders were sought (see Appendices for details of mood episodes):

- Bipolar I 296.xx (one or more manic episodes or mixed episodes and one or more major depressive episodes)
- Bipolar II 296.89 (one or more major depressive episodes accompanied by at least one hypomanic episode);
- Cyclothymic disorder 301.13 (chronic, fluctuating mood disturbance involving numerous periods of hypomanic and depressive symptoms insufficient in number, severity, pervasiveness or duration to meet full criteria for either a manic or a major depressive episode)
- Bipolar disorder not otherwise specified 295.80 (disorders with bipolar features not meeting criteria for any specific bipolar disorder).

Where the criteria for bipolar disorders were not directly verified from records, or known to participants, participants were regarded as includable if they were generally consistent with a bipolar condition. The opinion of the treating psychiatrist was then sought to confirm a diagnosis of bipolar disorder.

Where a diagnosis had not been previously recorded for a participant who was regarded as includable, the treating psychiatrist's opinion was not later recorded on the participant's case-notes. This was to ensure against labelling.

2/ Written and fully informed consent was obtained from participants (see Appendices for the Consent Form).

3/ A written commitment to regularly attend the training programme was obtained from participants.

4/ Participants were male or female, 18 years minimum with no maximum age.

**Exclusion criteria at screening and baseline:**

1/ Potential participants were excluded if there was the presence of any major physical illness or disability which would adversely influence their attendance on the training programme (for example, surgery for medical complaints requiring bed rest).

2/ Potential participants were excluded if they had any special precautionary measures against suicidality in their current treatment plan (for example, hospitalisation, restriction of access to medication, extra visits specifically to monitor suicidal status).

3/ Potential participants were excluded if they had a dual diagnosis of learning difficulties.

However, participants were not excluded on the grounds of a co-morbid psychiatric condition (such as a personality disorder, anxiety disorder, panic disorder, alcohol or substance abuse, eating disorder, etc) unless this co-morbidity was the current principal focus of clinical attention.

4/ Potential participants were excluded if they had undertaken prior or were undertaking concurrent self-management interventions for bipolar disorder, unless the researcher judged these to have no impact upon the learning involved in the training or considered them as ineffective.

5/ Potential participants were excluded if they were undertaking other psychotherapies concurrently (for example, cognitive-behavioural therapy, cognitive analytic therapy, psychodynamic psychotherapy, family focused therapy, interpersonal or social rhythm therapy) unless the researcher judged this participation as having no impact upon the learning involved in the training or considered them as ineffective.

### **Ascertainment and sample size for the pilot**

From the total sample frame of clients regularly attending the day centre and outreach projects (180 approximately), 18 were chosen as being diagnosed with bipolar disorder or, on the basis of their current medication (anti-psychotics and mood stabilisers) as having experienced severe mood swings and therefore 'likely' to have the illness.

Over a period of three months, the researcher approached these clients individually to speak about the research work and invited likely participants to attend a forthcoming talk on the illness held at the day centre for all attending clients.

Each day centre worker responsible for each client also approached likely participants to talk over any issues.

The researcher gave a talk on the disorder to all the day centre clients and invited likely participants to attend subsequent group introductory meetings about the research at the day centre. (c.f. Appendices for the Client Introductory Letter).

At these meetings, the clients were given the Client Information Leaflet and Consent form (c.f. Appendices) and were given the opportunity to ask questions about the research. The researcher encouraged the clients to talk over taking part in the research study with their family and friends.

For the pilot study, the participants were asked to commit to following a ten-week self-development training programme. All study participants were informed of the need to complete self-report questionnaires (measuring mood,

coping skills, quality of life and empowerment), to give individual interviews and disclose their medical notes to the researcher. All clients were informed of the need for the researcher to interview their mental health professionals to gain a more objective perspective on any changes following the training. Clients returned the Consent form after having consulted with friends or family and their day centre workers to ensure that the terms of the study were fully understood.

From a sample frame of 18 likely bipolar candidates from day centre attendees, eight individuals attending the day centre chose to take part in the study. All data were collected on all eight participants.

### **Group size**

All activities conducted at the day centre were scheduled and facilitated by day centre workers on a group basis. Whilst optimum group numbers were commonly practiced as being between six and eight participants, one or two groups ran with fewer or greater numbers of clients than this optimum range.

However, more than eight participants in one group led to little input for each group member from the day centre facilitator and often two day centre workers were needed to co-facilitate this larger group; fewer than six participants resulted in a dwindling sense of the 'group' bonding and solidarity between members. Often new groups that were announced but were taken up by fewer than four clients did not take place or groups with decreasing members signalled a diminishing interest in the subject with additional recruitment undertaken to 'fill the slots'.

With eight clients expressing an interest in taking part in the study, and at the pilot stage, with possible attrition during the study, the researcher considered

that the eight clients would constitute an optimum group size, falling in the commonly accepted standards of the day centre and of a similar group size as the other groups in which the clients were also participating. Randomising the interested participants into one group of four trainees and one group of four controls was not considered conducive to the group bonding or sharing of experiences and risked the training group discontinuing due to dwindling numbers.

### **Maintaining the three non-bipolar participants in the pilot study**

Whilst study participants with previously confirmed primary bipolar disorder were sought, out of the eight pilot participants, only five had this diagnosis recorded on their medical notes held at the day centre. Three potential participants who did not have a diagnosis recorded were accepted into the pilot study as likely candidates as having experienced 'severe mood swings'. However, neither their day centre workers nor the participants themselves were aware of their diagnosis.

There was a time lapse between return of the consent forms enabling the researcher to contact participants' mental health professionals and the availability of consultant psychiatrists to confirm the diagnosis of bipolar disorder. When the diagnosis of these three likely candidates was later confirmed as schizoaffective disorder (two participants) and schizophrenia (one participant) with secondary severe mood swings, the group training was advanced its ten-week delivery.

Whilst confirmation of another psychiatric condition prior to commencing the training would have excluded these three non-bipolar participants, the researcher faced a dilemma as to whether they must be excluded at this late stage or maintained in the study.

The researcher decided to maintain these three non-bipolar participants in the study for several reasons (c.f. section on Ethical Considerations).

### **Ascertainment and sample size for the main study**

Similarly to the direct recruitment undertaken by the researcher among the day centre clients for the pilot study, direct recruitment was also undertaken by researcher in a second day centre. The day centre manager assessed approximately 150 attendees for eligibility. The researcher gave a presentation on the research to the day centre clients who had a confirmed or a likely diagnosis of bipolar disorder (14 likely candidates) and held group meetings to discuss details of the study with interested participants. Interested participants were given the Client Information Leaflet and Consent Form and encouraged to discuss taking part in the study with their day centre worker, family and friends before returning the signed Consent Form.

Recruitment for the main study was also proposed and undertaken by mental health professionals who had become involved in the study through giving interviews about their clients participating in the pilot. Consultant psychiatrists had become interested in the study through this direct involvement and were interested in supporting the research through recruitment for the main study.

The researcher had also given a presentation on the research at a Practice Governance meeting that consultants had attended and was attending weekly meetings at the local psychiatric unit so that mental health professionals could be updated on the research as it progressed.

The researcher sent copies of the Client Information Leaflet and Consent Form to interested consultant psychiatrists and community mental health team

managers to inform them of the study. Community mental health team managers informed their staff of the study at a team meeting and as clients were seen by the team staff, or consulted psychiatrists at outpatient appointments, potential participants with a previously confirmed diagnosis of bipolar disorder were told of the study. Approximately twenty were contacted in this way.

When a potential participant was interested in learning more about the study and agreed to have his/her contact details disclosed to the researcher, the researcher forwarded the Client Information Leaflet and Consent Form. The researcher's telephone number was given for any further queries.

Whilst sixteen participants were sought, for two groups of eight trainees and eight controls, fourteen were finally recruited into the main study before the training commenced. The time involved in gaining the final two participants would have meant postponing the training until after the Christmas break, or dividing the training into two parts, one before the holidays and one after which would not have allowed trainees to build up a sufficient knowledge base or group support.

Random allocation using number tables was undertaken by a third party. Eight participants were allocated to the training group, six to the control group.

### **Control group for main study**

The main study incorporated a control group of six confirmed bipolar individuals who were measured at identical time lines of pre-, post- and six months post-training and similarly consented to the researcher accessing data on their situations.

## **Attrition**

All eight pilot participants completed the course and data was collected for all pre-, post- and six months post-course.

All controls continued in the study until the end of the measurement period and data were collected on all controls at these three time lines.

For the main study, eight participants commenced. However, one participant was withdrawn from the study by the researcher due to a primary diagnosis of personality disorder being confirmed and behaviours in the group that disrupted other participants in their learning. Two other main study participants withdrew themselves due to extreme mood swings (one experiencing an acute depression, one a manic high mood).

Data was collected on the remaining five participants pre-, post- and six months post-training.

## **Summary of participant recruitment & follow-up**

### **Pilot study**

180 assessed for eligibility at a 1st day centre
⇒ 18 considered as 'likely' participants by the manager
⇒ 10 refused to take part
⇒ 8 participants recruited

Of 8 participants recruited:
<ul style="list-style-type: none"> <li>⇒ 5 were diagnosed with bipolar disorder</li> <li>⇒ 2 with schizoaffective disorder</li> <li>⇒ 1 with schizophrenia</li> </ul>
All 8 assigned to the training. No controls. No attrition.
All 8 participants followed up at pre-, post- and six months post-course.
Data analysis undertaken for:
<ul style="list-style-type: none"> <li>⇒ the pilot group of 8 participants (5 BDs + 3 non-BDs)</li> <li>⇒ 5 bipolar participants only</li> </ul>

### **Main study**

150 assessed for eligibility at a 2 <sup>nd</sup> day centre
<ul style="list-style-type: none"> <li>⇒ 14 considered as 'likely' participants by the manager</li> <li>⇒ 11 refused to take part</li> <li>⇒ 3 participants recruited</li> </ul>
Concurrently, 20 diagnosed BDs were contacted through professionals
<ul style="list-style-type: none"> <li>⇒ 9 refused to take part</li> <li>⇒ 11 participants recruited</li> </ul>
Total of 14 participants recruited randomly allocated:
<ul style="list-style-type: none"> <li>⇒ 8 to the training</li> <li>⇒ 6 to the control group</li> </ul>

Of 8 in the training group
⇒ 2 withdrew due to mood swings, 1 withdrawn due to disruptive behaviour
Of 6 in the controls – no attrition
All remaining 5 participants and 6 controls followed up at pre-, post- and six months post-course.
Data analysis undertaken for:
⇒ 5 BD training group participants ⇒ 6 BD controls

**Summary of participants' gender and ages**

<b>Total: 19 study Participants</b>		
	<b>Male</b>	<b>Female</b>
Pilot (8)	5	3
Of which Pilot (5 BDs)	3	2
Main (5)	1	4
Controls (6)	2	4
<b>Total:</b>	<b>8</b>	<b>11</b>

Age was not considered as a point of interest and only an exclusion criterion if below 18 years of age. Ages ranged from 24 years to 76 years. There were equal numbers of ‘younger’ and ‘older’ participants divided between the intervention and controls groups. Average age was in the 40s range.

## **(D) PROCEDURE**

### **Writing and delivering the training**

The contents of the training were compiled over several years from the user-researcher’s own experiences of what she had to learn in order to come to terms with having experienced two episodes of bipolar disorder with psychotic features and her desire to move forward with and despite the illness. Current therapies referred to in the Literature Review that had found some success with the illness were also incorporated to establish one holistic group training that was delivered by the user-researcher in a self-help group format (c.f. section on Writing the Training – a Personal View, appendices for the “In-Sight” Course Contents and weekly session material, together with the course manual as a separate appendix).

### **Evaluative Focus Group**

Prior to delivering the training, five bipolar diagnosed individuals were sent a draft training manual and their comments were noted at a focus group. These comments were incorporated into the training so that it became more useful and accessible and the content less sensitive to the participants who would later follow it.

### **Delivery of the training**

The researcher delivered the training to the pilot group, over ten weeks, from September 2003 until December 2003. Pre-course measures were administered in September 2003, post-course in December 2003 and after one session follow-up in January 2004, six months post-training measures administered in May/June 2004. Interviews took place pre- and post-course with participants and mental health professionals.

For the main study, and due to feedback from pilot participants, the training was spread over 12 weekly sessions. It was considered by the pilot group that ten weekly sessions, which included group discussion time on issues relating to the training and their own personal difficulties that they brought each week to the group, were insufficient to cover the course material and encourage the self-help format adequately. Whilst both the training and these group self-help discussions and support were important, the main study group was extended to 12 weeks to ensure that this vital component in the training was not lacking. This was not intended to be action research; however, the training like the methodology, was also being piloted.

Similarly to the pilot study, main study pre-training questionnaires and interviews with participants and mental health professionals took place at similar times of the year, one year later: pre-course measures were undertaken in August/September 2004 and post-course interviews and questionnaires in

December 2004. After one session follow-up in January 2005, in June 2005 six months post-course questionnaires and interviews were undertaken.

The training was of three hours each weekly session held on a day which suited study participants (Tuesday afternoon for the pilot, Saturday morning for the main study). Weekly homework assignments were allocated and regular attendance and commitment to the training were emphasised. At the end of each weekly session, participants were encouraged to attend a meal at a local restaurant, free of charge, to enhance greater group cohesion and social support.

The study participants (focus group, pilot, main study group and controls) were invited to the presentation of the findings of the research Summer 2005 and the study was closed out shortly after this time.

#### **Pilot participant trains as main study group co-facilitator**

The researcher invited one pilot participant to train as a main study group co-trainer and coached this participant to deliver the training prior to the main study delivery in September 2004. (c.f. appendices for recruitment criteria).

Whilst both pilot and main study groups were followed at six months post-training, the co-trainer consented to being followed to 18 months post-training.

The main study group training was delivered by the researcher and co-trainer.

## **Exploratory Phase & Explanatory Phase:**

### **Exploratory Phase: a day centre in an urban town.**

1/ After recruitment, all study clients completed four self-report questionnaires prior to course commencement (c.f. Appendices for Outcome Measures).

2/ The data were then analysed to establish the group baseline.

3/ Informed from the quantitative analysis, the use of in-depth structured interviews pre-training enabled the researcher to explore individual situations and problems faced by participants. (c.f. Appendices for Major Themes covered in the interviews). Participant's mental health professionals were interviewed wherever possible.

4/ The lifestyle development training programme "In-Sight" was delivered by the researcher at the day centre over a period of ten weekly sessions of three hours each.

5/ Immediately after the course, each participant completed the same four self-report questionnaires to identify any significant differences through data analysis.

6/ Within a week following completion of the course, individual interviews were undertaken with each participant post-course to explore if, how and why this programme was useful and any changes in individual situation. Mental health professionals were also interviewed wherever possible.

7/ One month after course completion, a final three-hour follow-up training session was held with participants to review their progress.

8/ Six months after the training had finished, the same four self-report questionnaires were administered to participants and data analysis completed for the pilot study.

Throughout the pilot study, the researcher continued her participant observations in the day centre and outreach projects which all participants attended and at specific times during the six months post-training follow-up.

During the delivery of the training, the medical notes of each pilot participant were read and summarised and informed the study regarding participants' past episodes and general background.

The exploratory stage informed the explanatory stage of the study.

### **Explanatory Phase: a church hall in the urban town.**

Following modifications to delivery of the training spread over 12 weeks, the explanatory phase of the research adopted a similar format, following stages 1/ to 7/, with clients being randomised to either training or control groups. The training programme was delivered by the researcher and co-facilitator, formerly a pilot study participant.

8/ At 6-months post-course, participants completed the four self-report questionnaires. Participants and their mental health professionals also gave interviews.

9/ The co-facilitator completed four self-report questionnaires 18 months post-pilot training and both he and his mental health professional team also gave interviews.

10/ Data analysis of self-report questionnaires and thematic analysis of some 160 texts were undertaken.

The researcher was unable to make participant observations other than those during the training delivery, as the main study did not take place in a day centre.

Documentary analysis of the participants' medical notes, which were read and summarised during delivery of the training, informed the research.

## **(E) REGULATORY CONSIDERATIONS**

The researcher signed an honorary contract with the county NHS Trust as a clinical research fellow (February 2003) and was attributed a line manager also acting as second supervisor to the research project. This was due to the Trust retaining clinical responsibility for its patients taking part in the study and being liable for indemnity in the unlikely outcome of untoward events happening during the study.

Prior to commencing the study, the county NHS Trust's Research and Development Office approved a completed research registration form and study protocol (June 2003, c.f. Appendices). The researcher was considered as leading investigator, with second supervisor as secondary investigator, and academic supervisor as co-investigator.

The county's ethics committee approved the research study in July 2003, and later study protocol amendments in August 2003 (c.f. Appendices for ENHLREC/03-06-18/M109: The effectiveness of a user-led lifestyle development group training intervention for people with bipolar disorder).

The approved Research and Development and Ethics Committee documents were then forwarded to the Strategic Health Authority's Ethics Committee, representing the Primary Care Trusts in the County on ethical matters (August 2003).

These documents were then forwarded to the University ethics committee as having gained approval from the R & D office and NHS Trust's ethics committee. (August 2003).

Submission of certain items to these bodies (for example, Client Information Leaflet and Consent Form – c.f. Appendices) emphasised the need for headed paper that represented more than simply another piece of professionally-led NHS research with usual county Trust logo. The researcher, with permission from the Trust, the University and the voluntary sector charity where the pilot study was carried out, created her own letterhead representative of this collaborative piece of user-led research work, incorporating the two logos of the Trust and the University, and figuring the voluntary sector day centre address for correspondence.

## **(F) ETHICAL CONSIDERATIONS**

### **(i) Sensitive nature of the course emphasises the need for an ‘open door’ policy**

The “In-Sight” training was a personal development course that touched on sensitive and emotionally-charged aspects of participants’ lives, and encouraged them to be as open as they could in reviewing past episodes and long-standing patterns of behaviour in order to move forward. Group discussions also focused on upsetting and stressful week-by-week incidents that participants brought to the group sessions. Group discussions also focused on issues of stigma and discrimination with regards to family, friends and work colleagues and treatment by employers. Suicide and previous attempts were also brought to the group discussions by participants.

The researcher aimed to be as open and as frank about the course content and the personal development as possible in that issues were addressed on a practical, constructive and positive basis. At the beginning of the course, outlined in the ground rules at the start of the first group training session, the researcher emphasised that whilst there were equal shares for all group members in time that they needed in the sessions, they would not be expected to contribute if they were not feeling like doing so. The researcher pointed out that whilst regular commitment to the course was necessary for optimum learning, there would be an ‘open door’ policy, in that participants could leave the training sessions at any time, should they feel uncomfortable, and were welcome to return at any time.

In retrospect, group members did not feel the need to absent themselves from the group in this manner. Rather, group sessions were a time of ‘safe space’ and offloading painful feelings about long-standing issues that participants wanted to share and gain input on from other group members and the researcher. The group was an arena to be vulnerable in, not withdraw from, and feelings were allowed and entirely appropriate to be shown. Two group members cried, three showed anger, one showed intense aggression and three managed psychosis during the course; however all came through this by the end of the course and became more mood stable and settled. When such occurrences took place, the researcher considered that it was not a time to burden with more stigma only an opportunity to deal with the illness as it manifested itself which the researcher reiterated throughout the trainings through a practical and non-judgemental approach (c.f. Findings from the Qualitative Data).

Confidentiality of issues evoked by group members was insisted upon by the researcher, to be broken only in the event of the researcher given cause to think that participants might harm themselves or others. In this case, the participant would be addressed individually, encouraged to practice their coping strategies and seek help from their mental health professional team at the earliest opportunity. The researcher would outline what she would say to the participant’s care-coordinator and her reasons as to why she was breaking this confidentiality rule.

### **(ii) Mood swings were supported**

Participants were allowed into the study regardless of their mood status. Many study participants commenced the group training with a mood swing or experienced a mood swing during the delivery of the group training. However, the researcher decided to maintain these participants in the study as depriving

them from the knowledge base of the training and the support of the group would have done more harm than good.

Closer attention to these participants experiencing mood swings, by drawing on training material to aid them in their management of the illness and a closer exchange with their mental health professionals, ensured that the more acute phase of a mood swing and any suicidal behaviour were successfully managed. Group members were supportive of others who were experiencing mood swings during the training sessions.

As previously mentioned, procedures had been outlined and were in place in the event of participants experiencing mood swings during the study.

**(iii) Three non-bipolar participants were maintained in the study (c.f. section on Participants)**

Three non-bipolar pilot participants were maintained in the study as, in reducing the group from eight to five participants, this would not have resulted in an optimum number for a group. The group training, in a set format, could not have later admitted new participants, even if these had been recruited. Reducing to five participants would not have allowed for later attrition. The group had bonded well and this group bonding included the non-bipolar participants, who appeared to be benefiting from the training. It was considered harmful to deprive them of this benefit at such a late stage and through no fault of their own.

Questioned individually, these three non-bipolar participants confirmed they found the group helpful and wished to continue with the group training. At one group session, the bipolar group members also voiced their wish for the three to be maintained as friendships were developing and group solidarity growing.

The researcher considered that withdrawal from the study would represent further marginalisation through diagnosis of an already socially excluded group, that of people with mental illness.

The researcher pointed out to the three non-bipolar participants that the training might not cover certain aspects that they might find useful although the course would still be applicable to them.

The researcher considered that whilst the training was primarily for bipolar diagnosed individuals, other diagnoses might also benefit from the training given its holistic recovery-oriented nature and that this attendance would serve as a form of comparative, since the pilot study had no control group. Given the reticence of potential participants towards a new piece of health research despite it being user-led, the uptake for the pilot training was poor and prohibited recruiting a control group for the pilot study drawn from the sample frame of 18 bipolar clients attending the same day centre.

Finally, it was considered that within the study setting, it would not be well regarded to deprive clients if they were deriving benefit from the group and wished to continue.

#### **(iv) Withdrawal of one participant with a personality disorder**

However the researcher withdrew one participant from the study (main study group). Data were not collected on this participant.

This participant's diagnosis was initially confirmed by her consultant psychiatrist prior to commencement of the training as being that of a primary bipolar disorder. However, as the course progressed during its third weekly group session, it became evident that this participant's behaviour was

continually disruptive and detracted from the other group members deriving benefit from the course material and the group discussions. The researcher felt out of her depth. The co-facilitator remarked that more attention was needed for this one participant than the rest of the group put together. The researcher felt it necessary to clarify the bipolar diagnosis with the referring consultant psychiatrist and was informed that it was quite possible that the participant had a primary personality disorder and a secondary bipolar disorder, and not the reverse as was initially considered when the participant was referred onto the study.

After full consideration, the researcher decided to withdraw this participant from the study after attempts to encourage appropriate behaviours within a group learning context were not successful, disruption continued and was brought to the attention of the researcher by group members and the co-facilitator.

Withdrawn with tact, the researcher encouraged this individual to follow the training on her own, or with her mental health professional team, who had been given a copy of the training manual. No change of diagnosis was subsequently recorded on this individual's medical notes nor referred to in any correspondence relating to her withdrawal from the study by the researcher.

#### **(v) Controls received a copy of the training manual**

The six participants who constituted the control group in the main study and who kindly provided comparative data were each given a copy of the training manual at the end of the study. It was not possible through time nor funding issues to deliver a separate group training for controls. It was considered appropriate by the researcher, the evaluative focus group and the main study group trainees that a course manual would be a suitable present for their

participation. It was also considered by the main study group that the controls would be able to follow the exercises individually although without the benefit of the group support.

## **(G) OUTCOME MEASURES**

Participants consented to complete questionnaires and give individual interviews before the training started, immediately after the training had finished and six months after the training had finished. They consented to the researcher looking at their medical notes in order to establish an overview of their personal medical context and to inform the researcher's own participant observations throughout the study. They consented to the researcher interviewing their mental health professionals to establish any outward changes.

### **Quantitative data collection methods: self-report questionnaires**

The hypothesis was that participants would show trends of improved coping skills with the illness, and the outcome of improved coping would be improved mood stability. However, further outcomes were that participants would demonstrate promising evidence of feeling more in control and empowered having improved their coping skills and managed their mood, and that the overall result would be promising evidence of a general improvement in their quality of life.

Four scales were considered sufficient to measure these hypothetical outcomes and not too onerous in time that they would not be completed by participants and controls:

### **(1) Mood: Internal State Scale (Bauer et al., 1991)**

Designed as a simple mood state self-report that could be gathered at frequent intervals, the manic and depressive symptoms are tracked independently so that mixed states and depressive symptoms during manic or hypomanic episodes could be measured.

The four subscales cover activation for manic symptoms and correlates with clinician ratings of manic symptoms (Young Mania Rating Scale,  $r = 0.60$ ), depression symptoms which correlates with clinicians' ratings of depression (Hamilton Depression Rating Scale,  $r=0.84$ ), perceived conflict correlates with the Brief Psychiatric Rating Scale ( $r=0.56$ ) and also the Hamilton Depression Scale and Young Mania Rating Scales. Thus these serve as an index of global psychopathology. The index was particularly high with patients with psychotic symptoms.

### **(2) Coping: Brief COPE (Carver, 1997)**

Adapted from an initial 60-item scale, used with breast cancer patients and traumatic events such as the aftermath of Hurricane Andrew, the Brief version was chosen as it incorporated many different facets of coping. It has 28 items, one pair of items per scale. The 14 sub-scales were divided by the researcher into two sub-domains: good and bad coping strategies.

Although the deviser of this scale did not distinguish between good and bad coping, the aim was to give an overview of progress in coping in general, and to assess direction of change. The researcher took into consideration work undertaken by Lam et al. (1997) and Lam (2001) into good and bad coping

strategies usually employed by people with a diagnosis of bipolar disorder, and what the researcher herself considered as helpful behaviours to engage in to cope.

Bad coping strategies included: denial, substance abuse, behavioural disengagement and self-blame (four sub-scales).

Good coping strategies included: self-distraction, active coping, emotional support, instrumental support, venting, positive reframing, planning, humour, acceptance and religion (ten sub-scales)

### **(3) Empowerment: Empowerment Scale (Rogers, Chamberlin, Ellison & Crean, 1997)**

Constructed from what service users and former patients defined as a client and personal perspective of what constitutes empowerment, a 28-item scale incorporating five facets of this construct was chosen (esteem, power, activism, control and anger). One overall score is established from the scale.

This scale was derived from work with leaders of the American self-help movement and validated with participants from six user-run programmes in six different American states. It was validated a second time in further work undertaken on an outpatient population receiving mental health services in South Carolina (Wowra & McCarter, 1999).

However, validation was not verified on people with bipolar disorder, only mental health generic diagnoses. This measurement tool, as defined by mental health service users, was considered the best on offer albeit with further testing on certain populations still remaining to be done.

#### **(4) Quality of life: WHO-QOL BREF (1995, 1996)**

Rather than a model of medicine interested solely in measuring disease, symptoms or disability, this quality of life scale measures an holistic perspective. Defined as an “individual’s perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 1996 p. 3) this scale focuses on a person’s own perceptions of the multi-dimensional nature of their quality of life.

Tested in 15 field centres worldwide, four domains (24 items) are incorporated in the QOL BREF from the original 100 item WHO-QOL 100 scale. These cover physical health, psychological well-being, social relationships and the individual’s environment. Two items for Overall quality of life and general health are additional.

Copies of these four scales can be found in the Appendices.

#### **Qualitative data collection methods: interviews, medical notes and participant observations**

Client Interview schedules were semi-directive and standardised at pre-course (c.f. Appendices).

Post-course and six months post-course these interview schedules became more individualised as dependent upon each participant’s personal context and how they had developed within it.

Mental health professionals also gave interviews to ascertain if and what outward changes or reported changes had been remarked upon. These were also

standardised at pre-course and likewise developed as more individual depending on each of their client's personal context.

Mental health professionals taking part in this study were:

Six consultant psychiatrists

Five day centre workers

Three social workers

Two community psychiatric nurses

One clinical psychologist

One befriending group organiser and

One home support worker

Participant observations and documentary analysis of case files were also supportive and directed interview schedules. Participant observations were recorded as contemporaneous notes after each group session or during telephone calls received from participants.

By incorporating an experimental design employing participant self-report questionnaires, interviews from participants and mental health professionals, user-researcher participant observations and documentary analysis of medical notes within this case study approach, the aim was to achieve a "comprehensive research strategy" (Yin, 1994). This comprehensive strategy resulted in both subjective (i.e. participants') and objective (i.e. mental health professionals') perspectives on any benefits derived from taking part in the training in comparison with controls. This also allowed alternative perspectives to emerge from these different sources of information.

## **(H) ANALYSIS**

Please refer to the Appendices for four self-report questionnaires and interview schedules employed.

Please note that the quantitative data were analysed first, and then the qualitative data, so presentation of findings follow the same manner.

### **Quantitative data methods**

The Software Package for the Social Sciences (SPSS) was used for quantitative data analysis.

From the Nomogram table (Altman, 1982), and by eye, it was estimated that 50 participants in each of the training and control groups would need to complete all pre, post and six months data so as to detect at the 5% significance level with 80% power, assuming a standardised difference of 0.8. This estimate, increased by approximately 25% for possible attrition, was prohibitive in this case study approach conducted by a lone researcher.

The pilot group of eight participants included three non-bipolar participants. Hence, four separate groupings were analysed:

- a pilot group of eight participants (including five bipolars and three non-bipolars)
- a pilot group of five (bipolar) participants on their own
- a main study group of five bipolar participants
- a control group of six bipolar participants.

The researcher considered that analysing the pilot study data as separate from the main study data would serve to replicate possible outcomes.

Analysing the pilot data as two separate groups (with and without the non-bipolars) would clarify whether the study was more beneficial for the bipolar participants than for the non-bipolar participants.

Given the limited study sample, medians and quartiles are reported at pre-course, post-course and post six months course for the above four groupings.

However, and to clarify any potential pattern in findings, pre- and post-course and pre- and six months-post course analyses of participants' and controls' scores were carried out using the within group test Wilcoxon. Findings were purely illustrative and reported as p values of 10% (trends) and 5% (statistical significance).

This study's SPSS raw data and analyses were verified by the University of Hertfordshire's independent research unit at the request of the researcher.

Please refer to the section on Quantitative Findings.

### **Qualitative data methods**

Pre-, post and six months post-course interview data with participants and a wide selection of their mental health professionals informed the study. Participants' medical notes and observations made by the researcher during delivery of the training, during the meal after the weekly training sessions and at the day centre at certain times during the pilot study, together with spontaneous telephone calls from participants to the researcher also informed

the study. This data and method triangulation aimed to establish increased evidence of validity for the findings.

### **Capturing the data**

All participants and controls were interviewed at the day centre by the researcher pre-course. All main study participants were interviewed in person post- and six months post-course and all pilot participants were interviewed in person post-course; however, several controls preferred telephone interviews post- and six months post-course, as they preferred not to leave home to attend for interview as their mood was worsening. Telephone interviews were therefore the only way to capture post- and six months post-course interview data for these controls. All interviews in person were recorded on audiotape with a central microphone enabling good sound quality for researcher questions and participant responses. All audiotaped interviews were transcribed into word documents. Notes were taken during telephone interviews. All interview data and notes were entered into the study database for analysis.

The first training session of the main study group was also tape-recorded using a central microphone to try and capture the group learning process and interaction, following comments made at the progression viva; however a transcription was not made of this training session due to participant responses being stilted and participants commenting on the visible lack of privacy in this 'safe space' environment. Further tape-recordings at group sessions were therefore not pursued as the poor quality of the data collected did not justify its invasiveness and risked inhibiting the group learning process and interaction.

Medical notes for all participants and controls were read and summarised in note form at either the local psychiatric unit or at the community mental health team offices, depending upon where the records were kept. Approximately three to four hours was spent reading and summarising each medical file. During the interviews

with mental health professionals at these places of work, notes were taken and included into the database. One consultant psychiatrist allowed her interviews to be tape-recorded (the consultant who was following P1, the pilot participant who later trained as a co-facilitator). Interviews lasted between 45 and 60 minutes and for each hour of interview, five/six hours of transcription were required. Participant-observations made during the training delivery, or during the post-training meals, were recorded contemporaneously. Intermittent telephone calls received from participants were recorded in note form during the calls.

### **Verifying the analysis**

With a huge database forming, there was a need for an ‘extra pair of hands’ and an advertisement was spotted in the British Psychological Society magazine placed by an honours degree graduate in psychology who was looking for work experience in research in mental health with a view to training as a Doctor in Clinical Psychology. The researcher recruited this assistant for six months to aid in the project with a view to enabling researcher triangulation on any changes experienced by participants following the training, from the perspective of a non-user researcher.

The research assistant familiarised herself with the subject matter by reading through the training manual, many articles on research into bipolar disorder undertaken by clinicians, and articles by service users on recovery and by accompanying the researcher to a conference on bipolar disorder. She listened to a number of pre- and post-course taped interviews. She attended one post-session meal with the main study group to meet the people she was getting to know from the audiotapes and to put faces and gestures to names in a more relaxed environment. She then further familiarised herself with the main study participants by transcribing several tapes of their pre- and post-training interviews.

The research assistant paid particular attention to the data for P1 who was followed for 18 months. The assistant accompanied the researcher to a training day on Nud\*ist software, during which a sample of texts of P1's data were used to learn how to use free coding of important aspects of the text, and then to build up several items that hung together into more important categories, building these up further to establish overarching themes, as these smaller aspects were grouped together to form these larger categories. When the structure was forming with clearer categories of change and smaller sub-categories of change, free coding was transferred into final coding, which later formed the basis and structure of the final model.

The researcher and the assistant then analysed the majority of the data for P1 on their own, thus forming two separate study databases for the project (original pre- and post-course interviews, mental health professional interviews, telephone call data and during course participant observations, post-training meal data, and interview data recorded prior to commencement of the main study training). The analysis was undertaken with a view to clarify what changes, positive or negative, had taken place in P1 since commencing the training, which changes had been reported by mental health professionals, which changes had been reported by the participant, and also to determine if salient main categories appeared, which ones they were.

The analysis was also undertaken with the aim of the researcher and assistant later jointly preparing an interview schedule for P1 that would clarify which changes had occurred or were occurring, in his own personal context, and with a view to preparing to interview P1's consultant psychiatrist to clarify if similar changes had occurred or were on-going from the consultant's perspective. These final interviews were jointly conducted 18 months-post course by both the researcher and the assistant after this collaborative preparation.

After separate data analysis, the researcher and the assistant then met to discuss their analyses of P1's data. From printouts of the sub and main categories, and from further enquiry into the now two project databases and analyses, the main elements of positive change and on-going change could be detected and compared. Looking initially at the main categories, it was possible to detect similarities in emphasis for P1 accorded by both the researcher and the assistant regarding, for example, P1's growing management of mood swings and knowledge of his medication, his growing empowerment and contentment in his life in general, the importance of developing his social group, and his on-going challenges in being more assertive with others and in managing his wheat intolerance.

Initially, the sub-categories were simply considered as units or examples of these main themes; however upon closer inspection, the sub-categories contributing to these main themes (contributory), and the sub-categories resulting from these main themes (resultant), become evident as the researcher and the assistant examined which sub-theme was a contributory factor or a resultant factor, and looked at whether they were indeed isolated categories, or whether these might interlink.

Initially, emphasis was placed quite heavily by the research assistant on the positive change in P1's ability to manage a mood swing per se (illness management appeared to be given a huge category by the assistant), with many and varied examples of this management being incorporated. However, the researcher considered that on top of this main category of 'illness management', there were other (contributing or linking) sub-themes that also contributed indirectly to good mood management or were underlying. For example, the necessity to apply more assertiveness so as to express hitherto undisclosed personal needs to others and so avoid becoming angry with others about these unmet needs, which could disrupt mood (contributory to mood management). Another example was the necessity to manage a wheat intolerance, which had led to sleep disruption and to a mood swing (contributory).

The researcher also considered there were other (resultant) sub-themes that were linked to and derived from improved mood management. For example, increased self-esteem and confidence, growing contentment in life in general and growing empowerment were a result of improved mood management and skills development, rather than simply being isolated categories in themselves. More specifically, these represented the final endpoint of applying the training on a personal developmental level. In discussions with the assistant as to the overview of P1's changes and on-going challenges in his life, the beginnings of the structure of the final model were worked through and given form as the main categories or themes were dissected into greater detail in a collaborative way.

Interview schedules were jointly drawn up between the researcher and the assistant that accorded emphasis to these emerging focal points of interest and to clarify if what the researcher and the assistant had analysed as being positive changes and on-going challenges, whether resultant or contributory, were indeed occurring. Joint interview schedules were undertaken for both P1 and his consultant psychiatrist for their post-18 months interviews and the researcher and assistant conducted these interviews together.

The joint interview with P1's consultant was particularly important, not only to gain her perspective of changes or on-going challenges, but to confirm that such ingrained patterns of behaviour or attitudes could take some considerable time to shift, as a mood disorder had been diagnosed for this participant in his late teens, and that 18 months was a short duration to make a firm conclusion as to what might take several years or a decade before coming to full fruition. It was also important to clarify with the consultant that, as the assistant had emphasised the salience of managing a mood swing per se, whether these other contributory sub-themes were also of importance to mood management. The consultant considered these outside the domain of psychiatry but relevant indirectly to good mood management as the

result was that he was managing his mood much better than before, to the extent that the consultant and the social worker were reviewing the need to support P1 as much as they had previously been doing (c.f. 18 months post-course interview with Dr 2 concerning P1, p 213).

The consultant interview at 18 months post-course was also a time for reflection on the whole study and to discuss overarching personality traits which were emerging as common among all participants: for example, the need to become more assertive, the inability at times to express personal feelings although experiencing a depth of feeling, wanting to be independent but needing approval from others, perfectionism, putting others' needs first before their own, self-criticalness and at times high IQ. This was especially welcomed to inform a dimension to the analysis that would later emerge when all data were analysed although went beyond the purposes of the present analysis in clarifying evidence of effectiveness of the training (see Discussion). It was also a time of exploring how the benefits that participants derived through following the training might be sustained through regular follow-up or booster sessions, which the study was unable to provide, for example through continued regular monthly self-help group meetings.

Findings from the quantitative data represented another form of method triangulation illustrating a possible general trend as to whether the training resulted in benefit for the groups as a whole (the 'group snapshot' or the 'broad brush strokes'); whereas the analysis of qualitative data provided a detailed picture as to if, how and why these benefits took place (the rich detail that would 'fill these brush strokes in').

The qualitative data analysis relied on the theoretical proposition that following the training would result in improved coping for participants, compared to no change with controls. Although pattern-matching was not strictly used as a method of analysis, the researcher commenced from the premise that outcomes

of the hypothetical model could be employed to predict a similar pattern to the outcomes from following the training. In other words, that the predicted increased and variety of different coping strategies as provided by the eclectic training would result in an increase and a variety of different outcomes in coping strategies that trainees would exhibit, report on or be reported on by others either verbally or through their written medical notes.

The NUD\*IST software package was employed for thematic analysis of the texts. One hundred and sixty texts were coded in an open manner according to different topics in the data and how important and meaningful participants considered these topics to be. These themes were grouped together to construct main categories in a more structured way. Memos on areas that each participant might benefit from at pre-course and areas that were observed as having improved at post-course were employed to guide the structure of the emergent outcomes and to guide interview content, as individual interviews become more centred around topics that each participant demonstrated as areas needing development. A vignette for three participants was established and informed the structure of the model (c.f. the Appendices for the vignette for Participant no. 1).

All of one participant's texts were analysed (P1), followed by all the texts for a second participant, and another, until all participants' data were thematically analysed, feeding into the structure of the main categories and model as it was established. Data for controls were analysed after participants' data and incorporated into the categories.

Gradually these emerging outcomes helped to construct a model, with links between the outcomes. This aided to build the explanation of how the training appeared to benefit participants and how these outcomes were intrinsically linked (c.f. Building the Model).

Both pilot and main study data fed into the building up the model. The researcher considered that bringing the data together within one model would serve to strengthen and triangulate the findings thus building a more detailed explanation.

Change in participants over time was noted at post and six months post-course through interviews with participants and mental health professionals. These enduring developments fed into and strengthened the explanation of the model.

The analysis of medical notes enabled some form of chronology to be taken on each participant besides allowing for interpretation of these events by mental health professionals as to what the causes of illness were related to and how treatment might proceed. Mainly to inform the researcher of the background on each participant, one participant's medical notes were returned to during the study (P1) to ascertain whether observations and participant's interview data concurred with that given by the consultant psychiatrist.

This multi-method approach in this case study approach aimed to deduce training outcomes within the context of respondents' lives, providing necessary detail and seeking iterative cohesion between theory and the data. It was considered that these multiple data sources, would feedback back into the theoretical proposition and helped to build and develop the explanatory model regarding the training's usefulness as a tool in the context of people's everyday lives. (cf. Results and the Model).

Please refer to the section on Qualitative Findings.

## **(I) HYPOTHESIS & HYPOTHETICAL MODEL**

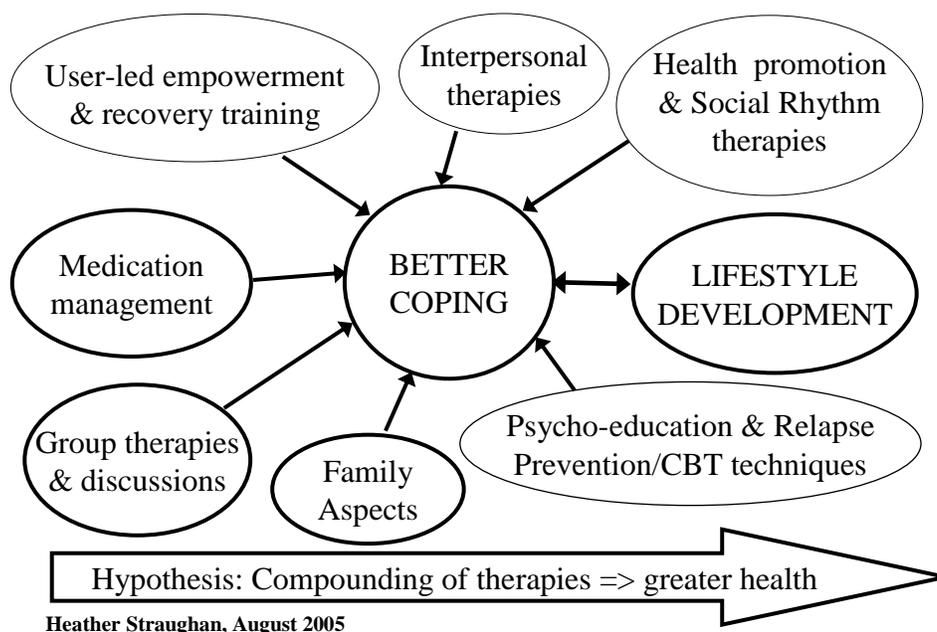
The hypothesis was based on the theoretical supposition that the “In-Sight” training, having drawn from several different therapies and techniques for bipolar disorder and having been conducted in a user-led self-help group format (cf. the hypothetical model), would result in many and various positive outcomes.

(1) The hypothesis was that participating in the “In-Sight” user-led group training would result in improved outcomes in terms of the self-report questionnaires for mood, coping, empowerment and quality of life in comparison with controls.

(2) A secondary hypothesis was that participating in the “In-Sight” training would result in improved general coping skills and lifestyle developments in terms of the textual data within participants’ own individual and specific contexts in comparison with controls.

## HYPOTHETICAL MODEL

### “In-Sight” Lifestyle Development Training for People with BD



It was considered that by drawing from proven professionally-delivered techniques and from recovery, the training situated within a self-help group format delivered by a person with bipolar disorder (the researcher) would optimise the outcomes and lead to greater health for participants.

## **4 Definition of “Coping”**

## **4 DEFINITION OF THE CENTRAL TENET**

### **“COPING”**

As coping is the central tenet of the hypothetical model, I have defined this as the following:

Coping is not just illness management in that the symptoms of bipolar disorder diminish and general functioning improves, as might be observed by a clinician on a Likert-scale measure.

It is about the management of symptoms that lead up to an acute episode and the practice of new ways of behaving and interaction with others that would avoid such an episode.

It is about owning the illness and adopting a certain perspective on the illness that allows these new ways of behaving and interacting with others to become more positive. It is about eliciting changes that encourage this new insight and making sense of the illness and the meaning this has in ones life.

It is about a range of ways of behaving towards the illness that would ensure a healthy lifestyle balance so that recovery from the illness is swifter and stability of mood is ensured for longer periods.

It is about taking a person’s whole life, not just a person’s illness, and enabling them to maximise their skills and perspective to live as full a life as possible. It

is about lifestyle development or personal development to be the best they can be in the circumstances in which they find themselves.

It is about hope of recovery and growth from the illness and self-belief and taking responsibility for oneself. It is about feeling empowered to be able to cope. It is not about standing still, it is about forward movement and development with and despite the illness. It is about connecting with others more positively.

It is about the learning path towards better coping and a learning experience of determining for oneself how best to manage the illness. It is about feeling good about being able to determine ones own life and having a growing mastery of the illness.

It is about how one feels about mastering the illness: sense of achievement, locus of control and psychological well-being to be able to direct ones life with the illness.

In conclusion, from the above definition of coping, it could be likened to how recovery from mental ill health might be defined.

## **5 Findings from Quantitative Data**

## **5 Findings from Quantitative Data**

General Note on analysis:

The pilot group of eight participants included three non-bipolar participants. Hence, two separate groupings were analysed from pilot study data. This resulted in four analyses:

- a pilot group of eight participants (including five bipolars and three non-bipolars)
- from which, a pilot group of five (bipolar) participants on their own
- a main study group of five bipolar participants
- a control group of six bipolar participants.

Extracting the pilot data from the pilot group as a whole and analysing as two separate groups (with and without the non-bipolars) would help to clarify whether the study was more beneficial for the bipolar participants than for the pilot group, of whom two had schizoaffective disorder and one schizophrenia.

Given the limited study sample, medians (to two decimals) and quartiles (25%/75%) are reported at pre-course, post-course and post six months course for the above four groupings. These findings are reported as trends.

However, and to clarify any potential pattern in findings, pre- and post-course and pre- and six months-post course analyses of participants' and controls' scores were carried out (using the within group test Wilcoxon). Findings were

reported as p values of 10% (\*) and 5% (\*\*). Findings of 5% are reported as statistical significance; findings of 10% are reported as trends.

Where direction of findings demonstrated the effect of statistical significance within the groups using Wilcoxon, the Mann-Whitney test was carried out to verify between group differences.

Not all participants were available for every comparison.

As the quantitative data were analysed first, quantitative findings are presented first.

Please refer to the Appendices for samples of each of the four self-report questionnaires used.

## **MOOD - INTERNAL STATE SCALE**

(Bauer, Crits-Christoph, Ball, Dewees, McAllister, Alahi, Cacciola, Whybrow, 1991)

The complex scale has been validated. It has 15 items, plus a 16<sup>th</sup> item as a global bipolar scale indicator. Each item offers a Likert-style choice of 11 circles, set out on a horizontal line, scored from 0 to 100.

There are 4 sub-domains to this scale - activation for manic symptoms (five items), conflict (global psychopathology) (five items), well-being (three items) and depression (two items).

Mood is determined by combining 2 domains (activation and well-being, at cut-off points)

Overall symptom severity is determined by adding 3 domains (conflict, activation and depression) for a total overall score.

## Activation

<b>Domains(Sub Doms)</b>	<b>Pre Course</b>	<b>Pre/Post Course</b>	<b>Pre/Post 6 mths</b>
<b>Activation</b>			
pilot (8 Ps)	55.56 (13.89 - 225)	75 (10 - 185)	50 (10 - 207.50)
pilot (5 BDs only)	55.56 (5.56 - 127.78)	10* (5 - 75)	10 (5 - 155)
main study (5 BDs)	120 (50 - 285)	50 (15 - 150)	40 (25 - 225)
controls (6 BDs)	125 (90 - 190)	80 (22.50 - 200)	145 (37.50 - 305)

(\*) p < 0.10 Wilcoxon - trends

(\*\*) p < 0.05 Wilcoxon – statistical significance

(25% - 75%) Quartile range

The bipolar participants who followed the training demonstrated trends of lower activation after following the course that were maintained at this lower level or decreased further six months later.

The pilot group demonstrated trends of increased activation following the course; however six months later scores had decreased in comparison with pre-course scores.

Controls however showed trends in decreased activation post-course but trends in higher activation in comparison with pre-course levels six months later.

## Well-Being

<b>Domains(Sub Doms)</b>	<b>Pre Course</b>	<b>Pre/Post Course</b>	<b>Pre/Post 6 mths</b>
<b>Well-Being</b>			
pilot (8 Ps)	130 (90 - 192.50)	180* (152.50 -197.50)	125 (30 - 165)
pilot (5 BDs only)	100 (60 - 180)	170* (145 - 190)	110 (15 - 195)
main study (5 BDs)	100 (50 - 175)	230* (145 - 260)	180 (110 - 210)
controls (6 BDs)	110 (87.50 - 162.50)	115 (37.50 - 292.50)	185* (120 - 210)

(*) p < 0.10 Wilcoxon - trends
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(**) p < 0.05 Wilcoxon – statistical significance
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(25% - 75%) Quartile range
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All participants who followed the training demonstrated trends of increased well-being post-course. At six months post-course, well-being reverted to pre-course levels for the pilot group but was maintained at a higher level in comparison with pre-course scores by the bipolar participants.

Controls showed no difference in trends post-course but increased their well-being at six months post-course in comparison with their pre-course scores.

## **Mood**

The following cut-off points were determined by the devisers of this scale Bauer et al. (1991) and are used to determine mood from the two scales of activation and well-being:

Mood State	Activation subscale score	Well-being subscale score
(Hypo)Mania	$\geq 155$	$\geq 125$
Mixed State	$\geq 155$	$< 125$
Euthymia	$< 155$	$\geq 125$
Depression	$< 155$	$< 125$

When these two scales of activation and well-being are taken together, those who followed the training – with trends of higher well-being and trends of lower activation scores after the training and six months later– would tend to move towards a more ‘euthymic’ (or stable) mood.

However, those who did not follow the training – with trends of low activation levels and trends of low well-being post-course and trends of higher activation and trends of increased well-being at six months post-course–would tend to illustrate they have experienced a depressive mood post-course and are verging towards a ‘hypomanic’ or ‘manic’ mood six months later.

It is important to note that all pre-course scores were recorded in September, all post-course scores in December and all six months post-course scores in May/June. Seasonal (Winter/Summer) mood fluctuations might therefore account for trends towards a Winter depressive state and trends towards a

Summer 'hypomanic' or 'manic' mood state in the controls; whereas those having followed the training did not show similar seasonal disturbances.

### Conflict (Global psychopathology)

Domains(Sub Doms)	Pre Course	Pre/Post Course	Pre/Post 6 mths
<b>Conflict</b>			
pilot (8 Ps)	90 (42.50 - 252.50)	20* (0 - 132.50)	50 (0 - 227.50)
pilot (5 BDs only)	50 (30 - 260)	10** (0 - 90)	0 (0 - 165)
main study (5 BDs)	130 (70 - 170)	40** (10 - 75)	40 (25 - 260)
controls (6 BDs)	125 (52.50 - 207.50)	130 (37.50 - 345)	135 (20 - 217.50)

(\*) p < 0.10 Wilcoxon - trends

(\*\*) p < 0.05 Wilcoxon – statistical significance

(25% - 75%) Quartile range

All participants who followed the training showed trends in the reduction of their perceived conflict post-course, with statistical significance of  $p < 0.05$  for the bipolar participants. Six months later, the bipolar participants showed trends of sustained decreased conflict or decreased their conflict levels further; however the pilot group showed trends of increased conflict, although did not revert to pre-course levels.

Controls showed no trends in change in conflict at post-course or six months later although some spread in quartiles was noted indicating that whilst some had decreased their perceived conflict others had increased this.

## Depression

<b>Domains(Sub Doms)</b>	<b>Pre Course</b>	<b>Pre/Post Course</b>	<b>Pre/Post 6 mths</b>
<b>Depression</b>			
pilot (8 Ps)	60 (25 - 107.50)	10 (2.50 - 80)	30 (0 - 90)
pilot (5 BDs only)	60 (30 - 140)	10** (0 - 45)	0 (0 - 70)
main study (5 BDs)	50 (20 - 165)	0* (0 - 75)	20 (15 - 100)
controls (6 BDs)	170 (0 - 140)	150 (0 - 142.50)	120 (7.50 - 105)

(\*)  $p < 0.10$  Wilcoxon - trends

(\*\*)  $p < 0.05$  Wilcoxon – statistical significance

(25% - 75%) Quartile range

All participants who followed the training showed trends in decreased depression scores post-course, with statistical significance noted for the pilot bipolar participants ( $p < 0.05$ ). These low levels of depression showed trends of sustaining six months later.

Controls showed trends of decreased depression scores from pre to post to six months post course.

## Overall symptom severity

<b>DOMAINS(SUB DOMS)</b>	<b>Pre Course</b>	<b>Pre/Post Course</b>	<b>Pre/Post 6 mths</b>
<b>SYMPTOM SEVERITY</b>			
pilot (8 Ps)	200 (120 - 582.50)	150 (27.50 - 292.50)	130 (10 - 547.50)
pilot (5 BDs only)	120 (105 - 495)	50** (15 - 190)	10 (5 - 390)
main study (5 BDs)	480 (145 - 525)	120* (55 - 255)	80 (75 - 585)
controls (6 BDs)	730 (175 - 492.50)	830 (90 - 687.50)	810 (72.50 - 597.50)

(\*) p < 0.10 Wilcoxon - trends

(\*\*) p < 0.05 Wilcoxon – statistical significance

(25% - 75%) Quartile range

Added together, sub-scales for conflict, depression and activation establish the overall symptom severity of a participant.

All participants who followed the training showed trends in the reduction of the overall severity of their symptoms following the training course with statistical significance shown for pilot bipolar participants post-course (p<0.05). This reduction showed trends of being sustained or reducing further at six months post-course.

Controls showed trends of general worsening of their overall symptom severity, although with an indication that whilst some controls improved others worsened.

## **Bipolars and non-bipolars**

The major trends of benefit from following the training course are seen in the bipolar participants.

However, the pilot group, of whom three were non-bipolars, also benefited from having followed the course albeit to a lesser degree: scores for the pilot group did not tend to achieve the trends of improvement immediately post-course or sustain the trends in improvement at six months post-course which were achieved by the main study bipolar group or the bipolar data extracted from the pilot group study.

However, the pilot group showed trends in improvements after the course and six months later, in comparison with controls.

## **Conclusions**

In conclusion, six months after completing the training course, those who followed the training demonstrated trends of a more stable mood, in comparison with controls whose mood demonstrated trends of deterioration, with seasonal fluctuations. Training participants demonstrated trends of a decline in the severity of their symptoms whereas those who did not follow the training demonstrated trends of worsening of their symptoms.

Whilst bipolar participants demonstrated trends of greater improvements following the course, the pilot group, of whom three were non-bipolar participants, also showed trends of improvement, albeit to a lesser degree.

At six months post-training the trends in improvement derived from following the training continued for both bipolar and non-bipolar participants, in comparison with controls.

## **Brief COPE (Carver CS , 1997)**

**(derived from Full COPE: Carver CS, Scheier MF, Weintraub JK, 1989).**

This scale of 14 pairs of items was divided by the researcher into two sub-domains: good (ten pairs of items) and bad (four pairs) coping strategies. Although Carver et al. (1989) did not distinguish between good and bad coping, the researcher aimed to give an overview of general progress in coping and to assess direction of change. As mentioned in the methodology, the researcher took into consideration work undertaken into good and bad coping strategies usually employed by bipolars, and what the researcher herself considered as helpful behaviours.

Good coping strategies included: self-distraction, active coping, emotional support, instrumental support, venting, positive reframing, planning, humour, acceptance and religion.

Bad coping strategies included denial, substance abuse, behavioural disengagement and self-blame.

Overall good and bad coping strategies were calculated together with each of the separate 14 sub-scales.

## Good coping strategies

<b>DOMAINS GOOD COPING</b>	<b>Pre Course</b>	<b>Pre/Post Course</b>	<b>Pre/Post 6 mths</b>
pilot (8 Ps)	51 (37.75 - 55.75)	53.50 (a) (43.25 - 62.75)	45.50* (neg) (b) (27 - 55.50)
pilot (5 BDs)	49 (41.50 - 55.50)	56* (c) (44.50 - 62.50)	39 (d) (29 - 59)
main study (5 BDs)	46 (38.75 - 52.50)	49.50* (e) (x) (46.75 - 59.38)	41 (f) (40.25 - 47.75)
controls (6 BDs)	38 (34.50 - 45.50)	34** (g) (x) (27.50 - 39)	35 (h) (28 - 36.50)

(\* ) p < 0.10 Wilcoxon - trends

(\*\* ) p < 0.05 Wilcoxon – statistical significance

(25% - 75%) Quartile range

(a) *more planning, *acceptance	TRENDS
(b) *less instrumental support	
(c) *more active coping, *planning, **acceptance	
(d) *less instrumental support /*emotional support	
(e) *more positive reframing, *religion, *planning, *acceptance	
(f) *less emotional support/*instrumental support, *less venting	
(g) *less humour	
(h) *less emotional support, *venting, *humour, *positive reframing *more acceptance	
(x) ** between good coping (main group & controls) (Mann-Whitney)	

All participants demonstrated trends in increased use of good coping strategies after following the course. These trends were most noticeable for the bipolar participants post-course. Post-course, participants showed trends in increased use of acceptance and planning, active coping, positive reframing and religion.

Controls statistically significantly reduced their use of good coping strategies post-course ( $p < 0.05$ ) and showed trends of reduced use of humour.

Statistically significantly, using the Mann Whitney test for comparisons between different groups, there was a difference in direction at post-course between the trends in improvement for the main training group in increased good coping strategies, and the trends in the reduction of good coping strategies for controls ( $p < 0.05$ ).

Six months after following the course, median values for participants demonstrated trends that fewer good coping strategies were used compared to those used before the course started, although the spread in scores indicated that whilst some training participants slightly increased or maintained their good coping strategies, others were using fewer of them. Those who took part in the course, six months later demonstrated trends of using less instrumental and emotional support and less venting.

Controls indicated similar trends in the reduction in median values at six months indicating fewer good coping strategies were used in comparison with pre-course scores.

However, there were also trends in the decline in the spread of scores indicating that the control group as a whole was generally using fewer good coping strategies six months later in comparison with pre-course usage.

Controls showed at six months trends that they were using less emotional support, venting, humour and positive reframing but were more accepting.

## Bad coping strategies

<b>DOMAINS BAD COPING</b>	<b>Pre Course</b>	<b>Pre/Post Course</b>	<b>Pre/Post 6 mths</b>
pilot (8 Ps)	11 (10 - 16.25)	8** (i) (8 - 10.75)	9.5 (j) (8 - 15.50)
pilot (5 BDs)	10 (9 - 14.50)	8* (k) (8 - 9)	8 (8 - 14)
main study	13.5 (10.50 - 18.75)	8** (l) (6.50 - 8.75)	11.5 (m) (9.50 - 13.50)
controls (6 Ps)	15 (10.50 - 18)	8** (6.5 - 10.50)	13 (8 - 18.5)

(\*) p < 0.10 Wilcoxon - trends

(\*\*) p < 0.05 Wilcoxon – statistical significance

(25% - 75%) Quartile range

(i) \*\*less substance abuse, \*denial, \*behavioural disengagement \*self blame

(j) \*less substance abuse

(k) \*less behavioural disengagement

(l) \*less behavioural disengagement, \*less denial

(m) \*less substance abuse

TRENDS

Immediately after following the course, the median values for both participants and controls showed trends that they were using fewer bad coping strategies. Main study participants, pilot participants and controls showed statistical significance in reduction of bad coping strategies post-course (p<0.05). Six months later, median values indicated trends that participants and controls increased their use of bad coping strategies; however for participants and controls, these trends did not revert to pre-course usage.

However, the spread of scores for participants indicated trends that six months later participants were still using fewer bad coping strategies as a group as a whole, in comparison with their pre-course usage.

At six months, the spread of scores for controls indicated trends that whilst some participants were using fewer bad coping strategies, some were using just as many bad coping strategies in comparison with their pre-course usage

## **Conclusions**

Following the training, participants demonstrated trends in immediately decreasing their use of bad coping strategies and at six month post-course trends in continuing to use fewer bad coping strategies as a group as a whole, in comparison with pre-course usage.

However, whilst controls also indicated trends in reducing their use of bad coping strategies immediately after the course, six months later some showed trends of using fewer bad coping strategies whilst others maintained their pre-course usage.

Training participants showed trends in increasing their use of good coping strategies post-course, with trends of variability within the group six months later in comparison with pre-course scores.

Controls showed trends in using fewer good coping strategies after the course, with the group as a whole demonstrating trends of continuing to decrease their use of good coping strategies six months later.

## **Empowerment**

**(Sciarappa & Rogers, 1991)**

This scale comprising 28 items gave one overall score for empowerment.

### **Empowerment**

<b>DOMAINS EMPOWERMENT</b>	<b>Pre Course</b>	<b>Pre/Post Course</b>	<b>Pre/Post 6 mths</b>
pilot (8 Ps)	73.5 (68.75 - 82.25)	80 (76.25 - 80.75)	76.5 (69.75 - 83.25)
pilot (5 BDs only)	73 (69.50 - 82.50)	80 (76.50 - 80.50)	78 (70.50 - 88)
main study (5 BDs)	79 (70 - 85)	83** (a) (73 - 89)	81.5 (77 - 84.5)
controls (6 BDs)	76.5 (61.63 - 83.50)	73.5 (a) (54 - 81)	82** (72.63 - 87.50)

(\*)  $p < 0.10$  Wilcoxon - trends

(\*\*)  $p < 0.05$  Wilcoxon – statistical significance

(25% - 75%) Quartile range

(a)  $p < 0.10$  between main group and controls (Mann-Whitney) - trends

All participants who followed the training demonstrated trends in increased empowerment after the course, with the main study group statistically significantly increasing its empowerment ( $p < 0.05$ ). Controls showed trends in decreased empowerment in the same time frame.

This visible change in direction between participants demonstrating trends in increased empowerment and controls demonstrating trends in decreased empowerment immediately after the training also demonstrates a further trend in difference.

At six months post-course, participants showed trends of maintaining this increased empowerment compared to pre-course scores with an indication that the spread of scores of the group as a whole had increased.

At six months post-course, controls statistically increased their empowerment scores compared to before the course ( $p < 0.05$ ), with an indication that the scores of the whole group have increased.

## **Conclusions**

Following the training, participants demonstrated trends of increased empowerment, and sustained increased empowerment at six months post-training.

However, whilst controls demonstrated trends in decreased empowerment post-course, six months post-course there were trends indicating increased empowerment.

## **Putting Mood, Coping and Empowerment together**

Mood state demonstrates trends in fluctuation at post-course (Winter) and six months post-course (Summer) in controls, yet demonstrates trends of stability for training participants.

A statistical ( $p < 0.05$ ) difference between increased good coping post-course for participants compared to reduced good coping post-course for controls may possibly explain resultant fluctuations in mood post-course as good coping declines.

However, at six months post-course these fluctuations are less clear: participants indicated variability in trends in good coping whilst controls indicated trends in reduction in good coping compared to pre-course usage. The trends in reduced use of bad coping, statistically significant for both participants and controls post-course, are evident; however, at six months post-course participants showed trends in sustained reduction of bad coping compared to pre-course scores, whilst controls indicated variability in trends.

Trends in decreased empowerment for controls post-course and the statistical ( $p < 0.05$ ) increase at six months post-course may be due to the same seasonal fluctuations noted in the findings for Mood State and the use of good coping strategies.

Perceptions of empowerment may decline when in a depressive mood (noted in trends for controls post-course taken in December) and may increase indicating a tendency towards a hypomanic or manic mood (noted in trends for controls post six months taken in May/June).

The scale of empowerment on its own may be a valid measure in that it purports to measure the five facets of empowerment as proposed by service users (anger, control, esteem, power and activism), although findings from this study indicate that it may only be a valid indicator when it is also linked to a measure that indicates trends in a concurrently stable or euthymic mood. This inter-relationship between the scales and validity of the Empowerment scale are dealt with in the Discussion.

## QUALITY OF LIFE

(WHO-QOL BREF, 1996) adapted from the WHO-QOL 100 Items scale (1994)

Overall quality of life includes 4 separate domains: physical, psychological, social and environmental.

<b>DOMAINS</b>	<b>Pre Course</b>	<b>Pre/Post Course</b>	<b>Pre/Post 6 mths</b>
<b>OVERALL QOL</b>			
pilot (8 Ps)	54.77 (48.35 - 58.47)	55.45 (52.10 - 58.79)	56.18 (45.42 - 64.24)
pilot (5 BDs only)	54.24 (45.69 - 59.31)	56.40 (52.24 - 60.42)	61.18 (49.89 - 69.68)
main study (5 BDs)	42.92 (38.76 - 51.16)	52.56** (45.72 - 61.28)	54.28** (46.92 - 59.56)
controls (6 BDs)	45.56 (43.04 - 57.88)	49.52 (43.72 - 58.28)	54.32 (43.52 - 62.04)

(\*) p < 0.10 Wilcoxon - trends

(\*\*) p < 0.05 Wilcoxon – statistical significance

(25% - 75%) Quartile range

The bipolar participants who took part in the training demonstrated trends in improved overall quality of life immediately after the course and at six months post-course they continued to demonstrate trends in improved quality of life in comparison with pre-course scores. The main study group demonstrated improvements that were statistically significant at post course and six months post-course (p< 0.05).

The pilot group, within which three non-bipolar participants, showed trends in improved quality of life post-course; however six months later the spread of scores illustrated variability in trends, indicating that whilst some participants in the pilot group appeared to continue to improve their quality of life, others appeared to experience a poorer quality of life compared to pre-course levels.

Controls showed trends in increasing the median value of their quality of life post-course, which is improved further at six months post-course; however, the spread of scores for the group as a whole indicated variability in trends, implying that whilst some controls appeared to improve others appeared to maintain their pre-course levels.

The sub-scales for physical, environmental, social and psychological quality of life that together establish the overall quality of life are reported in the Appendices.

## **6 Findings from Qualitative Data**

## **6 Findings from Qualitative Data**

### **Introduction**

The results of the Nud\*ist analysis of emergent themes showed that participants in comparison with controls provided promising evidence of trends in improving their coping strategies.

These coping strategies drew from a variety of evidence of trends in improved coping techniques which included:

- improved mood management and mood recognition, which were framed within the user-led self-help group format
- these improved mood management techniques increased participants' ability to cope with a mood swing
- improved development of skills
- improvements in a healthier lifestyle and structure
- improvements in intellectual perspective towards coping with the illness and responsibility of self

These coping strategies compounded and resulted in greater mood stability for participants.

This improved mood stability enabled participants to increasingly maintain their well-being and led participants to greater personal development and renegotiating the mental health system in which they found themselves.

These coping strategies in their entirety resulted in participants becoming increasingly empowered, improving their quality of life and outlook on themselves and their future over time.

The following will detail the above areas of interest, illustrated by participants' and mental health professionals' comments.

Non-participating controls showed no such improvements during the study. The majority (four out of six) showed continued unhealthy lifestyles and deterioration with a third of controls (two) experiencing a relapse with psychosis.

The following details illustrate the above themes in greater depth, drawing from participants', controls' and their mental health professionals' interviews pre-, post- and six months post-training, together with excerpts from medical notes and participant observations contemporaneous notes.

Participants p1 - p8 are pilot group members; p9 - p13 are main study group members; c1 - c6 are controls. (p6 - p8 are non-bipolars). Consultant psychiatrists are Drs1 - 6. Social workers, day centre workers, community psychiatric nurses, home support worker and befriending organiser are distinguished.

**A note to the reader:**

Please note that the following testimonies have been carefully selected from the total number of 160 separate texts so that readers might experience for themselves the lived experience of participants in this study through their own words and personal stories. It is the intention that through this "thick description" readers might also be allowed to reach their own "independent

judgement regarding the merits of the analysis” (p 150, Yin, 1994) and be able to follow the conclusions reached in the subsequent sections of this work, notably how these themes establish the Model. The major themes that emerged are underlined in **bold**, sub-themes are in **bold** and participants testimonies in ‘italics’ for easier reading.

## **Findings from the qualitative data**

Part **ONE**: The user-led training within a group format compounded learning and enabled participants to improve their COPING strategies p 132

Part **TWO**: Improved communication led to improved relationships including those with mental health professionals and impacted upon COPING p 141

Part **THREE**: Healthier lifestyle and improved structure impacted upon COPING and helped MAINTAIN WELLNESS p 145

Part **FOUR**: The practice of assertiveness and anger management skills enabled participants to improve their COPING strategies. Addressing past traumas and ingrained patterns of behaviour within group exchanges resulted in more assertiveness and improved COPING p 158

Part **FIVE**: Intellectual challenge of deeply-seated beliefs led to a change of perspective and increased personal responsibility which impacted upon COPING p 169

Part **SIX**: Coping with a mood swing impacted upon COPING and MOOD STABILITY p 174

Part **SEVEN**: Through intellectual challenge and personal responsibility a different 'mind set' was adopted which enabled improved COPING strategies and PERSONAL DEVELOPMENT. p 190

Part **EIGHT**: Outcomes from the combination of a variety of lifestyle improvements resulted in improved outlook on self and the future, greater empowerment and improved quality of life p 196

Part **NINE**: COPING in all its different facets led to MOOD STABILITY and PERSONAL DEVELOPMENT which resulted in renegotiating the 'system' to move forward p 210

## **Findings – Part One**

### **The user-led training within a group format compounded learning and enabled participants to improve their COPING strategies**

**Participants gained knowledge and insight into the illness after following the course. Some participants had lived with the illness for a number of decades; for others they had only recently received a diagnosis. This knowledge helped to exteriorise the problem and was the first step towards accepting the illness and dealing with it. It was also helpful for the family.**

**A consultant illustrates these positive benefits for both the participants and their family in following the course:**

``[p7] had more understanding of the illness as an illness. Attending the course had meant that the 'bogie' isn't the person, it is an illness. p7 maybe felt guilty (whether about himself or about his family), but the course put matters on the table and exteriorised the problem. This was an important step in management of the illness. In a way, the training had calmed down the family. The input had helped p7's family.. It is calming for families that something was happening to a family member. By attending the course, the whole thing is taken very seriously by the family. By attending the course, the family would consider this as a 'serious issue' and it is a ceiling for him, p7, giving credence''.  
(p7: post interview with Consultant 2)

**This knowledge of the illness was situated within a self-help group format of similar others which compounded this learning experience and made it more real and accessible, more meaningful as based on commonality of shared experiences. The group offered additional supportive avenues for learning, whether through sharing in others' experiences and so extending their own personal perspective on how the illness affected them, discussing what had hitherto been an emotionally painful issue to share with others**

**and generally normalising and de-stigmatising the illness. For those who had quite an extensive theoretical understanding of the illness, their knowledge was extended and became more practical and the group format offered what had until that point not been accessible. The wide age range also added to the group learning experience. For some, it was this sharing in others' experiences through group discussions and the social aspect of the group that was key to their own learning over and above the course material.**

**One participant talks about how the course represented the start of her health improving:**

``I did get a lot out of it because that was the start of me getting better ..I honestly think that if I hadn't been there, I don't know what would have happened'' . (p13 6 months post course interview)

**Another participant illustrates how much more enriching the group was than what she had hitherto learned from books:**

``...It was lovely to have loads of different things combined ..and being able to discuss that as well ... kind of leads to seeing where you would apply things much more, than just a ..relatively abstract level''. (p10 six months post interview)

**One participant explains how others' experiences helped:**

``I know I found it useful ..talking to others...You know, there is only so much you can get out of books .. but ... other people's experiences are quite valuable''. (P11 post course interview)

**These benefits of group sharing of experiences were confirmed by his consultant psychiatrist post-course:**

``p11 found attending the In-Sight group to be extremely helpful. Partly because the psychological approach was good and partly because of being involved with people with the same condition. Not professionals, who have the practice but not the sensation of the illness''. (P11 post course interview with Consultant 4)

**In this sharing experience of the group, the user-led aspect of the training emerged as overlapping with the group context and the learning of the course material. The researcher-facilitator was not set apart from this learning experience by participants but included as one of the group who offered guidance, did not judge their illness, was perceived as being genuine and caring, and offering a safe, protective and confidential space in which participants could offload as personal situations cropped up which they needed to share with the group as the training progressed.**

**One participant points to the equal shares and equal participating within the group and the research facilitator who was perceived as a caring individual by the whole group after the course:**

``I have always been able to talk about them (my feelings), so long as I know the person who I am talking to is a genuine person, who's got my welfare at heart, and not some nosey old cretin who wants to know all the ins and the outs of it. Well, we were all there, the eight of us, I think everybody had a good bit to share, and a good bit to offer the group, everybody was very, very ... fair towards everybody else, and it was a good group ... I am very pleased about what has happened, because I know that, from what I can understand, talking to the other members of the group they too share the same ... feelings that I have shared''.(p7 post course)

**Participants often brought their personal problems to the group training and viewed the training as a support beyond the actual course contents taught. One participant illustrates how he both expected and relied on this group support:**

P3 was visibly angry, tired, scowling. ..He said he didn't know if this ``group was doing him any good''. He ..told the group .. his girlfriend of a month had said that she wanted to be friends with her ex-boyfriend and was seeing him that evening. He didn't like that and he didn't know what to do. He asked the group for their help. (p3 - participant observations)

**After the course, this same participant showed that sharing of others' problems within the group had given him an insight into his own problems:**

``It really opened my eyes a bit more, to sort of how other people are feeling as well as me. I felt a bit ..at home you know. I didn't feel uneasy with other people's problems. I understood what other people are going through'' . (p3 post course)

**One participant mentions how he was able to relate others' experiences as they were reflected back on what he had experienced. This made the training within the group self-help format more real and meaningful :**

``..when we said the things we were going though, it actually tied in with things that ..have happened to me in my life'' . (p1 16 months post course)

**One participant indicates that the course material had been perceived within a self-help group context which led participants to take more responsibility for themselves:**

``I mean basically ..it has been a self-help exercise, cos ..people are reasonably intelligent and they can work things out for themselves, but they do need certain guidelines, and this is what you did, guidelines. You don't tell, do this and that and the other, you give them possibilities and people were able to stick to that'' . (P2 post course interview)

**Often this was the first opportunity that trainees had to express and share difficult often painful situations with others, whether these were deep-rooted stemming from childhood or simply day-to-day situations that arose as the course progressed.**

**One participant expresses how is now able to communicate better with others post-course:**

``I have become better at the kind of emotional ... exchange with people, ... I suppose I found it easier to do in a group, that ..I had come to know, ...that you kind of trusted in that way. ... but... actually trying to express ...kind of emotional things which are very personal, and ... are quite difficult to

express with strangers, it became much easier to talk with family and friends about feelings'' . (P11 post course interview)

**Participants were often unable to get to grips with the illness as they lacked the vocabulary and basic skills to understand it. One participant shows how he acquired this insight into the illness:**

``(Before the course) I wouldn't really have been ..aware of my mood ..and .. I couldn't have described it to someone else, as I wasn't really in a position to describe it to myself. I didn't really know what it's place was'' . (p11 post-course)

**Six months later, this participant had acquired an even greater understanding of the illness through taking part in the group:**

``I think it has helped a lot actually. It's been quite helpful for me to meet people with a similar condition and talk about something which is actually quite difficult to talk about. Well, I found it difficult to talk to people about. Partly because the condition gets mixed up in the events in your life and it is hard to untangle those things for example my friends own reaction to my excesses'' . (P11 six months post course)

**For participants, the secure and safe space of similar others was paramount as many dealt with a mood swing during the course which, for some, covered psychosis. The group support and user-led aspect served to strengthen the course learning for participants who were applying their coping strategies to manage the swing. In turn, the course learning strengthened the solidarity of the group as participants dealt with and shared aspects of their coping strategies with others.**

**One participant, who experienced psychosis with an accompanying sudden upsurge from low to high mood, relied on what he had learned during the training in order to manage this swing successfully whilst at the same time relying on the support of the group and positive affirmations from the research-facilitator:**

P2 related the kinds of thoughts he had been having recently (good & evil). I said that he showed an awareness of what was happening. He had contacted his consultant and increased the dose of Risperidone and ..it was slowly beginning to have an effect. He said that his moods were quick to upsurge. I said that his action plan must be reactive in the same deadlines .. he appeared to be doing everything he could (increasing meds, contacting people) that he should congratulate himself for doing this. He felt reassured. I then went through the checklist about going high or low and what steps to follow. Addressing myself to everyone but p2 in particular.

(p2: participant observations during the course)

**Later this same participant recounts how he had not felt stigmatised by his psychotic episode rather he was now better informed and more able to cope from this commonality of experience present in the group. He had successfully coped with his episode and now had a better understanding and perspective on the illness:**

``I've felt strengthened by the course. It is encouraging to meet other people and they have these problems. I think group therapy is good .. you know you learn a lot, having attended a group hearing others' problems you know, you wouldn't normally come across, I think it's detailed knowledge about ..what actually a high is and what a low is, ..detailed knowledge about medication, But its also that knowledge to me is power, so the course gives you more knowledge ..into ..having low .. moods is not an evil thing, its just part of the psychology. It is not a BAD (emphasis) thing. And you don't put any value (judgement) on it. I think the group helped get things into perspective ..people learn from other people's experiences, cos we all have highs, we all have lows. It was a common core of experience there. How you deal with it, people have different strategies ..people can learn what other people do, and that's good''. (P2 post-course)

**Participants often felt that they were the only people with the illness. One participant points to how taking part in the training reminded him that he was not alone in a group of similar others. This participant previously indicated that it was this group sharing that was paramount to his learning and now points to the comfortable environment he had experienced. At the time, he was dealing with hearing voices:**

``It has reaffirmed with me that there is people there who are just the same as I am, and I am just the same as they are ..I feel comfortable here, I know there is always ..understanding people here. And more importantly, there is nobody that is there to hurt me.' ' (P7 post course interview)

**The group also served as a ‘microcosm’ of wider society in that participants used this as a basis for expressing their difficult feelings about the illness and about sensitive aspects of their lives where before this had been impossible. Participants tended to experience strong emotions but were unable to express these. They started to use the group as a social support and made friends within the group. Expressing emotions with others was a sticking point for participants; establishing and maintaining relationships or friendships with others generally equally difficult. Often participants felt isolated due to the illness and due to previous episodes that had left them without a social circle. The group format followed by a meal served as a springboard for creating social ease and increasing this social support. Participants’ confidence in themselves grew as the course progressed.**

**One participant illustrates how the group was able to give her the confidence to express herself whereas before she had not been able to and how this made her feel better about herself:**

``Whereas before I used to go to a group therapy.. support group, I used to find it difficult to speak. I used to find it difficult to say what was on my mind. I used to listen to everybody. But now I’m beginning to say what’s on my mind. I haven’t been able to express myself properly. Whereas in this group you inspired me a certain amount. When people spoke up, it inspired me to speak up. I feel better for being able to express myself'' . (P8 post course interview)

**This was supported by a day centre worker who notes that one participant could now communicate better as his understanding of the illness had deepened:**

``This higher level of communication was maintained despite the mood changes that he had experienced recently. He was able to articulate, before he had difficulty explaining, maybe because he was around people who were going through the same thing as himself. Before he couldn't find the words to explain how he was feeling'' . (P1 post course interview with day centre worker)

**The group formed the basis for establishing social confidence and making friendships which previously had been lost due to recurrent mood swings:**

``I see p3 from the group and ..just being ..more confident about things ...in general now. Knowing that I can ..make friends and that ...I shouldn't have any problem with a swing in the future. I can build my...circle of friends now'' . (P1 post course)

**As the course progressed, participants grew in social confidence and widened their social support network:**

``Attending the group seemed to give p1 more social ties and his increased participation in activities at the day centre. He had effectively widened his social network'' . (P1 day centre worker interview during the course)

**They established friendships and became more involved in activities:**

``p1 had attended the day centre more in the 10 weeks the course had run and had bonded with people from the supper club who also attended the insight group (p6, especially p8 and p3). P1 had also bonded more with p3 who also attended the computer group at the shop. P1 was going to the swimming club weekly'' . (P1 post course interview with day centre worker)

**At the end of the study, this participant had developed his social network into a social group that he had created. This enabled others to develop their social confidence and also gave the participant a wider social circle to combat his own isolation:**

``Well, yeah, I am more confident, I know that by having groups of people, friends and that .. if I am stuck in on me own I can actually phone somebody up, and go out and do something ...So there is support out there ..rather than be on me own'' . (P1 18mths post course)

**This growing social network enabled participants to become more reliant on their friends and less dependent upon mental health professionals. One day centre worker notes that she has now become a secondary support to a trainee's primary support of the friendships he has established in the group:**

''p3 felt very isolated before the group started and ..with the advice of the other members of the group and also with the new friendships ... now he doesn't need to rely on me so much. He can discuss it with his friends and his new social network, instead of looking to me for answers, and I am here, but ..I am in the background, I am a safety net. But, he is confident enough to take control and make his own decisions, and discuss it with his peers and come back and say 'this is what I have decided to do'. So that's ..a big improvement'' . (P3 post course interview with day centre worker)

## **Findings – Part Two**

### **Improved communication led to improved relationships including those with mental health professionals and impacted upon COPING**

**The growing understanding of the illness, improved communication skills and the social ease and friendships made within the group of similar others enabled participants to express themselves outside of the group context. A developing insight into the illness gave them a new vocabulary and helped situate them with regards to the illness. It enabled them to have distance on the subject. It helped them improve their relationships with their mental health professionals as they had new skills to frame how they were feeling, what they were doing and what they wanted. Participants started to become more insightful and independent as their confidence grew. Their relationships with their mental health professionals took a step forward as the nature of the support that they had either relied upon until that time or had previously rejected due to what was perceived as an unhelpful possibly interfering input from mental health professionals became more constructive according to their own developing needs. The therapeutic alliance strengthened and become healthier.**

**As social networks grew, participants become more independent and less reliant on their mental health professional team. One day centre worker illustrates how her relationship with her client has now changed and how this change in relationship has also benefited her:**

**“He is not chewing my ear off. ( Laughter) I think the conversations I have with p3 are more constructive and it is more about how I can help him rather than listening to him get things off his chest and .. not come up with any solutions or answers for himself. Which is great because I feel he is more independent of me, he is more independent**

of the day centre. I wouldn't say he needs less input but it is a different kind of input, and it is two way now, rather than one way ...now .. he is ..making a decision for himself. They (our conversations) have improved, and I feel much more chilled out now'' . (p3 post course interview with day centre worker)

**This developing independence in the relationship between this participant and his day centre worker is illustrated by the worker recognising this and encouraging further independence. The participant takes this opportunity to reaffirm his wish to leave the centre and look for a job:**

``Employment Direct phoned me and asked if p3 was still interested, and ..p3 phoned them back that afternoon and told them that he wanted to take the opportunity .. I thought was excellent, because he did that off his own back'' . (p3 post course interview with day centre worker)

**One participant illustrates how she is now acting more independently in arranging and attending her own consultations:**

``..I find it hard to use the phone, but on saying that, I did do it the other day, and that surprised me. And that was another thing ..I said, ``..I will go to see the consultant by myself'. Because my husband always comes along. I said, 'I can do it, I can get the bus, I can do it'. ..so I did'' . (P13 post course)

**This growing responsibility is noted by a consultant psychiatrist for one participant:**

``He is now owning the illness. He felt optimistic. He takes responsibility for himself. He was able to be open with himself and can own the problem. He had gone through a major psychosis and hadn't understood it before. Now he was owning it and taking stock. He accepted his diagnosis of bipolar disorder'' . (p11-Consultant 4 post course interview)

**This participant illustrates how in the past developing a good therapeutic alliance had been difficult for him:**

``.. when ..I have been hospitalised .. I've never ..come away from the process with any kind of relationship with the .. medical staff .. they call you back .. and ..I am reluctant to go, and when the

opportunity comes not to go again, then I kind of take it really. Although, the consultant I have been seeing .. more recently ..He is doing his best to .. kind of form a relationship with me, and I suppose that's the .. key thing, isn't it? So I think I would have some confidence there ... (P11 post course interview)

**However, for the first time, this participant is able to develop a good therapeutic alliance due to the change in perspective on the illness and the ability to communicate on sensitive subjects:**

``If I'd gone to a psychiatrist at that time (when ill), I don't think I would really have been able to explain very well what was going on .. I think maybe for the first time, I've got .. someone I could relate to and ..trust .. I am quite comfortable, about .. talking to him ..he is quite approachable to me .. and that ..isn't always the case with psychiatrists or whoever .. So .. I am in a better position. I think the course gives me something .. gives me a better vocabulary to talk to him. Those are all things, that .. are incredibly difficult to talk to other people about .. ..to describe a high, or a low, .. I haven't had conversations like that with other people and so ..when I am in the situation, I go along to talk to psychiatrist ..I am actually trying to figure out, what on earth he is talking about ..in order to answer the questions .. Well.. I have kind of gone beyond that'' . (P11 post course interview)

**Six months after the course had finished, this participant is now discharged from secondary services. The participant points to how his growing understanding of the illness enabled him to develop a trusting relationship with his psychiatrist:**

``.. I got on well with him from the start ..I left puzzled sometimes if it's my attitude towards people or their attitude toward me (that has changed) (laughs) '' . (P11 six months post course interview)

**This improvement in therapeutic alliance is noted by one consultant psychiatrist as stemming from a participant's increased ability to manage the illness:**

``I think he is (perceiving himself differently now). I think (a) he thinks he has an illness, and (b) he thinks he's got the .. ability to manage it without devaluing himself ..he hasn't had one of those big dips. ..clearly he's managed his .. illness pretty well ..the quality of managing it has been different .. the whole process has been a more straightforward exercise'' . (p1 18 months post course interview with consultant 2).

## **Findings – Part Three**

### **Healthier lifestyle and improved structure impacted upon COPING and helped MAINTAIN WELLNESS**

**Participants adopted a wide variety of healthy lifestyle habits and a healthier structure to their lives. Healthier lifestyle habits resulted in participants being more relaxed, improving their diet with an aim to reduce weight and taking regular exercise to improve their ‘feel good’ factor. Caffeine and alcohol were considered in moderation; a displacement on alcohol and food reviewed as unhealthy choices when trainees felt they had taken a knock to their self-esteem. Good sleep patterns were adopted. These healthy lifestyle habits pointed towards participants getting ‘fit’ in general and contributing towards greater mood stability. Often adopting these healthy lifestyle habits were adopted as personal goals by participants during the course.**

#### **One participant remarks on how he has changed post course:**

“I am more aware than usual and .. I have got better insight ..” . (P2 post course interview)

**This participant’s social worker notes that he has become more aware of what constitutes a healthier lifestyle. This participant, morbidly obese when the course commenced, later lost four stone in weight:**

“Last month or two conscious preoccupation with dietary and losing weight issues. Would benefit from dietician. Talked about personal trainer. Had joined the sports and games group which was new. Was thinking of joining the weight watchers group. Used to binge on chocolate.” (P2 post course interview with Social worker)

**One participant illustrates her commitment to a healthier lifestyle:**

``I've been trying to get healthy, lose a bit of weight. .. I've lost half a stone.. I've joined a couple of exercise classes. I've been trying to eat things that they say boost your serotonin. I go for a walk in the morning and take the dog for a walk before I go to work'' . (p9 six months post course)

**One trainee, who spoke at a conference on recovery, explains how he continued in his healthy lifestyle long after the course had concluded:**

``Since ..this course I have given up eating microwave dinners and now cook every night and include plenty of vegetables and fruit. I have found that I enjoy cooking and it gives me less time to get bored in the evening. Since finishing the course I have lost 1 1/2 stones'' . (p1 10 months post course: from his speech at the conference on recovery)

**This healthier eating programme is sustained with further benefits at the end of the study:**

``I have actually lost 2 stone in weight ..I eat far better food. I am eating things that I know to be good for me. I eat a lot of beans and pulses .. I eat far more vegetables. I eat more fruit than I used to'' . (p1 18 months post course)

**One participant is aware of how her weight gain is linked to her comfort eating when she has low self-esteem:**

``I have got to learn ..that when I get sort of a few knocks, that my self-esteem might dip a bit, not to sort of comfort eat and things like that'' . (p12 post-course interview)

**This idea of weight linked to self-esteem and self-image is illustrated by another participant who now views exercise more positively:**

``.. I am actually trying to change the amount of exercise I do. I.. have never thought about it in terms of health before really. I can see that, how .. it definitely ..contributes to your own ..self-image'' . (p11 post course interview)

**Six months later, this participant illustrates how he has incorporated regular exercise into his daily life and is working towards this healthy**

**condition he wanted when he later returned to work after following the course:**

``I think I was aware. I tried to get out at lunch time and things. So the walking took me away from the tube. I cycled in today (for the interview). Partly due to digging the garden up. I've been clearing the shed out a bit. Shifting the tandem (to be sold). I used to enjoy cycling ..When I last saw you I was doing some running ..I do go swimming in the summer'' . (p11 six months post-course)

**One participant illustrates her plans to exercise despite her physical difficulties:**

``She ..and her husband had decided to take up Tai Chi together. ..she thought that it was an exercise she could do, having hurt her back some time before and other forms of exercise were not easy for her'' . (notes taken from p4 post-course interview)

**One participant notes how he has restricted his use of alcohol:**

``I am dealing with ..my drink habits, I am definitely cutting back on my consumption of beer ..in fact I may even get to the stage where I might not drink at all'' . (p7 post-course interview)

**Another participant points to her awareness that using alcohol, and previously mentioned comfort eating, is not helpful in dealing with difficult situations:**

``I like ..having a glass of wine, I think there has only been a couple of occasions in the past where I have just tried to blot things out ..and it doesn't work .. I'm not doing anything to excess'' . (p12 post course interview)

**One participant recounts his episode prior to commencing the training and how he would now be more aware of the importance of sleep as symptomatic and in the management of the illness:**

``..when I went high during the summer ..I knew that my thoughts were racing .. that something was not right.. if I got .. to that .. condition I would definitely be thinking ..I need something to knock

me out of it. I need to be able to sleep properly'' .  
(p11 post course interview)

**A community psychiatric nurse comments on how changes towards healthier sleep patterns to deal with a low mood were possible although at times quite difficult:**

''p4's sleep pattern had been a long-standing problem. There had been an improvement since the course, but issues had been discussed before for some years'' . (Community Psychiatric Nurse for p4 post-course interview)

**One participant however points to overcoming this unhealthy sleep pattern when dealing with a low mood:**

''And now I can probably deal with it more, by relaxing, or going out for a walk ..not to go to bed, that was my failing. I just went to bed to shut everything out. When I was really low, and it didn't get better ..I used to get up, feel bad and go back to bed ..it's not the way. Just get up say at eight o'clock and then don't go back to bed, and that is working'' . (P13 post course interview)

**Controls did not benefit from the groups self-help format nor the user-led aspect o of the training. Controls did however report continuing in their current unhealthy lifestyle. This included continuing to abuse alcohol and food, excessive sleeping, not exercising, poor physical health and continued or progressively worsening mood. This was noted as a sign of precipitating a relapse or symptomatic of an impending relapse with the result of deteriorating relationships.**

**C6 is noted by his consultant psychiatrist as having an unhealthy lifestyle and is unmotivated towards changing it during the study period:**

''c6 winds her (his mother) up with the alcohol. The pub - work - sleep is his pattern. He acknowledges this as his pattern but is not motivated to do anything to change it. He goes to the pub every night, drinking 4, 5, 6 pints a night. He can see himself now and the previous strong, alcoholic, raging character. I would be very surprised if c6 doesn't relapse. If the alcohol continues, he will

forget to take his medication. Alcohol and the mania had led to violence and this was a real risk in relapsing'' . (Dr 4 reports 6 months post-course on c6)

**C6 post-course however did not see this unhealthy lifestyle as a problem:**

''Still smoking and drinking, yeah - season to be jolly'' . (c6: post course interview)

**There appears to have been no change from Dr 4's pre course interview concerning C6:**

''If c6 was asked himself, he ..would shrug his shoulders. He would say that his life in not very exciting, boring, it was no fun. He misses the highs and getting plastered every night'' . (c6: pre course interview with Dr 4)

**Another control c4 appears not to have changed her unhealthy lifestyle at the post training period:**

''The only time she relaxed was when she had had a few drinks'' . (c4: notes from post course interview)

**Six months later, c4's preoccupation with alcohol is still evident:**

''I battle a lot with drinking - when I feel very very down or irritable, I feel like a drink. ..I sit at home all week and won't drink but it's always in my head (thinking about drinking). When I'm down, it grips me and I feel as if I've let myself down. I do have to watch it - it seems to be the only thing that takes it away (the low mood)'' . (c4 six months post course interview)

**However, c4's community psychiatric nurse at post course has not registered this alcohol use as a problem:**

''Bit low into new year, off the alcohol (one drink/week). Before had been drinking 1.5 bottles/day. Sleeps all the time. Tired. Really low'' . (c4: post course interview with community psychiatric nurse)

**Another control, c2 post course notes her unhealthy lifestyle:**

''I tried to give up smoking and drinking but didn't succeed'' . (c2: post course interview)

### **C3's social worker at post course notes many lifestyle difficulties still**

#### **evident:**

``Weight - still a worry, talked about dietician but hasn't seen her. Problems with tongue. Is worried because she is a smoker. ..Always excessively overweight'' . (c3 post course interview with social worker)

### **C3 post course interview demonstrates poor physical health and preoccupation with weight but with no structure to make changes:**

``I was going to Weight Watchers with my mum, then I ..missed about three weeks, so ..I have given up on that for the time being. I ..keep getting thrush ..I think I get it when I am run down ..When I am stressed'' . (c3 post course interview)

### **At six months post course, c4 has abandoned exercise:**

``I'm not walking the dogs, no. It's a chore'' .  
(C4 six months post course interview)

### **C4 at her post course interview illustrates how she uses sleep as a refuge from her low mood:**

``The aim when she got up in the morning was how quickly she could get back to bed at night ..Her kids had told her that she always seemed to be in bed'' (c4 post course interview)

**Healthier structures adopted by participants enabled them to achieve balance and routine in their lives and become more organised within their home environments which were often cluttered. Schedules were established so that chores were undertaken and to ensure against inertia during a low mood. Balance and a range of different activities in these schedules enabled participants to ensure against overload and extreme focus which would provoke a mood swing. Regular time out for themselves was incorporated to attenuate stress and breaks and holidays planned.**

**One participant indicates how having a schedule helped him achieve more at home during the day:**

``..I have changed. One of the factors is I have actually drawn up a schedule ..yesterday I cleaned out the kitchen ..another day ..I cleaned out the living room ..another day the bedroom. ..I have actually got each day listed as to what I have to do and that's much better because I tended to flitter away time watching television and not being focussed'' . (p2 Post course Interview)

**One participant speaks of how she is becoming more organised at home caring for her mother with the help of a new cleaner she hired since following the course:**

``p5 now had a cleaner who made a great difference ..She intended to make a New Year's resolution of becoming more organized and more prioritised in her activities'' . (p5 post course interview)

**For one participant, keeping his place tidy led him to undertake new refurbishments and gain more space at home:**

``He was doing his washing regularly, and doing the dishes regularly and trying to keep his place tidy. He had put down new carpet in the lounge and hallway and had started to clear up a lot of mess which had been there for some time. He had now rearranged the furniture and there was more room'' . (p1 18 months post course notes from interview)

**One participant illustrates how she has adopted regular breaks to avoid becoming overtired and in averting a low mood swing:**

``I just think sometimes that life is ..hard and it just ..builds up and I just need to have a break from routine ..Just going away for a few days and I came back and things were in perspective again..'' (p12 six months post course interview)

**One participant is aware that overload is to be balanced with rest so as to avoid a high mood swing:**

``I'll be spending a couple of days with my brother .. to rest and relax ..Being Christmas though there's a lot ...of activities going on .. But I'm not planning any extras ..I'm going to cut back as much as possible'' . (p1 post course interview)

**One participant continues to maintain this healthy balance to his week:**

``I found that actually trying to balance my week and getting some exercise, and doing some studying .. some work, and some social, actually balancing it out does actually help me'' . (p1 12 months post course)

**This balance is noted by his consultant psychiatrist:**

``P1 had taken on board the importance of a lifestyle balance'' . (p1 six months post course interview with Dr 2)

**One participant is also aware that his new work environment is more accommodating to maintaining healthy stress levels:**

``I enjoy the walking as part of it. Also they had a 9.30am start and they were quite comfortable me coming in at 9.30am or 10am. No ..stress me trying to get somewhere at a particular time'' . (p11 six months post course interview)

**Controls seemed aware of certain signs of a mood swing but appeared powerless to do anything about them. They had little structure to their time to enable them to make positive changes or have breaks to offload and became more stressed as the Christmas period drew closer. Often Christmas was perceived as additional stress rather than an enjoyable period. As the study period continued until six months post training, a mood swing or continued deterioration in health became evident for four controls. Of the two remaining controls who maintained their mood stability one was concerned about relapsing and so delayed her personal development plans until her mood had been stable for a longer period; the second's recovery was prolonged as he recovered from a psychotic episode.**

**C2 at her pre course illustrates a fear of relapse which is inhibiting:**

`` I am in a stressful situation of any kind, I tend to start getting a bit depressed, or slightly manic about things. .. I am much more careful about how much pressure I put myself under. And in some ways, that upsets me, because I know I can do a lot more maybe than I am, but I am just concerned that if I push myself too far, I will then end up ..back at square one.''. (c2 pre course interview)

**C3 at post-course demonstrates that false confidence in that she is aware of stressors but powerless to do anything to reduce these:**

``.. I am probably taking on a bit more than I would normally. And therefore I am sort of vulnerable to more sorts of stresses but .. it is more confidence in a way .. and ..Christmas .. this ..rush, rush, rush, to get everything done .... I have not been sleeping very well, ..I need to unwind. I end up going to bed really late. .. I am ..trying to fit everything in ..I had a lot of ..stressful things going on .. it was actually the stress was actually turning it into a bigger thing than what it was. .. when I'm not well or low or beginning to get into a low, I tend to get concerns about my health ..my whole .. body needs ..some pampering ..a proper diet really. ..I am run down. I ..do need time for me. I have just not managed to find it.. Definitely more stressed out, (in comparison with pre-course interview). I haven't got time to think about myself this time of year because I am rushed'' . (c3 post course interview)

**c3 describes her still stressful life six months later and how this had led to an episode:**

``It was not easier, she was flying around everywhere. She must be more organised. She had found relaxation helpful but was not doing it anymore...She did not have time for leisure.. She needed to find the time but couldn't do it at the moment. She had left it too late, and before she knew it, there was anxiety and depression'' (c3 six months post-course interview)

**This trainee's social worker at six month post-course outlines additional stressors yet to come:**

``It is very hard to see what is behind it (the episode). It may be the pressures of her daughter or the course. It is about pressures and achievements. The social worker saw her last week and will see her next week. Looking ahead to Autumn, when c3's daughter went to school, would mean more stress'' . (six months post-course interview with social worker for c3)

**C4 at her post course interview illustrates her lack of structure and her worsening mood:**

“She didn’t have any (structure) to her life. Everything was put off until the next day ..there were 4 Ikea bags of dried laundry waiting to be ironed, but .. said to herself “I should deal with it but it’s just too much to face”. ..She felt she was responsible for everything and not getting the support she needed ..Her husband worked and she felt guilty and angry and wound up. She was feelingless, not excited even about Christmas. Normally at Christmas she would go “yeah great”, now she was like “oh, God”. She was not having Christmas this year, She was not feeling any emotions either way. She was fedup-ish. She had tidied the house so many times. She would rush around and then just pootle about doing nothing in particular. She was tired and sleepy. She had not posted her Christmas cards .. She was doing things all the time but not getting anywhere. Christmas was all the hype and all the WORK (emphasis). It was crazy”. (post course interview with c4)

**At six months post course, after having experienced an episode, c4 is still unable to function:**

“All I do is tidy up, but it is a tip. Nothing seems to get done”. (six months post course interview with c4)

**At post course, c6 has financial difficulties:**

“Credit cards debt of £7,000 on one, loan on the other...Overspending when high. It happens.” (c6 post course interview)

**At six months post course, c6 still has financial problems:**

“Financially I’m coping but not brilliantly. I’m struggling ..(The debts are) still the same. ..I’m behind one month on the mortgage”. (c6 six months post course interview)

**Participants planned ahead for mood stability and in turn this increasing mood stability enabled trainees to secure this stability, maintain their wellness and establish further goals. Planning to maintain mood stability touched on the necessity to communicate personal needs and become more assertive.**

**P1 demonstrates how his initial social isolation and fear of losing friendships due to mood instability has grown into his personal goal of creating a social support group:**

``One of the goals I set myself was to improve my social circle and I have done this by starting up a social group. We currently have about 15 members and I have arranged events... I now feel that if I want to go out and do something I have always got someone to call on to go with and need never be stuck in on my own bored'' . (p1 10 months post course: speech at conference on recovery)

**p1 sets himself another goal a year after completing the course:**

``I have never been one to plan so it is something that I have got to start thinking about ..I could now think about planning for the future ..I'm going to start doing more exercise, and that is what I have set myself this year'' . (p1 14 months post course)

**For p12 post course, the intention is to plan for breaks, away from stressors. This participant previously attested to having coped well with regular holiday breaks:**

``My intention is to have time to myself, and if that means I can't actually get that at home ..then I've got to take myself out for that ..I can actually ..have ..some break from the pressures of work, the pressures at home, and ..I am going to make a conscious effort to ..do that ..on a regular basis, because I have got to ..make that as important as the other things I keep slotting in ..That's my plan, to really do that and stick to it, and .. make myself feel a lot better really'' . (p12 post-course interview)

**Six months post course, p12 has planned to cope better with a low mood at work:**

`` I know ..if I've got a REALLY (emphasis) bad day ..I've got ..my safety net .. I'm still getting up the support within myself and around me for the horrid times'' . (p12: 6 months post course interview)

**p2 plans in case of a sudden high mood swing:**

``..it's also quite a good idea to take a mobile with you, just in case ..Not awfully good with sense of direction, and I think that suddenly depression seems to go completely ... I have been

claustrophobic; I have also had agoraphobia through it, (although) not recently'' . (P2 post course interview)

**p10 post course points to how she has learned about structuring her activities. Interestingly, she mentions p11 who had resisted this scheduling of his activities during the course during one learning session only to later adopt this:**

``I resisted this (structure) for a long time ..p11 was about at the extreme end of where I was .. I am now very, very aware of, and I can see and it is obvious to me now, whereas before it was very hard to acknowledge. So, to look at myself, and go, ``That has to change'', just to make your life easier. ..a lot of these decisions are very, very simple ones to make. It's just that I was twittering around and not making them before hand ....I feel as if I can plan, structure and look to the future, which I don't think to be honest I have ever done before, and, I didn't realise I hadn't been doing it'' . (p10 post course interview)

**Controls however did not generally seem to be able to make plans whether these were short-term goals or major change. They experienced worsening mood which influenced their ability to plan and made the mood worse. They seemed entrenched in the moment which they generally experienced as negative. For those who were able to plan, this was with fear of relapse or undertaking projects which they found hard to be motivated about.**

**At post course, c4 demonstrates how her worsening mood made her unable to plan or think ahead:**

``C4 couldn't go shopping in big supermarkets, but would try to shop with her mother if she was not feeling panicky. She just couldn't trust anyone if there was company. C4 said that she just couldn't plan or make arrangements. C4 said that she might sound like a bore and a misery but they had planned to go on a football holiday ..but the idea of this left her feeling as flat as a pancake'' . (c4 post course interview)

**At six months post course, the consultant psychiatrist for c6 demonstrates the risk that lack of planning might result in:**

``In some ways he is very well, in others he could easily head towards a relapse. He has no goal. He is drifting at the moment'' . (six months post course interview with Dr 4 for c6)

**At post course, even with plans to emigrate, c1 is not enthused:**

``Sometimes he could be doing better ..He still worried about the comfort things. He was not particularly excited about work or in general. For example, his wife discussed the move to Canada saying 'you could be more enthused about it'''. (post course interview with c1)

## **Findings – Part Four**

**The practice of assertiveness and anger management skills enabled participants to improve their COPING strategies. Addressing past traumas and ingrained patterns of behaviour within group exchanges resulted in more assertiveness and improved COPING**

**Achieving this lifestyle balance meant being assertive so that participants did not overload and get tired or become resentful about the situations they found themselves in. Participants found that in some areas of their lives, assertiveness was easier than in other more long-standing patterns of behaving with close relatives, friends or work colleagues. Being assertive and constructive was a way participants successfully managed to put their needs across and respect themselves with regards to demands that others placed on them. During the course, participants brought up past difficult situations or childhood experiences which impacted directly upon how they currently behaved in certain situations, and how these unhealthy past experiences and unhealthy behaviours were influencing their lives and their mood negatively.**

**During the group training, one participant becomes aware of how the guilt resulting from a violent incident whilst in hospital had led to her feeling unable to say “no” to her daughter’s constant demands on her free time some twenty years afterwards:**

**“P4 volunteered that when she was in hospital and her daughter was 7 years old, she had been attacked by a woman .. her daughter had ..been v. upset. Her son ..had not witnessed the attack. P4 linked her wish to help her daughter out by ..doing as much as she could for her, so that it cost her her free time. She had felt v. guilty about not being able to protect her daughter and had ever since tried to make it up to her, by giving her things, by doing a lot for her, much more than for her son. She had**

felt ..a bad mother, and so felt a bit powerless to say 'no' and have her needs and wishes respected. That also her daughter had come to accept that her mother would ..give this huge amount'' . (taken from participant observations week8 of the pilot group)

**After the course, this participant illustrates how she was becoming more assertive with her daughter:**

''p4 had said to her daughter than she preferred to stay at home one day ..rather than go out and that it had made her feel better ..she had said 'no' to her daughter that day, thinking of herself ..She was still left feeling guilty about being responsible for the attack although she knew that she wasn't responsible for the it .. but a bit less guilty (about it)'' . (p4 notes taken from post course interview)

**This new assertiveness was borne out by this participant's community psychiatric nurse who saw it as an important step forward in the participant's own life despite ingrained patterns of behaviour developed over many years:**

''..our conversations have been more ..about what she thinks rather than what she thinks other people's view is .. P4 was more confident and more assertive now ..over the phone she was more assertive with salesmen.. She felt guilty being more assertive, but felt better for having acted that way.. She had been assertive in saying 'no' to doing all the baby sitting for her daughter and she would now have a few more free afternoons ... Her husband was also pleased about this ..She was still ..a bit guilty over not protecting her daughter as well as she would have wanted. But the guilt had reduced a little bit. ..in the new year it would be better as she would have more free time for herself, be able to have more of her own life ..do more socially, get around more and that would help with her agoraphobia'' . (p4 post course interview with community psychiatric nurse)

**One participant, whose mother had bipolar disorder, had issues of assertiveness that were widespread but centred around her misplaced feelings of responsibility for her mother and making things right for her. This participant describes her experiences of childhood and with relief how she now no longer feels trapped by refusing to take on that responsibility:**

``..all through the course ..it kept hitting me .. all I could see was `that was my Mum'. .. it made sense of.. some of the outlandish things she did ..it's like I was just being told really my life, through these symptoms of what she was like ..I didn't feel that I have got to keep making it right, because I will never make it right for her .. I was in a trap ..until I realised that there was a way out of it, that I didn't have to keep being responsible for her .. it was a relief, it was also quite a shock to think I can live my life .. without worrying what she is going to do from one minute to the next.. I have done ..it the old way and it's not actually done me much good at all, so now, I have got to do it this way. And, just leave it up to them, ..so that's really a change'' . (p12 post course interview)

**This participant, six months later, describes how she is now behaving differently towards her mother. In no longer taking responsibility for her mother, and by being more assertive in her relationship with her, this participant is able to gain the most from the her relationships with both her father and mother:**

``..I had to initiate any kind of conversation. .. She'd shut down. .. She's in the big sulk and ..I just thought well it's her choice ... she's ..the victim in that corner and there's nothing I can do. .. it's a very long-standing thing of always thinking that my Mum's in between us ..always has been. (pause) And now I'm thinking, oh I miss my Dad. I ring up... and if she's nice, she's nice. If she's not... my Dad will still talk and we'll have a reasonable conversation and he loves it. .. (I've re-established my relationship with my Dad but) There's nothing... I can ever do to make the world right for Mum...she has got to take responsibility for herself. .. I do (feel better). ..I think I learned that a lot from all the discussions I had with you in the group because there was a lot of that to come out but I hadn't been able to express it and get some sort of sounding board of how to handle it. Cos you can't make everything right all the time, can you? ..I think that's taken off a lot of pressure off me because I think I just felt that I've got to keep rescuing them.. but I can't cos I need rescuing sometimes (laughs). Just rescue.. myself'' (p12 6mths post course interview)

**This participant's consultant psychiatrist, in writing to the participant's general practitioner, supports how this feeling of responsibility had played**

**such an important part in her childhood and had resulted in both her father and the trainee trying to keep the peace in a subservient way:**

``The Saturday bipolar disorder support group has helped her articulate her feelings and feel more in control of her mood disorder. Even though she has suffered from depressions all her adult life, her one off hypomania led to the diagnosis of bipolar illness and she was therefore recruited into the group. What she has found so helpful in the group is gauging her own moods and developing coping strategies to help with her tendency to withdraw. She has also talked a great deal more about her mother .. I realized to what extent her childhood had been damaged by her mother's illness... her mothers' illness had huge influence upon her, as she was in and out of hospital a lot, and much of the time seemed peculiar and deluded. Her father had been encouraged not to challenge her mothers' delusional beliefs, and much time was spent trying to keep the peace and giving into her needs. P12 felt trapped, like in a spider's web, and it was difficult to bring home friends because her mother was so peculiar.. .currently she is quite well'' (taken from a letter written from p12's consultant psychiatrist to her GP, post course)

**The same participant indicates how her newfound assertiveness and expression of feelings have had a positive impact upon her long-standing friendships in which, like that with her mother, she no longer feels trapped as she can express her needs and boundaries:**

``..when she let me down again, I really thought I'd had enough of it but I was scared to say ..you're not really being fair ..I had another friend help me with the wording of ..it and to my surprise she ..said, yeah .. I was really out of order ..I was very relieved and then really pleased that I'd actually gone down that path. Otherwise in the end I would have just felt resentful and hurt and thinking I'm trapped yet again'' . (p12 six months post course interview)

**This participant's assertiveness is illustrated by her no longer taking unreasonable responsibility for her grown children's affairs so that they now learn to take on this responsibility themselves. Managing in this new way enabled this participant to have more of a life for herself that was not driven by her roles as subservient daughter or mother, friend or neighbour:**

``I'm still leaving things basically (laughs). And being going away is a good thing because when we've come back they have had to wash up and stuff like that. So we've said .. just because we're back, carry on. ..Before I went away ..there's so much ironing ..I'm just not going to stand here ..ironing ... I just have to shut myself off from stuff like that now. I ..see it and I think, 'no' it's there, its just STUFF (emphasis). I can walk through. It's not my stuff. It's all our home. That's all our responsibility'' . (P12 six months post course interview)

**One participant illustrates how his assertiveness has helped him put up boundaries so that he can ensure he rests and avoids a resultant mood swing:**

``I quite often I get a girlfriend or p3 wanting me to go out, and I just have to say ``No, I am having a night in''. .. I just stick to .. what I have decided to do, 'cos I know that I need the rest'' . (p1 18 months post course interview)

**This participant demonstrates how his boundaries and assertiveness have improved greatly when dealing with demanding and persistent friends:**

``..he has begun to realise that I won't just say yes ..he ..wanted to go to his Mum's at Christmas. ..And ..I said, ``well, I am sorry, but I am busy on the 18th'' ..And he said, ``Oh well, I will have to ..have beans on toast at home, stay in on my own''. So I asked him why he couldn't go on the bus, ``oh, well, my case is too heavy''. And I said well, you know, ``that is not my problem''. (Laughter) ..He said, ``so you are gonna take me?'' .. And I said, ``Well, no, the conversation is finished p3, ..I have given you my answer''. ..he phoned me back and another friend is going to take him, but it is going to cost him 25 quid .. and he said it was all my fault, and I all I said was, ``Oh, that's good, you have got it sorted'' . (p1 18 months post course)

**This growing assertiveness is borne out by this participant's befriending group organiser who points to improved coping skills because of this:**

``Better boundaries ..he has been empowered to get what he wants, e.g. job or social group. (His coping) had improved by 30 to 40% - he now takes a step back and thinks before saying. He copes by taking time out. He has self-restraint, especially with boundaries and therefore he is quite well'' . (p1 befriending organizer 18 months post course)

**The day centre worker demonstrates how one participant is becoming more assertive as a gradual process and that this is linked to his reducing fear of taking control over his life as he negotiates leaving the day centre:**

``..it ..ended with him stopping all of his groups entirely at the day centre with the agreement that he could drop in for a chat... I am quite happy because that is a step forward ..before ..it was what I wanted for him and not what he wanted for him. I think he has certainly got the right idea. I think he is assertive ....If you give him some time to think about it, he can be very mature in his response to you .. There has been a lot of change for him (during the course) .. He developed new friendships, he is in a relationship, he has dropped his groups at the day centre, and moved on. ..I certainly feel p3 is more independent of me. Whereas before he would phone up and say, ``I don't know what to do''. He is ..phoning me up and telling me what he is going to do''. (p3 post course interview with day centre worker)

**One participant demonstrates her growing assertiveness in her new job in the field of mental health quite succinctly:**

``I am a lot more assertive at work. I don't take any shit (laughs) anymore. That could translate to other areas (of my life)'' . (P10 six months post course interview)

**Participants who found anger a difficult emotion to manage were able to relax more and deal with their anger more assertively and constructively. This represented a turn around and a choice of behaviour that they had hitherto not been able to access. Anger surfaced in times of low mood and represented past situations that remained unresolved fuelling an on going angry perspective or scowling view on the world.**

**One participant demonstrates how she was able to express her anger with her mother and sister whereas before she had always adhered to their standards and their ways of behaving without being able to communicate how she felt:**

``..I just thought .. I don't want to do this anymore .. if people are going to say stuff to me .. they should know how I feel about it .. because in the end

they have had the balls to say what they have said ... my mum has always made me feel as if I am extremely aggressive ...I now realise it's not ..where anyone places the line, except my mother .. ..I have had several instances where I have just said, "Look, I am sorry, I am annoyed about that" .. the emotional confidence now is there .. it just fed into ..a new sense of .. I am kind of worth it .. and acknowledging the fact that that is what my parents think, because ..I hadn't got to that stage at all .. I really had no ..real true grasp on what had really happened over the ..development process. And what all that kind of stuff could lead to .. the course was kind of a practical evaluation of that, and to bring it forward". (P10 six mths post course interview)

**One participant recounts how she coped with her anger in a new way and expressed herself assertively with regards to an employee at work:**

"Well I got a bit angry to myself with this bloke ..Cos he's supposed to do some of my job ..but ..he's just.. playing games on the computer ..Anyway I thought ..I'll just pretend I'm going for a fag break ..and this is a.. unusual thing. I don't NORMALLY (emphasis) do this. This is the first time I've ever done it. I went out of the building ..for a walk.. and come back. And he was still doing it .. (so) ..I went to the loo (laughs) and he was still doing it (laughs). Anyway I ..said to him, "oh you're supposed to be helping me with this"...I said "it's alright for some, sitting there playing computer games. I've got to do it all". He said, "oh what have I got to do?" Oh, I says "are you taking the piss"? ..And the other day he asked me what he had to do but it was just to waste a bit of time, cos he was going home ..he'd packed all up. And I was busy but I thought oh well, I'd show him while he's keen ..Anyway he said to me, "oh I'm not going to rush into it".. ..he says, "what have I got to do?" Oh I said, "I showed you the other day", I said. "I ain't showing you again what to do" (laughs). I said "you said you didn't want to rush into it, if you'd done them straight away, like I said, you would have known what you were doing by now. Now I've got to show you again".., so he knew I was annoyed with him (laughs). No (I didn't get angry) I didn't shout or anything. Anyway he started to do them and I give him the whole tray (loud laugh) .. and he kept asking me and I said "do you know what you're doing"? He says "no" ..so I showed him a few. He said, "oh I'll do the rest of these now then", he said, "so I'll know what I'm doing" (laughs). So I thought ..I hope that hasn't made it awkward ..But he was alright.. (laughs)..

and I felt guilty ..even this morning I was laying in the bath thinking about ..what I said to him (giggles)... I'm not really his boss or anything but it annoys me when he's supposed to be doing it with me... And he's doing.. fuck all (laughs)'' . (P9 six months post course interview)

**This participant's consultant considers that there are improvements; however he is apparently unaware of the new skills that this participant previously lacked but is now practising in her work environment:**

``Regarding assertiveness, the impression I have with her job is that she is unable to assert herself ...because there weren't enough skills there. She doesn't seem to have a repertoire of behaviours. With regards to psychiatry, she is a whole lot better. She is more measured, more focussed, more able to tackle issues. She is not splurging out her anxiety on 13 different things at once. She is more organised, not in a fragmented or worried way'' . (P9 six months post course interview with consultant 5)

**One participant demonstrates his change in perspective recounting an incident that would previously have made him angry and physically aggressive but now he feels calmer and more assertive in managing his anger:**

``I was angry at a lot of things ... it was just making me feel like crap ..now, I just feel relaxed about things .. I feel calm.. I am a bit more patient with other people. .. (certain) things ..I just ignore now'' . (P3 post course interview)

**This participant's day centre worker demonstrates how he is better at managing his anger and his moods:**

``He used to have frequent angry outbursts when he would get very upset with people and he would make threats, or say he was feeling threatened ..we haven't had any of that ..generally, his mood has improved a great deal ..he is obviously managing his mood better than before. He is certainly picking up and recognising things'' . (P3 post course day centre worker)

**The day centre worker illustrates how this participant is now able to manage his anger in his relationship with a particular friendship on his own:**

``..he is obviously managing his anger a lot better .. he could and he would hold onto that for several days, and he wouldn't let that go. So .. I think he is more in control now. I think he feels more in control ..and I don't think he is as frightened as he was (before) to take control'' . (p3 post course interview with day centre worker)

**Controls however showed worsening mood and worsening anger.**

**Accompanied by an on-going alcohol problem and difficulty in communicating, this started to point to a relapse or was indicative of an impending relapse with potential for aggression and violence.**

**At post course, c4 demonstrates her growing irritability in comparison with her pre-course interview:**

``.. her mood never changes. She often had a right moan at everyone when she was in a bad mood and couldn't give a monkeys. Everyone is too hard work. It was too hard work to keep people happy, so why bother?'' . (c4 post course interview)

**At six months post course, c4 illustrates increasing aggression towards others in comparison with her post course interview:**

``I sometimes feel ..aggressive and very very irritable and intolerant. And it seems to be worsening. When I feel irritable and fed up, I am not very particularly a nice person to be around and I feel it is getting worse'' . (six months post course interview with c4)

**At six months post course, c6 demonstrates his reduced anger due to the last year spent in therapy:**

``I try not to bite back at people. The problem was that I didn't like myself and had faults in the way I perceived others. Maybe it is (me) coming down... It's been about the last year I've had therapy ..It has not inconvenienced me. It is not a great plus, but someone else to talk to, who doesn't know me ..I don't like talking too much to others'' . (c6 six months post course interview)

**C4's consultant psychiatrist demonstrates at six months post course the worsening mood and the increasing difficulty to manage the accompanying anger:**

``c4 came with an appointment because her community psychiatric nurse was worried. There was a lack of motivation, agitation and anger. C4 was scared of the illness and crying a lot. This state had worsened since the new year. C4 was preoccupied with relationship issues. She had ups and downs but could not hold onto the anger because she wasn't well and had to stay away (from people). She was really quite depressed'' . (six months post course interview with Dr 2 on c4)

**For c4 this angry depressed state was due to her inability to express how she was feeling to her husband:**

``In the new year .. there was a review. C4 said she was hiding her feelings although was quite depressed because didn't want to upset her husband. It was about ..the relationship between her and her husband'' . (six months post course interview with Dr 2 on c4)

**At six months post course, c6's consultant psychiatrist demonstrates diminished but on-going anger and risk of relapse:**

``C6 describes himself as 'no rage in me'. He has had the stuffing knocked out of him, but feeling flat. ..Dr 4 read from the notes: some apathy, no rage. ..He can see himself now and the previous strong, alcoholic, raging character. (later) I would be very surprised if c4 doesn't relapse, if the alcohol continues, he will forget to take his medication ..the alcohol and the mania had led to violence and that this was a real risk in relapsing'' . (six months post course interview with Dr 4 on c6)

## **Findings – Part Five**

### **Intellectual challenge of deeply-seated beliefs led to a change of perspective and increased personal responsibility which impacted upon COPING**

The group was also very much an active learning ground with participants having certain things confirmed for them, reinforcing previous learning or the focus of previously held unhealthy ways of behaving that the training and the researcher-facilitator now challenged. When long-standing patterns of behaviour or deep-seated beliefs emanating from childhood were challenged, discussions raised a number of issues which the course and the group addressed. In times of challenge, the researcher-facilitator and later the co-facilitator reaffirmed the positive effects of the course. The researcher-facilitator, rather than being a member of the group, now stood outside the group to establish authority, maintain discipline and continue group learning. The course advocated medication to stabilise mood swings; however the greater message was one of personal responsibility and personal choices to stay well and in times of a mood swing. These on-going course discussions and debates pointed to a challenge of accepted ways of behaving by participants and what would later develop into their adoption of a different perspective on the illness and how they would later come to view their lives with the illness and coping with it more positively. At the time however these ‘learning exchanges’ which challenged participants’ beliefs and rigid ways of behaving could be quite heated.

One participant (p11) demonstrates this process of learning through his development during the training and at subsequent interviews with p11 and his consultant psychiatrist (Consultant 4). This learning session

**indicates, as with the majority of participants, that a number of issues are apparent in his resistance to change:**

``P11 appeared not to want to change and was challenging the training and perceptions of the trainers and other group member .. he didn't see the point of doing the exercise ..as this did not fit into his life. ..he was not taking medication, which p12 immediately supported the usefulness of ...he found a weekly structure too restrictive ..P12 supported this and spoke of pacing herself and how medication had helped her ..P11 denied that he had said that he had not found the diary exercise useful ..the co-facilitator .. said that that was what he had said. .He said that he did do things, but that a weekly diary was not how he viewed things ...He left it to the last minute to do things and then rushed to get things done ..because he did not engage in things with enough time, he felt guilty about his free time and enjoyed this less. I said I .. did not want to present myself as a sergeant major, but that these techniques were useful tools, that if they found their mood swinging, they might hate me, but would be glad of these when they needed them most .. that it was his choice and his responsibility for himself that was an important part of the course .. It seemed as if P11 was the outsider ..and still he found counter-arguments as to why he would be OK to continue in his own way ..if he mulled this over, he might see that he might make some positive changes to his situation, but that we would continue with the exercise for all the group. (Taken from contemporaneous notes made immediately following training group session five)

**This participant, who had experienced depression since childhood, later illustrates how his long-standing lack of motivation due to comparing himself with others' high standards was a self-defeating negative spiral:**

``I've .. struggled throughout my life ..to want to be motivated in doing things .. But can you see the negative feedback you'd get if ..you're ..poorly motivated .. you don't do so well .. but then you are still judging yourself against other people's standards..? You fall into a .. loop there .. I have been trying to do the arrangement with myself, whereby ..to get up and go running, and to do things like that'' . (p11 Post course Interview)

**This participant changed his perception of how useful the learning had been as he now realised how his self-defeating negative thoughts due to**

**these high standards had inhibited him in planning to engage in activities.**

**As he stated at the post course interview:**

``The mood chart that you showed early on was .. very helpful, .. because, before.... I actually had quite a lot of difficulty understanding what the question was about. .. now ..it's not really that.. I couldn't plan, but it is more that I would put off planning, because .., I'd be feeling this cycle of, ``Will ..I feel like doing it?'' ... In the work context I would get caught up in work ..of being focussed on it... you then put off ..doing other things, and ..just ..hone in on that particular .. task, ... the way I think now, is that I really have to be stronger in the work .., situation ..so that when the contract ends, ..I'm not going into ..almost like a recovery period.'

(P11 post course interview)

**This participant later indicates he is aware of this healthy lifestyle balance by not getting too focused on any one activity:**

``I ..try to make ..an effort to not get stuck in one place, not to get too focussed on one task but to keep them all moving. And not to let things take over. In the past, I would ..do them until they were done. Now, I find I can complete a bit and come back to it later ..So I get less stressed out. I don't really plan things but try to get involved in activities. At the moment, I'm involved in my company accounts which are a bit late and also involved with digging the garden, so a bit of variety there'' . (p11 six months post interview)

**This participant, whose previous major psychotic episode was triggered by work stress and the inability to communicate his needs in a work environment, demonstrates how he has now come to view a more healthy relationship with his business partner:**

``..I would have known that there were stressful situations, but ..I don't suppose I would have had a very good idea of ..how to react ..what to do.. I think I would be aware, that ..I should be ..expressing my feelings ..in that situation ..I was.. avoiding doing that. Well, it may be ..mistaken ideas .. it may well be true that a working relationship comes better if you are expressing yourself more clearly, have a better understanding of each other's ..needs ..it's about learning how to do it .. it's about not ..shying away ...not holding back from doing something

because you are fearful of the outcome. I have learnt ..about .. fear ..I am ..often.. fearful of some eventuality and.. most if not all of that is within the mind, but the actual outcome can often be quite different. I was playing up to my fears really'' . (p11 post course interview)

**Six months later, this participant gained greater insight into his previously persistent depressed state and demonstrates how he now copes with this more effectively. The combination of motivation coming from himself, less self-criticalness and the previously mentioned balance to his schedule is illustrated:**

``I have a better understanding of what is going on, how you react to things and what you should do when the mood is going out of kilter. Before, I did not have a good understanding of what a high was or how it occurred and how to kind of spot it. Also I've been battling with a low mood for a very long time and ..have moved out of that ... In the past, I actually hyped myself up to get out of a low mood and was not able to control it. ..As going into a high mood, I would have felt quite energised and pleased I was escaping from that period of lowness but then I was not able to control it or even be aware of it. ..I don't have such high expectations, I used to be self-critical, that you're down so try to do something but don't do it particularly effectively and then criticise yourself for that. That kind of cycle, whereas... By letting go ..I don't worry too greatly about my level of accomplishment. I just get on with things and then actually find the enjoyment comes along with it. Not the hyped up position or excitement, more the contentment ..By not trying too hard, it actually comes easier. You CAN (emphasis) use others to pick you up but there is a chance you're going down ..the over stimulation route... if you can ..keep your own motivation level up in the quiet periods then there is less of a need to get others to kick start you. In recent months I have been (able to do that). (P11 six months post course interview)

**This participant illustrates how not switching to a high mood from a persistent low mood is representative of a change in outlook on his life. Six months after the previously noted course 'heated debate' in which this participant was resistant to change, this participant is illustrative of the**

**intellectual challenge that all participants went through to a greater or less degree, and the resultant change in outlook and greater mood stability:**

``Since childhood, I've had long periods of being low and to some extent it has shaped my personality and I have been someone who has ..tried to raise the mood ..it is a shift in perspective really ..I don't necessarily feel I need to do that in order to get on. A feeling you can accomplish things in a quiet way ...that keeps you in that stable area'' . (p11 six months post course interview)

## **Findings – Part Six**

### **Coping with a mood swing impacted upon COPING and MOOD STABILITY**

**During the study, participants commenced the course with a mood swing following an earlier major psychotic episode, experienced a swing during the course or during the six months follow-up period which sometimes covered psychosis. All participants coped well with the mood swing by being more aware of it at an early stage and putting into practice the coping strategies they had learnt. Improving coping included awareness and adjustment of their medication with the support and prior approval of their mental health professionals although for one participant management of medication meant the choice not to take mood stabilisers. Coping with a mood swing gave participants growing confidence that they would be able to manage in future, a growing empowerment that they could take control of the illness and steer a course through it where once they did not have this hope. The experience of coping enabled participants to start to adopt a new perspective on the illness which entered into their own common sense beliefs as they realised that being responsible for themselves through a change in perspective in how they viewed the illness was vital for mood stability and maintaining wellness. Participants' relationships with mental health professionals progressed as they were credited by them as being more responsible for themselves with regards to coping with the illness. This development contrasts starkly with comments made about participants' lack of ability to manage their moods prior to commencing the training and the consequences that participants would have envisaged if they had not been able to manage their mood swings.**

**P1 demonstrates how his mood fluctuated before commencing the course:**

``I'd had ...long periods of lows. I tend ....to pull away from ..people, places .. I just... can't...function...at all ..it seems as though you could ask me what my name is and I wouldn't be able to tell you ..that's always my fear ..if I start to go low ..I could ...lose my job again ... I .. was finding it difficult to actually cope ..the manager ..said that everything that I was doing was fine ..but it was just the way I felt. But ..I just couldn't ..cope with things ..I do get very negative ..I think whether life is actually worth living. And one point I did think about doing away with myself ..I came close ...18 months ago'' (p1 pre-course interview)

**After the course, p1 illustrates what would have happened if he had not successfully managed the mood swing he experienced towards the end of the course and how this has given him confidence in managing in the future:**

``I would probably have scarpered somewhere. (laughs) Running round in Scotland .. (laughs). Buying gorillas .. So I'd ...acted even before I'd seen the consultant. I now know... what the first steps of my mood are now. Cos when I was asked long ago, I couldn't have told you. In the past, my mood has always been so slow to increase that I don't actually notice it. But then I've never been on ...Sertraline where I've been going ...high before. I feel that there's hope for the future now .. I feel that I can actually stop my moods .. swinging and .. I've controlled this upswing within a week, so you don't lose contact with me friends. If I would have been in a job, I probably would have been able to ...get through it and still have the job at the end of it. So it's given me a lot more hope for the future'' . (P1 post course interview)

**At the end of the study, some 18 months later, p1 illustrates how his knowledge of the illness is helping him manage a second mood swing much better:**

``It actually followed exactly the same pattern as a year before, and so this time when I was expecting my mood to actually escalate upwards, I actually cut back on Sertraline .. before ..I was even slightly high. I was still actually quite low, at the time I cut back...I actually plotted the graph, how it went this year, and ..I did it at the right time. It was

better to actually cut it back before I actually got to the stage where I was going high. So, I won't now have the rebound from going high. I won't go back down again'' . (p1 18mths post course)

**Similarly, at 18 months post course, p1 is more knowledgeable about how the anti-depressant he takes might influence a high mood::**

``I am far more confident about managing my own illness, my own medication, and .. there are occasions when the medical team actually get it wrong. And so, I now tend to manage it on my own. (I read through) all my notes from the Care Plan meetings ..on every one of them I was going back to 100 milligrams of Sertraline ..I find that if I stay on 100 milligrams, I am actually far better '' . (P1 interview 18 months post course)

**During the course, p1's mental health professionals noted a positive change in how he was now coping with the illness. His consultant psychiatrist illustrates this in his medical notes post course when he was dealing with a mood swing:**

``Sleeping well but last night had only been five hours. Euthymic but describes times when his mood climbs very fast. Medication, Sertraline reduced to 100mg. He is much more aware of his mood. He is able to reflect on what is going on'' . (extract from p1's medical notes post course)

**P1's day centre worker demonstrates this mood management:**

``P1 had told her that he had been well these past few weeks but that ``Well never stays well for long'' and he feared a high mood. He had noticeably been implementing certain coping strategies to bring his high mood down ..These strategies had had a noticeable effect on making him appear more in control and restrained'' . (P1 post course with day centre worker)

**This confidence expressed by P1 is supported by the day centre worker who notes:**

``He certainly now seemed to recognize it (mood swing) at the early stage, act on that and with support had alerted all the people who needed to be alerted. He had taken action recently with his high that maybe before he might not have done. Overall, I am

cautiously optimistic'' . (p1 post course Interview with Day Centre Worker)

**And by his consultant who in previous medical records had noted that:**

``When manic, he creates companies and loses money. His highs had led to significant debts, whilst his lows severely reduced his ability to work. His girlfriend says he has needed help and been ill for some months every year for the last years. Even when well he is often caught on the back foot. He does not stay well long enough to pull himself out of the mire on each occasion. His illness reduces his ability to plan forward.' (Extract from medical notes written by Consultant 2 14 months before p1 commenced the course)

**And in a pre-course interview in which the consultant talks about p1's**

**health and outlook:**

``p1 was not always making judgements. It could be that he was ill or just ill-informed. Sometimes he was difficult to deal with ..When he is low, he is very low, which covers psychosis. If he was depressed, he can't do the work and everything stops. His partner takes over. P1 was swinging about at the moment. He is like two different people. He feels violated by the illness, like an invasion. He has a poor self-image. If he is high he thinks he is good-looking. If he is low he is not unworthy but feels invaded by the illness. He says that it is a 'bloody nuisance in my life'. He hasn't accepted the illness model'' (p1: pre-course interview with consultant 2)

**But at the post-course interview, the consultant notes that P1 has been successfully managing his mood:**

``When p1 had been high, he had enjoyed it a bit and then stopped ..P1 had taken on board the importance of a lifestyle balance. The following low downswing was not so much a downswing, since the high had been limited, so p1 is managing his moods'' . (Six months post course interview Consultant 2)

**At 18 months post course, p1's consultant notes positive changes in his management of the illness:**

``..he has been much more responsive in trying to change it (medication), which is the most important issue. .. officially ..medication should be as prescribed, but ..if he changes it, he tends to change it in sensible fashion .. in a way that is helpful to him. So consequently when he phones up

and says "I have changed my medicine", I don't go in panic. He is taking responsibility in a very different way. And he has been much better at reading what is going on. He's been pretty good really (during this last year), he had a little dip, but ..that was easily managed. He didn't go down as far ..he is ..actually managing brilliantly ..I think now, what ..he's got used to it, so, he is more ..stronger in his own understanding, so it has got more depth to it ..change had happened, but he is more comfortable with that change as well. So he has got more of ..his own resilience'. (p1: 18 months post course interview with consultant 2)

**All participants successfully managed mood swings and were reported as doing so by their mental health professional team.**

**The consultant psychiatrist for p2 reports after the course:**

"P2 had increased his Risperidone for a few days and then it (psychosis) seemed to settle, so he went back to his normal dose. The incident was quite minor. P2 didn't need to go into hospital because of it. p2 had BD primarily but it tended to become worse during the winter months. The incident was not as bad as it had been two years ago ..looking back through p2's notes, he had a general major decompensation during the Winter, so this Winter was better than the others. The last few years, especially last year and the year before that, he had". (p2: post course interview with consultant 3)

**p2's day centre worker reports the participant rehearsing his coping strategies during the course:**

"P2 had said that his mood had just plummeted one afternoon and gave an action downward. I observed p2 count on his fingers, as a sort of checklist, that he had: contacted his GP - contacted his family - he was getting out and socializing - he was attending the sports and games group. This surprised and pleased me". (P2 during course interview with day centre worker)

**p3's day centre worker reports mood recognition and management after the course:**

"I think the biggest difference with p3 is his mood ..at the beginning of the course he had a little bit of a dip. .. But ..he got through that with the help of the group .. his mood now is a lot more stable. .. he was always a bit high and I still think he has

potential to go a little bit high, but ..it is less frequent and he recognises it very quickly and can act accordingly ..he is recognising it a lot more for himself as well. Where before it would take for somebody to say to him, ``you are a little bit high'' or ``can you calm down''. ..he will recognise it for himself without anybody having to say anything ..which is really good'' . (P3 post course interview with day centre worker)

**p4's community psychiatric nurse reports that this participant was managing better:**

``(Before the group) When p4 had first been contacted, she was low, and used to go into her shell, but when she started the course she was very positive .. P4 had said that the relapse prevention was very positive. P4 currently described herself as very very well. Not high or low. P4 had gained a lot of it by recognising the signs ... She had found it nice and felt supported ..Her general mood was more stable, more confident. ..She is able to identify her problems and those of others, and tries very much not to take on responsibility for others' problems. ..She now has a lot more people around her, before she had no one. She said she works through the course and uses the professional team. She now faces up to her illness, she does not run away from it. She speaks to someone if not able to cope on her own. Her mood was fine, stable and she was happy, looking forward to Xmas. She felt she was a little better able to cope and her quality of life was good. She felt a little more in control of things despite her agoraphobia being worse at this time of year'' . (P4: post course interview with community psychiatric nurse)

**p5's community psychiatric nurse remarks on swifter illness management:**

``P5's coping had improved ..she had recently sought advice ..at an earlier stage than she would have done before. This advice seeking had tended to generally be much later, when she was very ill and may have needed hospitalisation. Her mood recognition had therefore improved ... When high, she does reduce her activities ..but needs reminding to cut back from her community psychiatric nurse .. She recognized this need to cut down'' . (p5: Post course interview with Community Psychiatric Nurse)

**p5's outreach worker remarks on this participant's progress after the course:**

``..if you met p5 today, you wouldn't think she had any form of mental illness'' . (P5 Post course interview with outreach worker)

**p7 points to one incident that marked the realisation of his coping skills and change in perspective:**

``P7 phoned me ..to say that he had wanted to cook something but really didn't feel like it. But he had said to himself, ``no, I will cook myself a meal'' and he did. This then inspired him to write a few Xmas cards - he had not written any cards for the last 10 years, since his wife had left him. He had kept himself busy during the day, doing ..little jobs, nothing frantic, and had written two e-mails to friends in the evening, going to bed at 1am. ..He said ``it's a state of mind, you have to work through it. ..it can be a downward spiral, this illness'' .  
..He said ..``I'll mark that day'' . (P7: contemporaneous notes following a telephone conversation during the course)

**At the end of the course, p7 has incorporated the course material into his own common sense beliefs:**

``I ..always knew when I was in a bad mood even though I didn't properly know why ..I just felt grumpy and moody. But ..having seen it sort of dealt with and spoken about on the course .. it's reaffirmed things in my mind.. and there is the possibility there, I think that by using the .. coursework, it may lead to heading off these sort of things, if they come along maybe there is a way of getting rid of it.. it sounds like good common sense to me'' . (P7 post course interview)

**p8 demonstrates she is now coping with her intrusive thoughts:**

``p7 and I are just friends. On the way we have to walk past the canal and I thought that he was going to push me in the canal. These weird thoughts, negative thoughts - I am now telling myself that these thoughts are not true, I try to dismiss them and challenge them. ..There are certain parts of it (the training) I find very helpful. Oh god, yeah, certain parts were really helpful'' . (P8 post course interview)

**p9 points to having avoided an acute episode:**

``So, although I haven't actually been ill with bipolar, I think I could have been ill, but ..maybe

because I had taken that time off, and what I had learnt on the course ..it prevented me getting ill ....I have prevented myself maybe getting worse .. being ill for Christmas and going into hospital ..''.

(P9 post course interview)

**After the course, p10 illustrates her learning of coping strategies to deal with a low and high mood:**

``Right OK, lows, I need to get out of bed at the same time every morning, and I need to structure my wake up routine .. and then ..it needs to be low activity, but ..complete activity ..at that point if I was working ..everything would be put into ..getting into work, doing the amount of work I do and everything else around that, has to fit in. if I am not, then gentle activity, walking ..I try to spend time with people although it is very difficult, but I tend to spend short periods of time with people, so, I will, try and make a meal with somebody, so, it is not all based on me and talking, and communication between me and an intensive group ..and going to bed at the same time ..every evening ..and trying to get a good lot of sleep, and trying to make myself sleep all the way through. If I wake up in the night, I don't get up in the night, I will try and sleep. OK, (for highs) I have been thinking about this and basically, what I want is ..I might not be sleeping my full quota, but I want to be in bed for 8 hours a night. So, I would try and force myself to stay in bed. And that point, I completely slice down my routine to bare basics, just work, and getting ready for work, coming back, eating, and that is it ..and if I thought it was bad enough, I would ..ask my sister to take away my mobile phone, my credit cards and my car keys ..at that point. And, I am basically going to insure that, when we are living together that that's all set up, because, we are all starting to do wills and stuff like that'' . (P10 post course interview)

**At six months post-course, this learning served p10 well as she had successfully coped with a mixed mood state and psychosis on her own:**

``I've been marvellously stable until about one month ago when I subsequently found out that my Lithium level was low. It led to a mood disturbance. I managed to keep working but had to cut down on everything else in order to keep working. It was one of my weird phases - I feel depressed but my thoughts are racing, I can't keep still and I have a bit of paranoia. I'm a lot calmer (now). And for a

couple of weeks I increased my Lithium. I isolated myself a bit too much but coped well. I was stringent with myself but not ferociously as I would have done before. I did not over-stimulate myself this time. I would not have managed (if I had not followed the course) ..I managed because of 1) the course 2) knowledge of the illness and 3) the acceptance of the illness in the last year. When I have a mood disturbance, I normally have others around me. I used to be back home or went back home, but this time, except for my sister who comes and goes, especially this time, she wasn't here. I was doing it on my own. From the course, I learned quite a lot of knowledge of coping, in depth side of things, a continuous way. It was extremely helpful. A group of people to talk to. I refer to the file an awful lot to reacquaint myself especially when I had the mood disturbance. I was not distracted. It was a logical and linear way of coping. When you're not coping, you don't... (see things in a logical/lineal way). I was not the perfectionist, if I felt that I was failing. ..It taught me how to deal with the level of stress ..I am a lot more aware ..And I am a lot more able to stand back and just go, "well, it is you, you are lying to, and it is going to be your problem in the end". And I do jump in a lot quicker now as well. I am much more confident at being able to spot, acknowledge and put in to place some coping strategies that I know will work now" (P10 six months post course interview)

**After the course, p11 remarks on how his mood, his knowledge of the illness and his coping with a high mood have improved:**

"I think that's definitely better actually ..yeah ..the mood chart that you showed early on ..was very helpful ....to kind of see that, kind of laid out, in a kind of graduated way ..it kind of made quite a lot of sense really. I wouldn't have recognised going high ..and certainly not the early, the early ..signs of it, and .. even now ..thinking back, and .. finding pointers earlier and earlier on, if there was something missing or something astray, and .. at the time when it would still be possible to ..kind of take corrective action and make a change. ..yes, yes, (I've been able to pinpoint my mood pattern) much better, yeah ..that's right .. partly because some of it was quite painful to ..think about ..unless you know what you are looking for ..you get caught up in the emotional ..response to kind of ..like the idiotic things you might have done .. rather than actually thinking about more kind of, mundane, things about sleep pattern ..and stresses and things like that. So you ..think of .. the more

headline hitting things, that are going on ..Without the benefit of the course, I wouldn't, really .. look back ..about how was I living at that time, what was going on'' . (P11 post course interview)

**p11 illustrates how he is now able to cope better with a low mood:**

``..in being able to recognise your mood ..it puts you in a better position to kind of understand, if you have a low mood, you .. have quite low expectations of the outcome. Now, if you recognise your mood, and you will realise you have a low expectation ..then .. well you can make the choice, between kind of ..waiting for some improvement in your mood, before you tackle something, or ..just kind of knowing that .. at the moment I don't think this is going to turn out great, but I am going to have a go anyway'' . (P11 post course interview)

**p11 demonstrates how he would use medication in future:**

``I'm not ..100% against medication .. ..if I was to go high ..I have agreed to do that, and I would... there was a stage when I went high during the summer (prior to the course) when I knew that my thoughts were racing .. I knew that something was not right, well, enough that I wasn't sleeping particularly well .. but I was still .. functioning ..if I got .. to that condition I would definitely be thinking ..I need something to kind of knock me out of it. I need to be able to sleep properly'' . (P11 post course interview)

**Six months post course, p11 is practising coping strategies and is able to express his needs clearly to avoid a mood swing:**

``I'd be much more aware of it, much earlier and I would be thinking about corrective steps at the earlier stages rather than let it happen, then think back and think 'oh, gosh' you know ...I'm much better to let my other half know ..I needed sleep and she recognised that she wanted to do something else but it was more important to... I can remember 'I have to flop out here' as opposed to throwing myself into some other activity that keeps you buzzy a lot'' . (P11 six months post course interview)

**P11's consultant demonstrates that this participant is coping well with the illness since a major episode prior to the course:**

``p11 had discussed the dangers of becoming unwell and the worse thing that could happen to him. If he could detect the signs earlier and accept medication on a short-term basis he preferred this, rather than be on mood stabilisers in the long-term .. p11 felt optimistic. He takes responsibility for himself. He was able to be open with himself and can own the problem. He had gone through a major psychosis and hadn't understood it before. Now he was owning it and taking stock. He accepted his diagnosis of bipolar disorder'' . (p11 - Consultant 4 post course interview)

**Post course, p12 demonstrates how she successfully coped with a stressful period during the course and how this gave her new insight into coping with a high mood for which she had previously been hospitalised. P12 previously illustrated how her assertiveness enabled her to avoid overload and stress:**

``I have learnt a lot really ..particularly the coping strategies, so I have been using those accordingly.. and making that more of a habit to get into. Rather than falling into the old habits, (laughter) ..at that time, I had a lot of demands on me, a lot of people under a lot of stress themselves. And I was trying to rescue them for their stress a lot of the time, this was over and above my usual roles, ..But ..I didn't feel high with it, because I was pressured, it wasn't like I was getting a buzz out of it .. I just got totally exhausted from trying to clear everyone's problems, and also seeing a lot of people in distress is very frustrating, because you don't want people to be like that ...I think it's the frustration that .. gets to me. But I was just totally getting myself washed out and tired ..even then I didn't feel that I was like, racing into a high ..my only experience was being in hospital and being alright, and suddenly I sort of wasn't. I didn't have a process of things happening it was just, such a combination, I just went from this to that, and there was nothing, it was just ``ooh'', sort of thing. (To cope) I just looked after myself, and because ..they (the family) are all at work, I knew I had the day ..it was guaranteed .. that they wouldn't be home until their time, so I could just properly rest, and please myself.'' . (P12 post course interview)

**Six months later, p12 describes coping with a low mood and continuing to work whereas previously she would not have been able to do so:**

``On the whole it's been alright ..I've only had one maybe two periods when (I felt) low.. and.. just wanted to stop in my tracks altogether but I just got up and still went to work. And I just.. (did) things at home.. if all I could do was the bare essentials, that's what I did. ..It's fine (at the moment) ..I have coped with it. ... I think that when ..I've been at that point before, it's literally, put the breaks on and I couldn't get myself going to work .. and if I had pushed myself, I'd be running out of work again ..or.. it would just completely get hold of me and I just couldn't carry on.. (pause) ..it's different ..silly little things but I pick up a lady in our department at the bus stop ..To know it's not just me getting up to get in there ..it's like it's worth it (laughs)... I always try to learn from a horrible period. I do try and do something about it and then hoping it won't last as long and it hasn't. .. it didn't last as long. I was really pleased that I got through it. I was really relieved to be leaving again at 4pm. As soon as I got in I thought, in 7 hours you'll be going ..and then you'll be off and ..home ..safe again ..I just think get in at half eight, half ten go for a coffee, that'll be another half hour gone, I just did that all in my mind, just get through that little bit and do that task and ..I'm just gonna go and walk round the block .. and come back and have a bit of paper in my hand (laughs). It all looks very official .. And I catch up. I suppose it's a bit like at home sometimes. If I'm feeling really not right or whatever.. I suppose I can always put washing in. Even for me ironing is .. not always my cup of tea .. but I know that once I get GOING (emphasis), it'll get done. And I think that's what I'm like whether it's work or at home. Once I get into something I can really be thorough but when I'm a bit iffy it just seems what's the point ..it takes time doesn't it to sort it out in your mind?. (p12 six months post course interview)

**Six months later, p12 demonstrates how she coped with her time of stress and how she would cope with a slightly high mood in future:**

``I think (I'd be able to manage a high again). Because I know it's unusual (laughs) to have that kind of state ..Because before I had some time off .. if that was to happen again, that's how I would handle it. I think I would ..just retreat and stay safe at home ..that's the way I'm thinking I'd handle it .. I'm very aware of that. ..And the last time I saw Dr 1 .. that was one of his questions, if you felt really really poorly, I just want to know what you would do ..and I said that I would ring him

..if I felt that I wouldn't be able to cope ..I think he ..was pleased that ..I wouldn't discard that side of it (professional help) ... That's gotta to be in it as well, hasn't it? That support network, of the group, and your friends and family ..but you've still got that side of it as well .. but ..I haven't contacted him. I've managed without him'' . (p12: six months post course interview)

**p12's consultant psychiatrist notes six months post course that this participant had improved her coping skills:**

``p12 was fine. He had hardly seen her at all this year (following the training). She had had a major depression towards the end of last year (preceding the training). She was clinically well at the moment - he would have heard from her if this was not the case. Nothing untoward was happening this year. From her medical notes he read: 'Well for quite some time and feels well prepared for a next episode of depression because she has better coping skills than before'' . (p12: six months post course interview with consultant 1)

**After the course, p13 demonstrates how she is coping with her rapid cycling high mood. This participant previously attested to how she was successfully coping with low moods:**

``I know when I am on a high, not to rule the world, with parties and everything. Not to keep chatting to people. No, I will know now to stop me chatting ..I will have to shut up and listen ...that has been hard, in the past... Well, what I wouldn't do, when I used to be high, I used to stay up and play on the computer ..do ironing, and then go to bed. But that is definitely something I have stopped... I used to love it. Even doing the washing in the middle of the night ..I was so proud of all my achievements but .. now I have learnt that is not the way, no'' . (P13 post course interview)

**Six months post course, p13 demonstrates how much change she has experienced in comparison with her pre-course interview in September:**

Researcher: ``.. in September last year, you said you had a sense of being a failure?'' .  
P13: ``Yeah. Not now. ..you have interviews every so often at work. And I say, I'm worrying I'm not

doing it right. She (my boss) says, no, I've got glowing complements .. (later) That will be a year ..a year's worth (without having a mood swing). .. that'll be three... I think it's amazing ..My husband says he's proud of me (laughs). Specially with this new job. And I'm even thinking of having driving lessons ..I can have a go and the man can say you're dreadful, you'd never do it but ..I just think I CAN (emphasis) cope ..So if I was feeling low, I'd just think well, I've done it before ..I can do it again'' . (P13 six months post course interview)

**This change contrasts with p13's consultant psychiatrist's pre-course interview:**

`She just feels low and waits for it to end. She doesn't feel she can lift her mood. She just waits and lets things slip a bit at home. She has tried lots of different therapies ..Empowerment implies that she can modify her mood. She does not feel she can modify anything. She feels that there is not much she can do'' . (P13 pre-course interview with consultant 1)

**This consultant psychiatrist later attests to p13's mood stability at six months post course:**

``There was no mood swing in Christmas, no low. Her energy levels were low but she was doing different things during the day and she was not depressed. She was coping up till April 2005 (when last seen). She had had a better year than the year before, she hadn't had the depression. Effectively, what had been a pattern of 3 mood swings a year (Xmas, Spring and Summer) had been halted in that Xmas and Spring had passed without disturbance'' . (p13: six months post course interview with consultant 1)

**Controls however continued with a worsening mood during the study period.**

**At post course, c4's mental state had worsened:**

``c4 was just plodding on. She had gone through a stage of many emotions with friends due to paranoia ..She had believed that people were talking about her. She didn't want anyone to know and couldn't

remember having felt like that for a while. She found anything too tiring and she can't go through the day ..She just didn't feel. She just didn't get anything out of it. Life was hard. She just didn't get anything out of it. She said ``I'm here and that's all'' . (c4 post course interview)

**The consultant psychiatrist for c6 attests to his worsening situation at six months post course:**

``He lives at his mother's still and winds her up with the alcohol. ..It is his mother who phones or writes that he needs treatment but I can't do anything about it'' . (c6: six months post course interview with Dr 4).

**At pre-course, this consultant demonstrates that there has been no change, rather an on-going situation:**

``He drinks too much and acknowledged that. He would say that his life is not very exciting, boring, it was no fun. He would just do things. He is not terribly responsible and relies on others quite a lot ..he is kind of stuck and he has no belief that he can re-establish a life that has fulfilment. He will probably continue on with his mood swings and hospitalisations that he has had in the past. He seems to be interested in change but can't achieve this or won't achieve this'' . (pre-course interview with Dr 4 about c6).

**C3 post course demonstrates an absence of coping:**

``I am actually on a bit of an ..automatic control ..It's ..doing what you have to do. But I wouldn't say that ..am ..thinking as clearly as I would back in ..September (pre-course interview) ..it's just doing what I have to do and that's it. Getting through the tasks you have to. Getting through the tasks'' . (c3 post course interview)

**c5 post course illustrates how her lack of coping and low mood are due to the deterioration in her physical health:**

Researcher: ``Are you coping?'' .  
C5: ``..some days .. its made me feel a bit ..I think they know ..that it has made me feel a bit low since I have had that turn. I thought I was going to heaven ..'' . (c5 post course interview)

**At six months post course, c3's social worker illustrates the deterioration in mental health:**

``c3 has been a bit shaky recently. Problem is real life stress. Real in nature, c3 starts to worry and said that she thinks she has a depression. I am seeing her weekly at the moment, generally it is monthly. I think c3 had agitated depression, a lot of anxiety and was worrying about the symptoms and making it worse'' . (six months post course interview with social worker for c3)

## **Findings – Part Seven**

**Through intellectual challenge and personal responsibility a different ‘mind set’ was adopted which enabled improved COPING strategies and PERSONAL DEVELOPMENT.**

**Participants, as they adopted and practised their growing repertoire of skills and made change to their lives in a variety of ways to do with successful mood management, communication, assertiveness, anger management and healthier lifestyle and structure, balance and planning, they developed a new perspective on the illness and themselves. This new perspective was incorporated into their own common sense from the holistic nature of the course material and from the group discussions that reviewed past trauma in their lives, reinforced by the user-led aspect of the group learning experience. This enabled them to become more responsible for themselves and less responsible for others whose burdens they had previously taken on and adopt a more considered approach to their activities, their relationships and develop a new outlook or ‘mind set’. This new ‘mind set’ was evident in the group learning processes and outcomes previously demonstrated by p11. This new ‘mind set’ impacted directly upon COPING as participants now viewed coping with the illness in a completely different light. It impacted upon their own personal development in that it enabled them to develop and move forward with and despite the illness in a completely different way. This could be quite an epiphany or a gradual realisation. Participants moved forward in how they now viewed the illness and their own skills to deal with it. This resulted in participants starting to renegotiate what had been their mental health**

**'system', in that this system now had to expand in order for them to progress and sustain these developments.**

**Post course, P12 demonstrates this new perspective she has adopted:.**

``I am just trying to keep myself steady, and just make a conscious effort to look after myself, and then everything else ..will happen, and what doesn't get done today, it really doesn't matter'' . (p12 post course interview)

**Acting in a new way is not without some guilt as previously mentioned in practising new assertiveness skills but the overriding benefits are evident as p12 recounts her recent stress at work and how she is now acting differently at her post course interview:**

``I .. was trying to rescue them for their stress.. and .. I thought, ``Well, I've got to start ..saying that I can't help people'', and I just ..directed them to other people or said I didn't know the answer, instead of ``I don't know, I will find out'', leaving the pressure on me. So, I ..let the responsibility be more on them .. It was hard to start with, to sort of consciously do it, but once I realised that they weren't going to think badly of me ..then it proved to me that it could work. So, that's what I have been trying to do ..ever since ...I am determined it (the course) will (make a difference). But I have got to again take my own responsibility ..and because until this course I didn't know there was even any coping strategies. I just thought, you just get down and depressed and have got to pull yourself out of it, and then it happens again... the first few weeks I was here I thought .. it was like .. the best thing that had happened to me, coming to something where I could see that just by taking responsibility for actions ..you can actually change your behaviour to help yourself ..I am really thankful ..that something had at last come along. Otherwise, I would just be exactly the same as before. And just get trodden into the ground, and just be down. And it's strange because I look back, I am trying to sort out my leave at the moment at work, and I have been asked to trawl back over the past six years that I have been there and ..all my certificates in my file are for depression ..I have been off an awful lot in the last ..six years ..through depression ..signed off for two or three months at a time ..so ...I have got to use the coping strategies. Because, no one is

going to do it for me, they ..are not actually going to be inside my head, doing it for me. I have got to do that'' . (p12 post course interview)

**At six months post course, p12 is now able to reflect on her development, how she is no longer as guilty about acting a different way and how this new perspective has been beneficial for her:**

''I ..used to carry on with my old mindset with a lot of things. Keep on feeling I've got to help so many other people intensely because other people weren't doing it. Which obviously was wearing me down emotionally.. And being resentful as well ..by being this way, I couldn't change them. I couldn't make them do it. So I've had to change me a bit. And it is hard. ..And by not having the guilt. By changing, you're not lowering your standard for them. You're just changing the way things are done. And they'll still survive.. it's just your perception of it, how you think things should be done. Because I think that for me there's a lot of emotionally charged things. Everything for me was driven by emotion all the time and it .. wears you out. And it's a mixture of this burrow of things, all ..going together trying to do something. But if you try to do things from a slightly different angle, so you're still caring but perhaps not putting so much of yourself into every decision. It's just changing the placement of it all...It's just stepping a different way ..Just when you're asked to do a lot, and just that little pause just to think a little bit before plunging in .. Just ..reflecting back on it ..first of all you're just trying to do it and it's not until ..you try reflecting back on things ..''oh yeah, I am different because I wouldn't have done that before'' (laughs). ''Who is this person? Oh, it's me!'' (laughs). And I don't think anyone's suffered through it (laughs). They've all survived'' . (p12 six months post course interview)

**Participants demonstrated a shift of perspective away from suicidal thoughts and towards a more hopeful outlook. p10 indicates a fundamental change in how she is now taking on this personal responsibility for the management of the illness:**

''...a massive change from how I felt last time we spoke .. just having ..belief in yourself, and what you now know, and that you can cope ..I think, that dealing with ..things like suicide, suicidal thoughts, if ..that ever ..comes about again ..I believe that I will

have many more tools to handle it, and much more resilience ... it certainly made me... review the fact that in the end, whatever is said about it, this is my shit, and I have to .. take responsibility for it'' . (P10 6mths post course interview)

**p3 at his post course interview demonstrates his changed outlook:**

''I don't have those (suicidal thoughts) now. No. I think it is not worth it. I have a fairly good life the way I am and I have this Employment Direct thing ringing me up the other day, and offered me a support worker to get into work'' ..(p3: Post course Interview)

**p12 demonstrates her change in perspective towards suicide:**

''..when I was high (I had suicidal thoughts) ..my strong intention within myself is that I am never going to get to that low ever again, and the coping strategies will save me from that, and there'll be ones that I will learn and that I will know automatically what I will do. And obviously 'till I know them, I'll be referring to the chart ..even when I am feeling good'' . (p12:Post course Interview)

**p9 illustrates how she has worked through her attitude towards suicide resulting from migraines:**

''I don't think the suicidal thoughts have been as bad ..mainly because of these headaches that I keep getting, and I ..have tried so many things .. And I just think, ''Oh, I can't carry on with it'', you know, ''I cant see it just going, because it has been here all this time''. And that's when I say it (I wish I could die). If I could get rid of the headaches, then I probably wouldn't have them (suicidal thoughts), I hope'' . (p9 post course interview)

**At six months post course, p9 demonstrates an attitudinal shift towards her migraines associated with low mood, hence reducing thoughts of suicide associated with these:**

''That was me who worked that one out, wasn't it? (link between migraines and low moods) (laughs). I do still get a lot of them everyday really but you just put up with them'' . (p9 six months post course interview)

**Six months post course, p9's consultant psychiatrist attests to this**

**attitudinal change:**

``She is not NOT (emphasis) taking Amitriptyline which is an anti-depressant originally but also an anti-pain drug which was prescribed by neurology, not psychiatry. I am pleased she had decided not to take it anymore. She took this for headaches. She does mention them but the nature of the discussion is different about them now. She has learnt that if the symptoms (headaches) are there, it doesn't have to have a remedy. She is more tolerant. She has managed to separate the headaches. She has learned that there is always going to be an insoluble part (ie. Headaches) which is different to the soluble psychiatric part'' . (Dr 5 for P9 six months post course interview)

**Later in her six months post course interview, p10 describes her attitudinal shift towards the illness and her new job helping people with mental health difficulties:**

``It's been quite a revelation ..I feel really ..confident, I don't worry about going out in public anymore. I don't worry about my life going down the tubes anymore, me not fulfilling my potential. I am just going to chill out and take it as it comes and I am doing something that I hope I am really going to enjoy (new job) ..I think, there is a very deep rooted confidence now, because in the end I think it was really this issue ..which ..was the ..central problem ..Manic depression, and ..your root attitude or mindset towards that thing ..everything else seems to fall into place. So, ..that's where the confidence has come from, that I have just sorted out a lot of stuff in my own head, .. and I have been blaming myself for .. me interacting with having manic depression, and what that would have led my personality to form into, and where I can unpick that, and re-sew it to how I want it to be ..'' . (P10 6months post course interview)

**p10 demonstrates that another attitudinal shift is due to relinquishing what she enjoyed of a high mood so that she can move forwards with her life:**

``I always said I have been very boring when I was relatively stable ..... but now it's definitely diluted ..with a certain degree of sensible ..knowledge that, if I let this go, it is going to fuck up my life, and it will do forever more ..and that will be it .... in the end it is going to teach me that it's really not that boring because I can't

believe that real life in whatever form it takes isn't extremely interesting if you let it be,.. so yes I suppose another attitude which is in it's making..' (P10 6mths post course interview)

**p10 demonstrates the grieving process that she has now gone through.**

**Previously, she had stopped taking her medication:**

``I just don't want that to be the pattern in my life ..that's been a massive attitude shift in the last nine months ..a complete radical overhaul in which this (the training) was a structuring force behind it all ..it is all tied up with what you could possibly be in those moments. It is as if you can actually reach everything about yourself, the only problem is ..you can't .. because it is not sustainable.. It just doesn't work ..And I think coming to terms with that in a grief kind of aspect ..is very potent ..I don't think psychiatrists give enough ..time to ..non-compliance with medication''. (P10 6months post course interview)

**As already mentioned, unrealistically high standards were evident within the study group. p10 indicates an attitudinal shift away from her previously held values of perfectionism:**

``I am a bit more aware of how ..negatively it (perfectionism) perhaps could be perceived. I will have to adapt ..and live with it ... I have had to kiss a lot of dreams and my ambitions ..away.. and it's a fine decision for me to make ..but that has taught me an awful lot about the fact that in the end, the only dream and the only thing you can really aspire to .. is making the best out of the situation you are in ... I have just limited it so it is no longer perfectionism ..because that's not feasible ..but it's still a great necessity to achieve ..to a very, very high standard''. (p10 6months post course interview)

## **Findings – Part Eight**

**Outcomes from the combination of a variety of lifestyle improvements resulted in improved outlook on self and the future, greater empowerment and improved quality of life**

**Due to successful mood management, participants achieved confidence in their ability to manage, a better outlook on themselves and a more positive future outlook. They felt they could now make plans whereas before they had not done so or were unable to carry them out. They developed their self-determination and self-belief. They developed their independence away from services and towards developing more challenging areas of their lives. Their suicidal thoughts were replaced with more positive and constructive thoughts for a better future. This sense of greater control over the illness enabled them to become empowered, more in the driving seat of their lives rather than being a passenger. A sense of enjoyment is present.**

**P10 at six months post course demonstrates her confidence:**

``..my ideas have crystallised .. I have ..been bringing a lot more things together over the last 6, 9 months ..all of that has lead to ... having the confidence in myself to know that ..I have got a lot of knowledge and experience behind me to go, ``if I'm starting to feel a bit funny, this is a problem'', rather than before, when I was like, ``I am feeling a bit funny, it might be anything''. (p10 six months post course interview)

**At post course, p4 is more confident and relaxed:**

``She has been ..more open. P4 has always been ..quite reserved, like having a reserved smile ..and so, ``I don't know if I should do this, in case I am doing something wrong'', that kind of attitude. But she has been quite different over the last few weeks. Seeming genuinely happy, a real smile, not a forced smile ..today was an example ..a relaxed ..friendliness ..a relaxed way of ..expressing herself. I think in the past she was always very, very conscious of what she was doing ..She is much more confident''. (p4 post course interview with outreach worker)

**p8 illustrates more confidence and less sensitivity:**

``Before I used to worry about things .. I worried I had upset people or wonder what they had meant when they said things to me. ..I'm not so much sensitive now... I used to worry about all sorts of things ..I

used to think 'is she alluding to this or that?'. I had sort of a dark cloud but now I can laugh about it. I think now I would challenge people who said things that might be hurtful or misinterpreted ..I would ask them what they meant by that now. I think I have more confidence now'' . (p8 post course interview)

**P1, at a conference on recovery ten months post course, demonstrates how he is managing and how this has impacted upon his belief in a more positive future:**

``..I have been a manic depressive for 24 years and have experienced many months totally depressed and unable to enjoy anything, interspersed with short periods of highs, when I would spend vast sums of money only for the debts to catch up with me and swing me in to another depression. The course teaches you to monitor your moods and thoughts and then how to counteract your moods and negative or over positive thoughts. After monitoring my moods for a few months, I began to pick up on the kinds of activities that raised my moods and ..decreased my mood ..when I'm feeling low I can concentrate on the things that raise my mood and conversely if I felt high I would concentrate on relaxation and bring my mood down. Also I became more aware of my mood changes and therefore picked up on them quicker. I was therefore able to counteract the mood change earlier and ..stop them becoming severe. This has given me the belief that I am more in control, and I am more confident that I will be able to stay in employment and stay healthy''.( P1 ten months post course: taken from his speech at a conference on recovery)

**Eighteen months post course, p1 demonstrates his hopefulness for mood stability and for his future job prospects:**

``I am confident I will be able to manage my mood swings now ..but because I have had so many years of being really low and depressed ..I haven't really been at all hopeful about the future ..I am having to learn to let things go. I now feel more confident that I can make plans and will be able to stick to them I ..am a lot more hopeful now ..I have never really set myself goals ..because ..I've never known if I am gonna be well enough, and so, you tend not to ..now I ..would start to make plans. I've always gone for a job that I've known that I can do even if I went down to a -3 (a moderately depressed mood) ..I can still do it without anybody really noticing very much. And that is how I managed to stay in

work, most of the past 20 years. So I haven't been in a very challenging job. I would be more confident now going for a higher, more challenging job, because I think I can actually control my mood. I am more hopeful than I was'' . (p1: 18months post course interview)

**At post course, p12 is optimistic for the future:**

''I feel optimistic ..I am optimistic for myself. I feel no matter what happens, I will be able to cope with things, rather than dreading what is going to happen, and worry that I am not going to be able to cope. I believe more in myself ... within myself and what I have learnt. I'll get there. I feel that I have learnt a lot about how I have been processing things, in my mind, to get me through things, and why I have done certain things .. and know that despite feeling depressed a lot of the time in the past ..I have still managed to achieve quite a lot. So if I can do that feeling dreadful, then there is hope that feeling a bit better will be more positive and therefore I'll feel even better in myself'' . (p12 post course interview)

**p13 demonstrates her positive outlook for herself and her future:**

''..definitely being on the course has helped me, there is a future, Well, the future is now, I have got there .. I just think you can see other people who have been really bad, really worse than me, dreadfully worse ..before I came I was the only person who was ill ..I was the worst one there, but I could still see other people, they had been worse than me. And, ..that did help, there was a light at the tunnel, ''They're all right now, I can be all right'' . So, I was. And I will remember the people .. they were fine, they were all fine. And then everyone was fine in the end, even me. No, I think I will never forget the course, no ..I don't think I would have got better if I wasn't on the course. Because before I started the course there was nothing, it was so bleak... it was just there I thought, forever. And no future at all then'' . (p13 post course interview)

**p9 demonstrates her happiness in achieving something she had always**

**wanted:**

''My husband bought me an MX-5 (happy voice, laughs) ..cos I've been saying about it for YEARS (emphasis) ..that I'd like one and ..he just went out one night ..straight from work ..and he rung me up and said,

``oh I'm going to be a bit later'' (laughs). And he come back and said, ``oh look what someone's done to the Peugeot''. And I looked out the door and there was an MX-5 waiting there. It's just something I've wanted.. I've always liked and ..I didn't know anything about it''. (p9 six months post course interview)

**p11 demonstrates his plans to motivate himself and his self-belief:**

``I used to play football ..I have more recently in the last couple of years been going skiing. I ..do hill walking and things, but I have never really looked at it, in terms of health and actually trying to achieve a healthy body, losing weight and all that kind of stuff ..maybe because I had never really ..I almost didn't have the belief I would get there''. (p11 post-course interview)

**p10 demonstrates at six months post course how she is more independent and empowered:**

``My independence is very important. Now it is an actual reality, not just longed for. Independence from mood swings. They are not part of me. It is my lot in life but I can control them. It is a positive thing really. Without a psychiatrist being there either. I'm very proud of myself. I am much more in ..control of everything. I'm finally on my way to doing what I want to do. I'm not at the mercy of the amount of stuff I didn't understand. Definitely more empowered. Making my own decisions''. (p10: six months post course interview)

**p8 at her post course interview demonstrates her empowerment in an area of her life she previously felt solely responsible:**

``I feel more empowered to get people to act for me with regards to the help my mother needs ..I put her first for so long, but now I have all my family members helping me, the occupational therapist, the (residential) home. I am bringing in support for myself and my mother. I feel more empowered to bring in others to help me do this for my mother''. (p8 post course interview)

**p1 demonstrates how he is now asserting himself to empower others:**

``There is a fine line ..as a friend I want to help him out, but ..then he will always come to me for help. And so, it is best to actually ..get him to

help himself if he can . I realise now that .. it isn't my responsibility to do everything for everyone else, 'cos I do tend to be somebody who does actually help people all the time, and so I have cut back on (that) .. and trying to get people to do it for themselves'' . (p1: 16 months post course interview)

**p1's consultant psychiatrist notes the change at six months post course:**

``..there were two things: - being empowered is at the same time a developmental thing - the difference between what is bipolar disorder and personality issues ..P1 was a little bit more empowered. He was now appropriately empowered. P1 had shifted his empowerment into better areas'' . (p1: six months post course interview with Dr 2)

**At 18 months post course, p1's consultant psychiatrist has noted an even greater change in his empowerment and development:**

``..now, he has moved on to the stage of looking at other's empowerment rather than his own and ..also .. he's bridged ..a gap ..in terms of recognising ..the separateness of people's needs, and differentiating and not thinking of all the emotions as well. Which is quite a big development for him ..the social group thing (he created) has been very useful as ..finding his way within the social group has become extremely useful .. he seems to ..be much happier in the people he sees'' . (p1: 18 months post course interview with Dr 2)

**Participants' quality of life improved in all its different facets.**

**p1's sense of enjoyment is evident:**

``.. the last year and a half ..I have noticed that if you look through my diary .. the word 'enjoyment' has actually cropped up quite a lot, whereas in the last 20 years, I didn't know what enjoyment was. I am just going out and enjoying myself. You see in the last 20 years, most of the time I have been severely depressed, and it didn't matter what I did, I couldn't enjoy myself'' . (P1 18 months post course)

**p2's consultant post course noted increased enjoyment:**

``p2 seemed to have benefited from the course and was enjoying life more'' . (p2 Post course interview with Dr 3)

**For p10 six months post course, quality of life is about having the skills and the wish to make changes in her life:**

``..just ways of putting ..really simple things into action, but things that will make my life a hell of a lot better .. I have seen it working already ..it was that ..just a practical kick up the arse ..I .. have been wanting to do all this stuff for years, and now you have got the tools to do it, just go off and make these things happen. I've much more confidence than I ever had before. On both levels I think, because, it does keep you grounded and ..when you are floating off up there and kind of yanks you up a bit when you are low ..I just needed a bit of ..application to what I knew I had to do, but I had never really sat down and thought enough about it, because it's very simple ..but I ..have never really got off my arse and done it ..Possibly because I didn't want to change, but now I think I do, which is interesting'' . (P10 six months post course interview)

**p13 illustrates her goal to go on holiday, cancelled the previous year due to a major episode:**

``The other day I went shopping... I thought we'll get some beach towels. I had to cancel it because of this (mood swing) ... We never had some for a few years and then there was this mat for the beach ..and then ..I'll get one of those hat things, I said ``can I try it on?'' and he said ``yeah'', and I went in there and he said ``was it alright?'' and I said ``nah! It looked awful'' but I said ``nobody knows me on holiday, so I've never been''.. I'm MAKING (emphasis) myself WANT (emphasis) to go. Like the passports are due for renewal and they were joking, ``don't do Mum's, Dad, she won't want to go anyway'' (laughs). That's it.. so I went and got my photos done. I mean I got to go, I can't waste the towels or the hat, can I? ..(usually) the day before its like ``have I got everything?'' . (laughs). And I keep looking at the picture of it. We got like a photograph of it and I keep thinking of that. ..So, yeah, things are looking up on that front'' . (P13 6 months post course interview)

**The community psychiatric nurse for p4 noted at the post course interview an improvement in quality of life:**

``p4's quality of life had definitely improved. Three years ago, she was attending the day base, with the work of the occupational therapist .. Her getting out more had improved. She was more positive and assertive. She was planning to go on holiday with her husband. She looked well and relaxed. (p4 Post course interview with CPN:

**p3 at his post course interview illustrates his optimism and empowerment:**

``Before the course I said I wasn't ever optimistic. I didn't feel very in control, and ..``what will go wrong, does go wrong''. And it pissed me off a bit. But now I feel a lot more optimistic ..I think ``that's not going to happen'' and it doesn't, you know. I am not going to let anyone walk all over me, like my ex-friend did'' . (p3: Post course Interview)

**The day centre worker for p3 notes this increased empowerment resulting in being able improve his quality of life:**

``I think he is a lot better ..he is working toward doing a lot more of the things he wants to do and he is more equipped to make decisions, more in control and empowered ..if he keeps all of those things up and continues the way he ..has got great things ahead of him'' . (p3 Post Interview with day centre worker)

**Quality of life is linked to mood stability for p12's consultant at his interview which took place during the course. The resultant mood stability for p12 has previously been noted:**

``It is reasonable, most of the time it is OK. If she is depressed, it is poor. When she had been high, she had to come to hospital'' . (p12 during course interview Dr 1)

**p12 also links her quality of life to mood stability pre-course:**

``At the moment, I am enjoying life. I was ill from ..February, 'til March off work, so ..it's only been the last month, I have really ..come alive again ..I have been going to work and getting through ..but it seems the lower I go, the harder it is to come back'' . (p12 Pre course Interview)

**Post course, p12 notes an improvement:**

``Generally I have got a good quality of life. ..I mean ..job and health and car and kids and all that sort of thing,. I have got ..more of a (glass) half full ..than half empty'' . (p12 post-course interview)

**For p7's consultant psychiatrist, quality of life was linked to getting rid of the stigma associated with the illness:**

``Working through the course and the details were very important, like looking at minor episodes in his life .. p7 going to the Citizens Advice Bureau and applying for benefits was an example of his realization that the illness was an external thing ..he was de-stigmatizing the illness and could then receive the benefits due to him by having the illness'' . (p7 Post course Interview Dr 2)

**p1 demonstrates that his quality of life is linked to his mood at pre-course:**

\* P1: ``I would say it's fairly good at the moment. ...Obviously, I've had a little dip the last couple of weeks ...and then you start ...to worry about whether you're gonna..., it's a vicious circle innit, you start to worry that things are gonna get worse... (laughs) and that in itself makes things worse (laughs)''

\* Researcher: ``..are you someone who worries a lot?'' .

\* P1: ``I do. I worry a lot'' .

(p1: pre course interview)

**At 16 months post course, p1 describes the improvement in his quality of life:**

\* Researcher: ``Overall quality of life a year later?'' .

\* P1: ``Far better ..it has been a lot of things together ..actually changing what I eat, that itself has just made my health that much better ..I am looking better .. I didn't think I looked too bad last week. (Laughter). SHE (my girlfriend, emphasis) is always mentioning that I am looking healthier these days .. I was £20, 000 in debt, 2 years ago but that is all clear now, and now I have money in the bank to buy my new car'' . (p1 16 months post course interview)

**At 18 months post course, p1's befriending group organiser notes a change:**

``His quality of life? It is good now. A definite improvement'' . (p1: 18 months post course interview)

**At 18 months post course, p1's consultant psychiatrist attests to improvements in his quality of life and contentment, and a stage in his development that might take place:**

``..it's better .. he would like to achieve more in certain areas. .. that's maybe a phase of change for him ..female relationships and close relationships that might go that way .. certainly, the entanglements that were going on, elsewhere seem to have come to an end, which is good. I think he is actually more content ..that's actually what ..has changed the most ..he's a little bit more circumspect about things .. I haven't quizzed him about it, because I don't need to ..he has changed and now he can still move on with the right relationship'' . (p1: 18 months post course interview with Dr 2)

**p11 at his pre course interview rates his quality of life quite low:**

``..you have to put it fairly low on the scale ..you would have thought, over the last few years ..in general, my quality of life is OK. ..I wouldn't ..have that much cause to complain, but I do. I do think there is something. I do think I have a difficulty ..relating to people at work ... those social relations you have, which are not necessarily the deepest ..friends or whatever. But I feel as though I don't do very well. ..there is something unsatisfying about that. (p11 Pre course Interview)

**At six months post course, p11 demonstrates his change in perspective and resultant improvement in quality of life:**

\* P11: ``I don't have such high expectations. I used to be self-critical.. I don't worry too greatly (now) about my level of accomplishment. I just get on with things and then actually find the enjoyment comes along with it. .. that it is a shift in perspective'' .

\* Researcher: ``Your quality of life?'' .

\* P11: ``Quite enjoyable at the moment'' .

(p11: six months post course interview)

**Controls however did not experience improvements in their quality of life. Changes that were perceived indicated a deterioration resulting from poor mood stability, lack of social support or lack of direction. Mental health professionals were also doubtful as to improvements in the future, given the health status of the controls. Materialistically, a situation might infer good quality of life, but the essential of quality of life, good mental health and a supportive environment were lacking and coloured their whole lives.**

**C1 at post course illustrates his quality of life:**

``Not quite brilliant. NOT (emphasis) own place, not own job, not really that fulfilling, not doing the best from life. Still trying to figure out what he wanted to do'' . (notes taken from c1 post course telephone interview)

**At six months post course, the consultant psychiatrist for c6 demonstrates an on-going poor quality of life:**

``He ..has nothing outside work and the beer. C6 would say an OK-type of lifestyle. He would want to be back with his wife'' (six months post course interview with Dr 4 for c6)

**For c5 quality of life at six months post course was assimilated with physical health and the deterioration she had experienced:**

``I dried out when I collapsed. My lithium levels were high. I woke up in hospital. I think I have deteriorated since then, what with the fall and all'' . (six months post course interview with c5)

**Some mental health professionals acknowledged this poor quality of life due to little contact with family members. At post course, c5's home support worker demonstrates:**

``She does not see her family very often. She had ..limited social support. Sometimes she has loneliness, as she is estranged from her son and her daughter is at a distance away. Her neighbours go with their family and c5 is upset because she is not invited by her family in the same way'' .(post course interview with home support worker for c5)

**However, at post course, Dr 6 demonstrates takes a harsher view of a dependent quality of life:**

``She is now as good at it gets. She has a risk of hypomanic episode but is not currently on extra medication. Her quality of life is good but a bit institutionalised. A lot of contact is with services. She attends a day centre with the help of the home support team and her shopping is done by them. She has a dependent quality of life and accepts it on the health services'' . (post course interview with Dr 6 for c5)

**At six months post course, this home support worker acknowledges on-going poor social support and physical frailty as inferring poor quality of life:**

``It could be better with more family contact and if physically she felt well'' . (six months post course interview with home support worker for c5)

**Other participants generally rated their quality of life poorly despite materialistic comfort. At six months post course, c4 illustrates:**

``I have nothing really to complain about ..Sometime I feel in a rut, I want to go out and do voluntary work, then there are days I don't want to speak. I want to go to bed (after seeing the kids off to school). That puts me off because I would let people down in that case'' . (six months post course interview with c4)

**At post course, c3 rates her quality of life as poor, upheld at the six months course interview:**

\* C3: ``Well, it is not brilliant, but it is not bad either. I suppose about a four out of ten'' .  
(post course interview with c3)

\* C3: ``It is 4/10'' .  
(six months post course interview with c3)

**Control c6 illustrates at post course how his lack of empowerment is linked to poor quality of life:**

``Empowerment? No changes, just keep taking the tablets really. Don't know if I really feel comfortable using a network of family and friends. I Just live me life. I survive. Don't have to focus on where ..with all I used to have. ..Quality of life? 5/10. It's shit'' . (c6 post course interview)

**Controls did not feel empowered. Empowerment was assimilated to illness management with the illness although this was not on a positive footing.**

**Two controls, who had had previous therapy, questioned whether this had been helpful or whether they still needed the medication as they felt well enough without it. Self-esteem and self-confidence were generally low in controls. Such was the low mood or frenetic activity experienced by the control group that they appeared caught up in the present without being able to look to the future. When there was a future outlook, it appeared restrained by the illness and if physical frailties or clinical depression were evident, their future outlook became morbid and led to more dependency upon mental health services.**

**Control 2 demonstrates how her coping, due to previous therapy, is now making her question whether she still needs medication at her six months post-course interview:**

Researcher: ``How is your empowerment? ``  
C2: ``..I have had a little bit of anxiety about staying well ..whether it is the medication or me or the counselling or a combination or what. Do I need to be taking the medication or what? If I don't need it? I am in control enough'' . (c2 six months post-course)

**C1 assimilated empowerment with continuing difficulties in illness management at his post-course interview:**

Researcher: ``Your empowerment?``  
C1: ``Do you mean control? If I did feel slightly stressed, I deal with it. I still have confidence issues, slightly nervous for no apparent reason'' . (c1 post-course interview)

**At her post course interview, c3 illustrated her powerlessness when asked about her thoughts for the future:**

``I have got so much here and now, I can't think about the future .. I am hoping things will actually settle down for me in the Spring. I just really want to get Christmas over with and move on''. (c3 post course interview)

**c5 demonstrates at her post course interview her view of a rather despondent future after an adverse reaction to her medication:**

\* Researcher: ``.. are you hopeful, about the future ..?

\* C5: ``Well, it has got to end innit? ..when he takes me, I shall be quite happy .. that is the way I would like to go. Just like that. The way I went last month. I thought I was going up to heaven ..all I know I was in a lorry or something, and then an oxygen mask..''.

\* Researcher: ``Do you think about death and dying often?

\* C5: ``Well ..you must understand I have had so much grief this year''.

\* Researcher: ``Is it more on your mind now?

\* C5: ``All the time''.

(post course interview with c5)

**Six months later, c5 still shows this morbidity of thoughts:**

\* Researcher: ``Are you hopeful .. of the future?''.

\* c5: ``What future have you got when my age? The only one you've got is where you go, innit? Not a positive outlook at the moment ''.

(c5 six months post course interview)

## **Findings – Part Nine**

**COPING in all its different facets led to MOOD STABILITY and PERSONAL DEVELOPMENT which resulted in renegotiating the ‘system’ to move forward**

**Participants were led to renegotiating their relationships with their individual mental health team or ‘system’ as they progressed with their new skills and new perspective or ‘mind set’ for what they wanted out of life. This renegotiation of the ‘system’ has previously been illustrated in participants developing a more constructive therapeutic alliance with their mental health professionals. Mental health professionals viewed participants in a more positive light due to their mood stability and responsible approach to managing the illness and so their behaviour towards them became more adaptive; participants viewed their mental health professionals as more collaborative and supportive but with their growing independence sought to move forwards towards further independence and change. This dialectical process of change was often not in synchronicity with professionals supporting participants too much and being viewed as interfering or too little in the areas that participants then sought to develop into and were viewed as unsupportive. Professionals remarked on participants’ progress and possible developmental transformation but the recovery model is tinged with scepticism concerning potential relapse.**

**P3 demonstrates how the system is not in harmony with his current wish to move forwards:**

**“It was his life and he should choose how he lived it. He wasn’t getting the support he needed, he didn’t have a social worker, but he was getting all the hassle instead. That community mental health**

team didn't want to see him anymore. He didn't feel he was getting the support he needed, but getting too much restriction from his activities and from his workers at the day centre'' . (p3 participant observations training session 5)

**p4's community psychiatric nurse at post course demonstrates how the training enabled the trainee to be considered for a further training, rather than attend one of the usual groups:**

``p4 had talked endlessly about attending the Thursday club, but her community psychiatric nurse thought that she had moved on from that and mentioned that an anxiety management course would be more suitable and follow on from the In-sight course'' . (p4: Post course interview with community psychiatric nurse)

**p1 who was followed for 18 months post course illustrates his renegotiation of the system.**

**P1 has changed in his outlook towards his mental health professional team and his team has change in their behaviour towards him:**

``..They tend to listen more to what I have got to say ..just the way they treat me now as opposed to the way they treated me before. Not just the day centre manager, my social worker ..my consultant psychiatrist .. they give me more leeway ..they agree with what I am doing ..and they think I am actually doing the right thing most of the time ..We just get on far better at the moment. (and later) I do think maybe that some of these arguments (with my mental health team) could have been because I was more confident, more bolshy towards the other people ..maybe I was ..over confident and ..I came across as being bolshy. Maybe that's why they took the view they did?'' . (p1: 16 months post course interview)

**p1 attests to a change in attitude and treatment from mental health professionals after having been discharged from the day centre he previously attended:**

``..p1 is being treated differently by the day centre manager ..more as a person now, rather than a client, he felt he had a bit more respect from her ..The manager asked p1 what we thought of giving

each new client a red file to keep all their papers in, so that they could come with a file to CPA meetings, rather than a dog-eared piece of paper. P1 thought this a bit novel to be asked his opinion by the day centre manager where once he might just have been told things by her'' .. (p1: observations made during the delivery of the main study group training)

**p1 demonstrates how his relationships with his previous mental health professionals have moved forwards:**

``He had applied to the trustees of the charity he worked for to have the social group he created associated with the charity. This would enable him as leader of the group to gain funding and could lead to using office facilities. He said that the manager at the day centre had applied to become a trustee of the charity he worked for and that his boss had asked him for his opinion about whether the manager would be suitable. He found this very funny as he remembered what had happened at the day centre and being told that he couldn't go for a month. It was like role reversal'' . (p1: notes from telephone call 18 months post course)

**At 18 months post course, the befriending group organiser describes the developing needs of p1, who now volunteers for the befriending group that he previously attended:**

``I am trying to set up a group for those who work, an evening group. P1 has moved through and is moving on in his recovery. The day centre is to offer a structure of support to continue to move on. Only 5 or 6 people have actually gone back to work. This new evening social group might be helpful to become independent and be discharged to a self-maintained group with the local MIND. P1 was going to move on a lot quicker than others, steady progression and the way he got involved'' . (p1: 18 months post course interview with befriending group organiser)

**At 18 months post course, his consultant psychiatrist demonstrates that p1 now has choices he can make in his life:**

``..has the choices now because he is well enough. ..and when he is well enough to make choices about what he wants to do, and if he wants to be looking after people or doing things, that is up to him. I don't think he is now doing things because he is

unwell. I think when people have been well for that amount of time, they have long periods in which they can change those things ..it's their decision ..once it gets to that point'' . (p1: 18 months post course interview with Dr 2)

**At 18mths post course Dr2 describes the changes that p1 has undergone during the time he has been in the study, how his outlook towards services has changed and how too her support and relationship with him is also changing:**

``..he's not been ill in that time ..he's certainly .. become much clearer in his focus in terms of his life, and his being well ..and he's also ..re-orientated .. after the group, he became slightly anti-psychiatry, and then he became a bit more pro-psychiatry. And now he has got a ..balance ..a ..more sensible view, which he can take bits and leave bits. Which has been quite different. And he's ..taking things forward, in a kind of careful but sensible fashion ..that he hasn't before ..(and later) I think he sees us (his mental health team) as being on the same side, ..I think he has moved on. I think (my relationship with p1) has (changed) actually ...I think it has been much easier going the last few months because he's been well ..it's been fairly straightforward. His social worker has a view, that ..she is still assessing him, I know she said it in the last meeting, and she reminds him a bit, about the balance. At the last Care Plan Approach meeting, she was sort of giving a gentle prodding .. which is different than saying .. previously where we have said, ``Don't do it, that's it, just don't do it''. Well, we would (before) have to sometimes take executive decisions in that sense. I think his social worker prompts him a bit, but he is better. I think he is more like, if we said he was alright, I think he is more likely to hear that positively ..And I think he had got more real, he has got this other relationship in other parts like his social group ..outside of the services, so that's different ..I am sure there will be a point at which he could come to see (only) me. .. we are looking at reviewing (his level of support from the social worker) ..because..the support he is getting from his social worker .. is not as intense as it was ..and it is looking to that probably going ..at the moment ..that's occasionally 2 weekly but probably 6 weekly. I am seeing him less frequently. I think there was a time ..when he is not well, he gets stropky . .. he hasn't got to that point, because he has managed things very well, so ..that

has been easier ..he is more trusting, because he believes that it's worth it. I think he feels very differently about it, and I think he does like himself more. So that means he doesn't feel so put down by coming to us. I think, it has settled down ..it has actually worked out in a way that is now kind of comfortable ..he was saying to me that he had talked to another person that had fallen out of the system very badly, and ..he was extremely angry with those people, and had said that, ``my way of thinking isn't like theirs'' . It was differentiating, but was able to laugh about it and recognise it, and say, ``Like they did'', but actually see it as something which he might have got himself into the same situation before, and .. much more able to see it from a distance, rather than sort of flat in front. .. it's just basically been easier. I think he is more comfortable with it, I think sometimes he probably does it less acidulously ..with less kind of, fear, that it is all going to go wrong if he misses a day. I think.. it's the comfort zone that has increased'' . (p1: 18 months post course interview with Dr 2)

**Controls however, in experiencing a mood swing or general deterioration in health, had to call upon their mental health team more often than before they had before the study period. Rather than consulting a community psychiatric nurse or social worker monthly and a consultant every three or six months, these visits were weekly or fortnightly, with regular telephone access. Where physical ill health and old age became a compounding factor in mental stability, home support, whilst necessary, inhibited any further growth rather fostering an increasing dependency upon services. A dependency which was not wished for or adopted easily.**

**At six months post course, the home support worker for c5 demonstrates her increasing support of this control during the study period:**

``There was a deterioration in self-caring abilities. C5 experienced incontinence, it smelt in her flat, so we brought in home care because she was not bathing, had poor hygiene, and to do her shopping. This dependency was worrying to c5. She was bathing in front of strangers, but has accepted this now. She is shaky as she has arthritis. Her blood pressure was up and down. She was initially treated

and responded in an adverse way (with a fit). We thought she had had a stroke and we took her to hospital. She was found unconscious at home. The medication was stopped and reviewed. She was put on another medication, and she responded to it well. It was frightening for her'' . (six months post course interview with home support worker for c5).

**The consultant psychiatrist for c5 illustrates how this dependency fosters further dependency:**

``She is getting more (support) than absolutely required but c5 is not someone who would live independently. Even when she is not disturbed, she needs help in daily life. It (her coping) is limited, with a lack of insight ..she is not empowered because she is used to having things done for her. She does not challenge or question that. There are no expectations for any improvements now ..She attends a day centre with the help of the home support team and her shopping is done by them. She was fairly medicated by the home support team (later) She would have difficulties taking on responsibility. The problem is that she is not very amenable to change. She is not good at psychological insight. She is a difficult client to deal with. '' .  
(consultant 6 for c5 post course interview)

## **In conclusion**

**Like the ‘burrow of little silly things’ (cited from p12) that together contributed to improved coping and resulting in greater mood stability, maintaining wellness and personal and intellectual development, change in ‘mind set’ and resultant positive outlook on self, the future and greater empowerment and quality of life, it was the combination of the individual aspects of the course material that together had such a positive benefit for trainees. This resulted in trainees learning to ‘step a different way’ in their lives.**

**As p9 demonstrates at her six months post course interview:**

``I didn't REALISE (emphasis) like the WHOLE (emphasis) overall thing can have an impact on your health as much. Like food, what you eat and everything ..I've lost nearly a stone ..I have been trying to make changes to my life. I'm just trying to get healthier and fitter and... I don't think I would have done all that if I hadn't been on the course. It's just really.. not ONE (emphasis) particular thing ..it's the WHOLE (emphasis) overall.. lifestyle ..Just recognising that you've got an illness.. and just trying to do just little things. .. just lots of little things... that come together. And ..I haven't been ill so touch wood hopefully it's working (laughs)'' . (P9 six months post-course interview)

## **7 Bringing the Quantitative and the Qualitative together**

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### **MOOD**

The self-report questionnaires indicated promising evidence that trainees demonstrated trends towards a euthymic or more stable mood. Controls however demonstrated trends towards a deteriorating mood: Winter depressive and Summer hypomanic or manic mood. Seasonal fluctuations could account for controls being vulnerable to mood instability; whereas trainees showed trends of stability despite Winter post-course measures and Summer six months post measurement. Overall symptom severity demonstrated trends of improvement for trainees, whereas controls showed trends of deterioration in their symptoms.

The qualitative data suggested that trainees demonstrated trends in improved coping, despite experiencing a mood swing at some point during the study period. By managing their illness, trainees were able to limit its impact and attenuate a mood swing, bringing their mood within the normal range. Controls however showed trends in variation in their mood stability. Some maintained their pre-course mood throughout the study albeit with a longer recovery period post episode, on-going anxiety and fear of relapse (two participants), or gradually worsened in mood due to deteriorating physical health and on-going unresolved issues (two participants) or experienced a major episode with psychosis which severely disrupted their mood and their lives, and necessitated immediate psychiatric support (two participants).

## COPING

Quantitative data for coping strategies gave a fair indication as to the difference in trends between the trainees and the controls. Data indicated that trainees demonstrated trends of increased use of good coping strategies although at the end of the study period there was variability; bad coping strategies used by trainees demonstrated trends of decrease. Controls however demonstrated trends in the decrease in good coping strategies, whilst bad coping strategies showed trends in decrease, although tended to show variability at the end of the study period.

Qualitative data suggested that all trainees demonstrated promising evidence of coping well with a mood swing and were successful in changing their lives so that mood swings were less likely to occur in future. Controls showed that whilst they could be aware of changing moods or lack of support, they were less equipped to cope, to ensure that they adapted their lives or called upon the support they needed to avoid a major mood swing. It was not until controls were not coping that support was called upon. This earlier coping mechanism in trainees helped them deal with a less powerful mood swing earlier by calling on their 'support network' within which their mental health team and additional medication, and prevented it from developing into a more serious episode.

Coping with the illness impacts directly upon mood; however the self-report questionnaire did not pick up the myriad of what it takes to 'cope well' that the qualitative data were able to provide.

Why the controls demonstrated trends of decreased use of bad coping strategies at post-course is difficult to account for through the qualitative data as the reverse is evident with an increase in bad coping strategies, although the

variability at the end of the study period pointed towards some demonstrating trends of being more equipped than others to cope. At post-course, four controls were experiencing an on-going deterioration or worsening of coping skills which later pointed to an major episode for two participants, so it can only be that those who were coping well at this stage were coping extremely well, and skewed the data for the group as a whole.

Another point could be that the self-report questionnaire did not pick up on those skills directly related to coping with a bipolar disorder mood swing per se, rather coping in general.

Why the trainees at the end of the study period demonstrated trends of variability in their use of good coping strategies rather than on-going or increased use of these is also an important point as the qualitative data showed that they were coping well and making further changes to their lives that would ward off a future swing. One trainee at six months post course who did not complete the coping questionnaire as he felt “this no longer applied to him” (p11 six months post-course) may indicate the reason. Rather than using ‘coping skills’ as a separate entity from themselves and viewing these as tools that have to come out of the box in times of need, these skills may have been incorporated into their lives, as a new perspective integrated and a new reflex, that trainees were perhaps not recognisant that they were using these at all.

Six months post study qualitative data suggested that trainees, whilst conscious of these new coping skills post-course with in some cases additional over-awareness of mood fluctuations and the remedies for these, became almost forgetful of the changes they had put in place or how they were now living. It was only when they reflected back on how they had coped with events at the six months post-course interviews, what new ways they were currently adopting,

that they realised with surprise “Who is this person? Oh – that’s me!” (p12 six months post course).

## **EMPOWERMENT**

The quantitative data suggested that trainees demonstrated trends in increased empowerment; controls however showed that trends in decreased post-course empowerment were followed by a trend in increased empowerment at the end of the study period.

The qualitative data indicated that trainees experienced a huge impact on their empowerment throughout the study period as their successful coping with the illness, their mood stability and their sense of control over the illness and their lives gave them new confidence in setting themselves goals of what they wanted to achieve out of life, where previously their fear of relapse constrained their outlook. This sense of empowerment was on a solid footing and set to continually rise. Controls indicated through the qualitative data that they were not empowered. They did not appear to have any sense of control over their lives, or the illness, and lived in fear of relapse or curtailing their activities to ensure against relapse.

Why controls should report trends in decreased empowerment post-course and trends in increased empowerment at the end of the study period could be explained by the adjustments in their mood at these time frames. Feasibly, if reported post-course Winter low mood equates with low empowerment, six months post-course Summer ‘hypomaniac’ mood could also equate with increased empowerment. This scale is therefore a good indicator but not enough in itself to record ‘true’ or valid measurement, in that a ‘healthy’ empowerment is also based on a stable or euthymic mood.

## **QUALITY OF LIFE**

The quantitative data suggested that trainees demonstrated trends in improved quality of life and sustained this improved quality of life during the study; controls however demonstrated trends in variability with little improvement during this time.

The qualitative data indicated that trainees improved and continued to improve their quality of life in its different facets. Some trainees were accepting of areas of their lives they could not change whilst ensuring they changed the areas they could, to improve their quality of life. Trainees experienced a readiness to make major developments in their lives and the confidence to carry these through whilst accepting that some issues were out of their hands ie. new relationships. The majority of controls however, whilst experiencing a good quality of life in the materialistic sense, were very bound by their powerlessness to manage their moods or make changes in their relationships and this coloured their perceptions making their quality of life poor. Mental health professionals and participants linked quality of life to mood stability although it was evident for trainees this now encompassed a much broader view, as their perspective on the illness had changed. Rather than changes made in their lives, they had changed their attitude.

### **Bipolar and non-bipolar participants**

The quantitative data indicated that three non-bipolar trainees taking part in the pilot group (when taken within the pilot group of eight, five of whom were

bipolars), reported fewer trends in improved mood stability, symptom severity, coping, empowerment and quality of life than the trends reported by the bipolars and that this benefit was not as long lasting. However, they generally indicated trends in benefit in comparison with the controls during the study period.

The qualitative data also suggested non-bipolars benefited to a lesser degree than the bipolar trainees. The course was not specific to schizophrenia (one trainee) or schizoaffective disorder (two trainees); however non-bipolars reported benefits from the bipolar-specific content of the course that helped them cope better (for example, the challenging of negative thoughts, belief chaining, mood management). They also reported developing their skills and healthy lifestyle, taking on a new perspective towards the illness and having benefited by the user-led group format and socialisation. They were less open about but also able to address sensitive issues in their lives and make changes and their relationships with their professional team and family improved.

However, elements specific to voices or flashes of disturbing scenes were not addressed in the course although covered in discussions on psychosis. One non-bipolar trainee, whilst not psychotic, was experiencing an unhealthy relationship during the study period that became obsessional. He viewed professionals as interfering in his life as he grew in his empowerment. However, professionals considered him as a person vulnerable to exploitation. It appeared that whilst the bipolars could be (eventually) 'reasoned with', the non-bipolars, and especially this one trainee in particular, were less open to viewing their situation from differing and possibly more constructive perspectives.

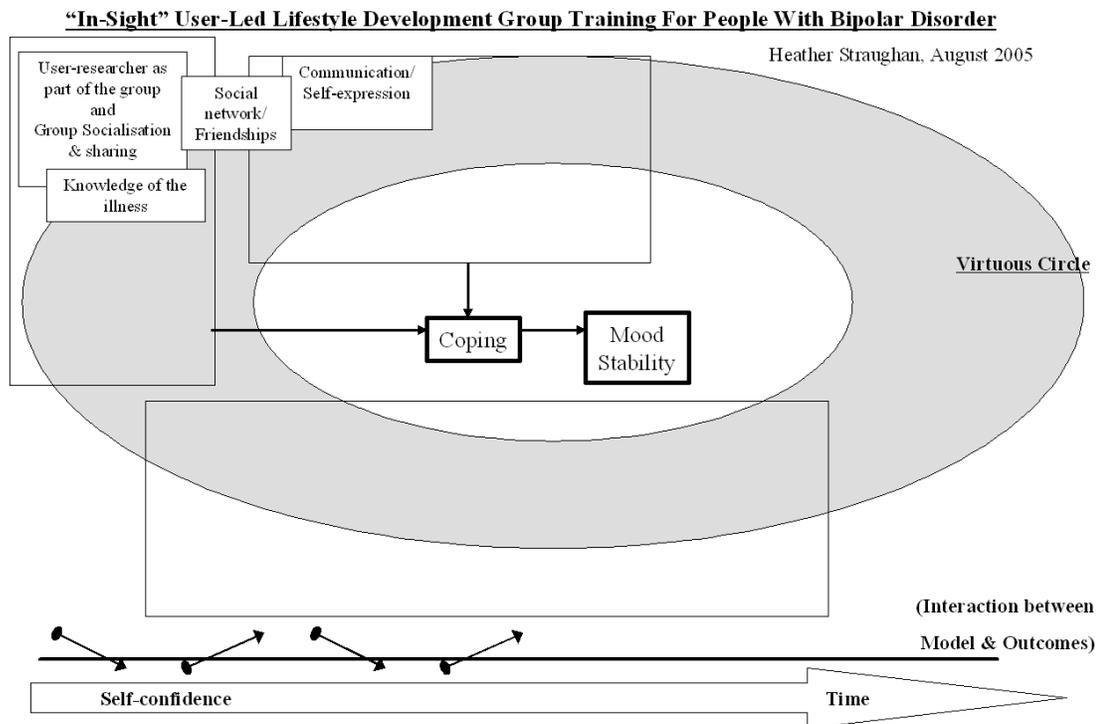
## **8 The Model – How it Works**

## 8 The model - how it works

Please note: the major emergent themes are in capital letters for greater clarity. Please refer to the nine sections of the thematic analysis from which these were derived.

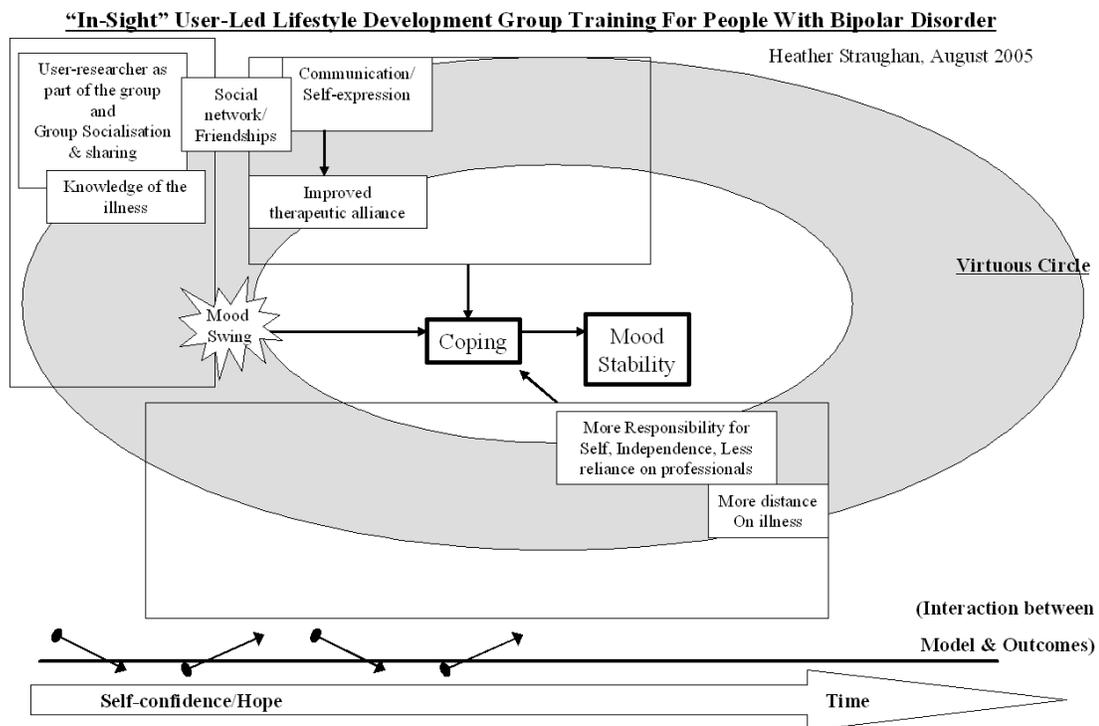
### **Part ONE:**

The user-led training situated within a self-help group format with socialisation and group sharing compounded participants' knowledge of the illness and enabled them to develop a wider social network and friendships within the group. Self-expression and communication were enhanced. This fed directly into and enhanced their COPING strategies.



## Part TWO:

Improved self-expression and communication helped to improve relationships with participants' mental health professionals and improved the therapeutic alliance. This impacted upon their COPING strategies. Coping with a mood swing, with the help of the group support, fed into COPING strategies. Trainees became more responsible for themselves, more independent and less reliant upon their mental health professionals. They had more distance on the illness. These changes fed into COPING strategies.





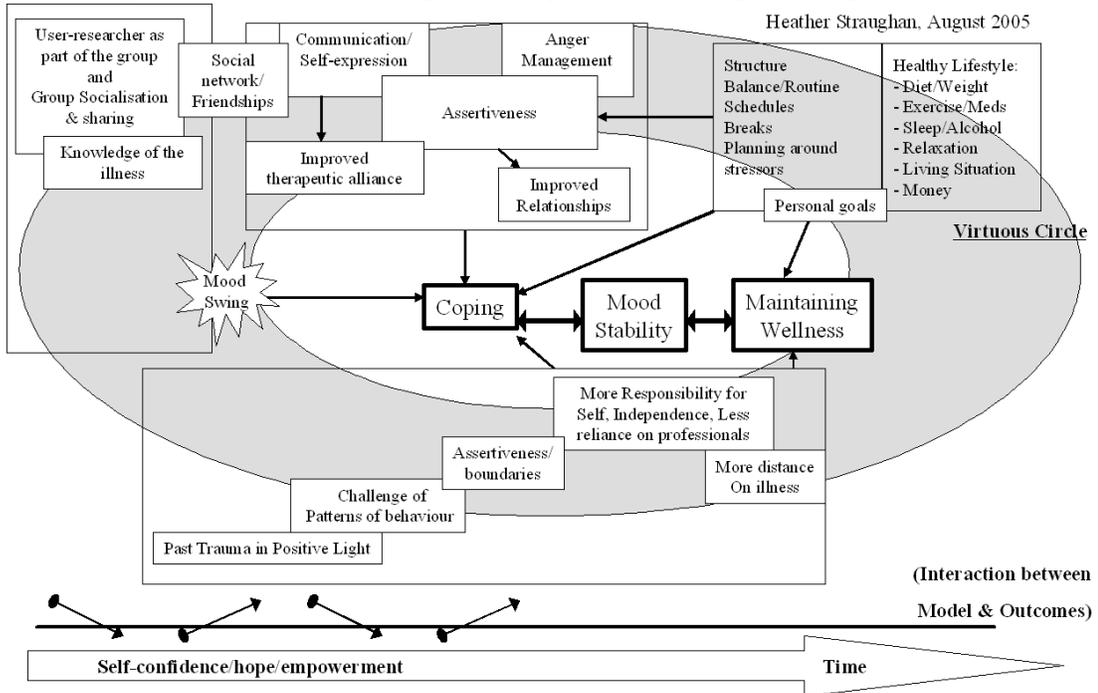
## **Part FOUR:**

The increasing practice of assertiveness and anger management skills enabled participants to improve their relationships with others. This fed into improving their COPING strategies. Addressing past traumas in a positive light and challenging ingrained patterns of behaviour necessitated greater assertiveness and the establishment of improved boundaries with others, resulting in a greater responsibility for self and greater independence from mental health professionals. This impacted upon and improved COPING strategies and helped to achieved MOOD STABILITY.

There was a dialectical relationship between COPING and MOOD STABILITY, between MOOD STABILITY and MAINTAINING WELLNESS. The more participants had a greater range of COPING techniques, the more likely they were to achieve MOOD STABILITY; the more likely they were to achieve MOOD STABILITY the more likely they were to progress to a stage of MAINTAINING WELLNESS. The bedrock linked back to COPING which derived from the various sub-themes that emerged.

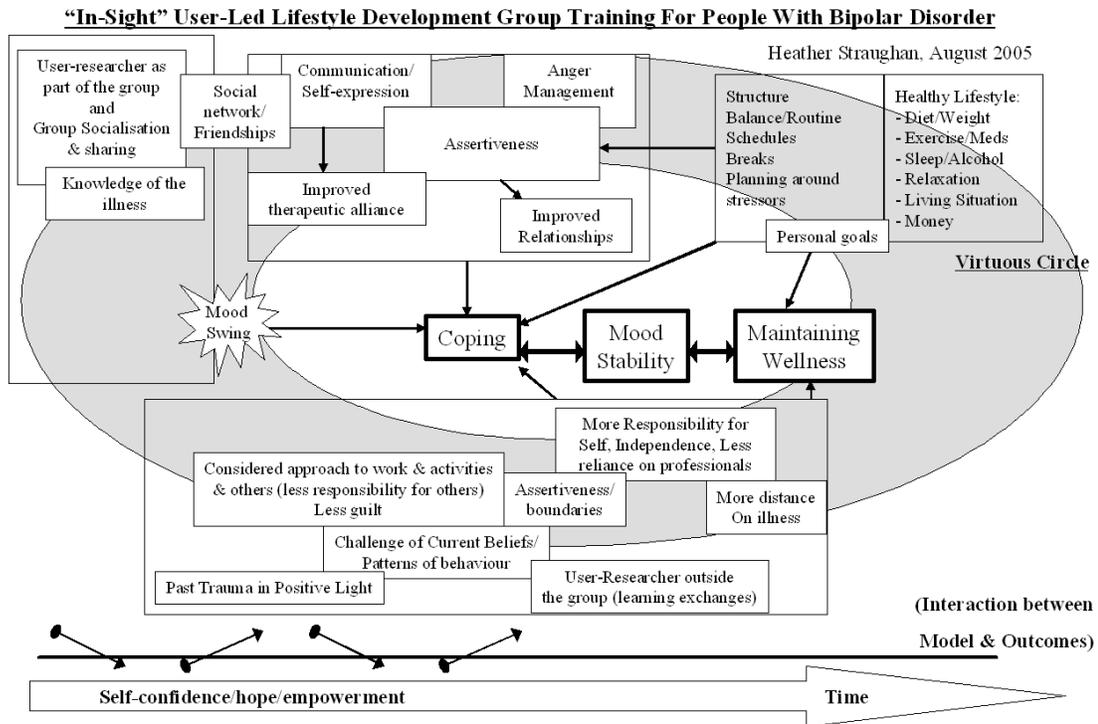
**“In-Sight” User-Led Lifestyle Development Group Training For People With Bipolar Disorder**

Heather Straughan, August 2005



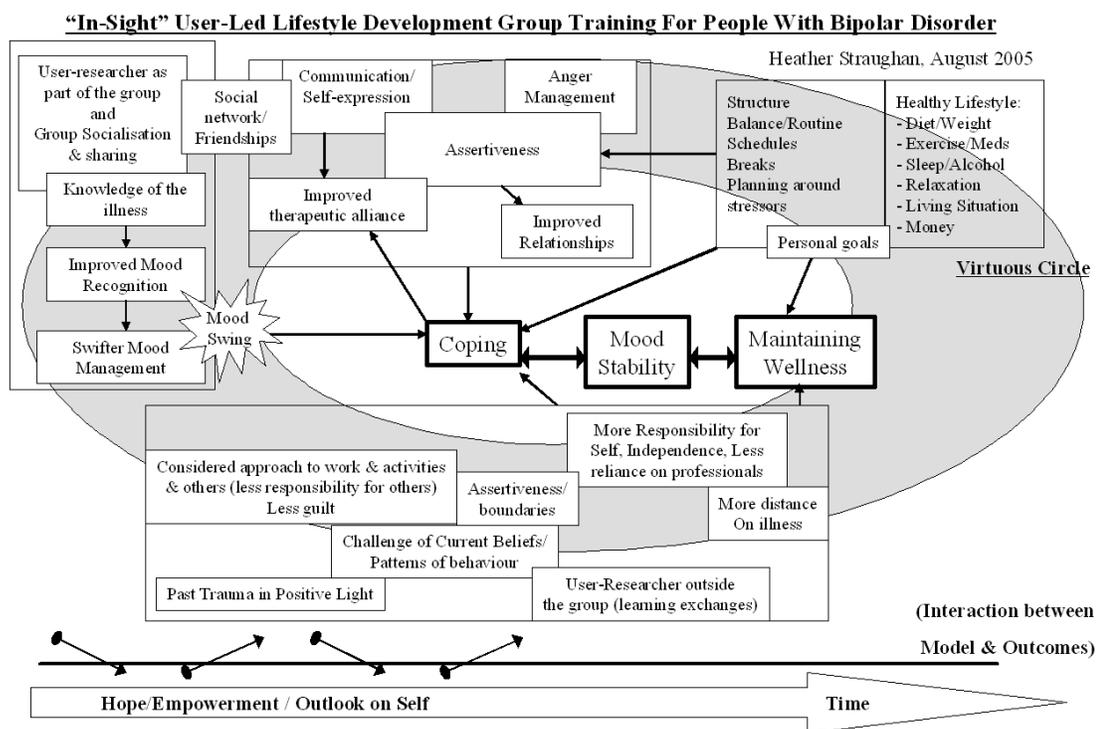
**Part FIVE:**

Intellectual challenge of deeply-seated beliefs and ingrained patterns of behaviour led to a considered approach to work, activities and to others in that participants became less responsible for others. They gradually became less guilty for taking less responsibility for others. This necessitated greater assertiveness and a greater responsibility for self with a growing independence as they gained more distance on the illness. During these challenging learning exchanges within the group, the researcher-facilitator stood outside the group to maintain discipline and continue the learning process. This change of intellectual perspective impacted upon COPING and helped MAINTAIN WELLNESS.



## Part SIX:

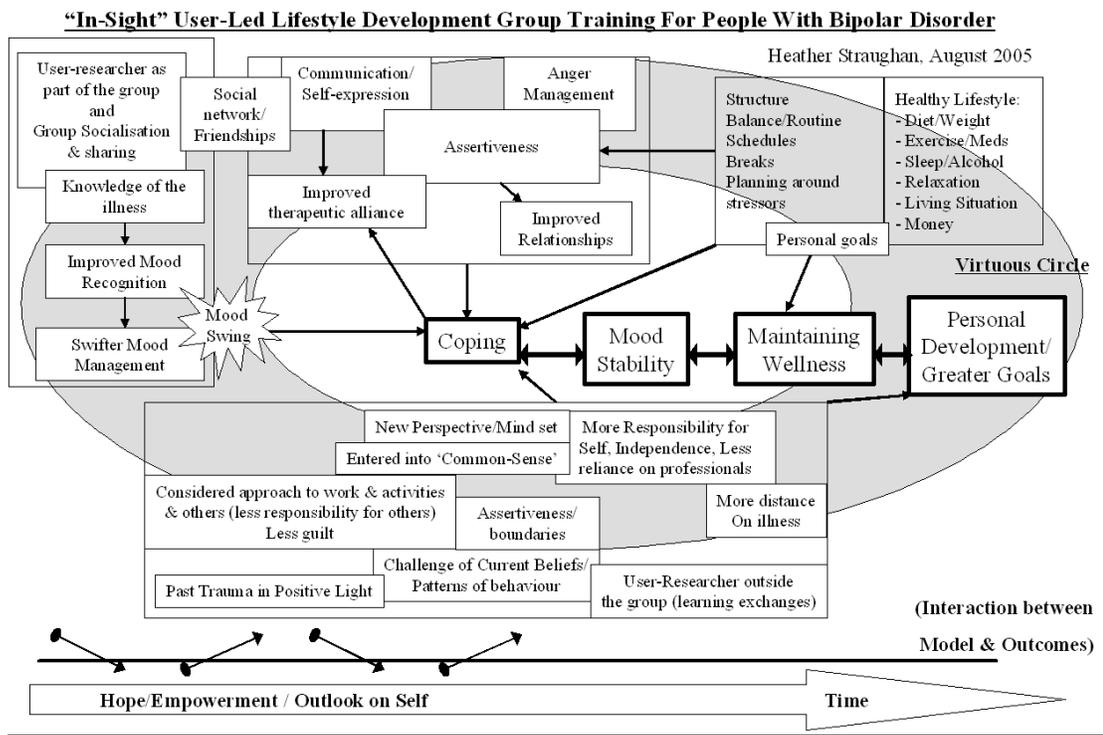
Participants coped with a mood swing by drawing from improved mood recognition and swifter mood management within the self-help user-led format of the training. This impacted upon COPING and enhanced MOOD STABILITY. Coping with a mood swing, which enhanced COPING strategies, helped improved the therapeutic alliance with mental health professionals.



**Part SEVEN:**

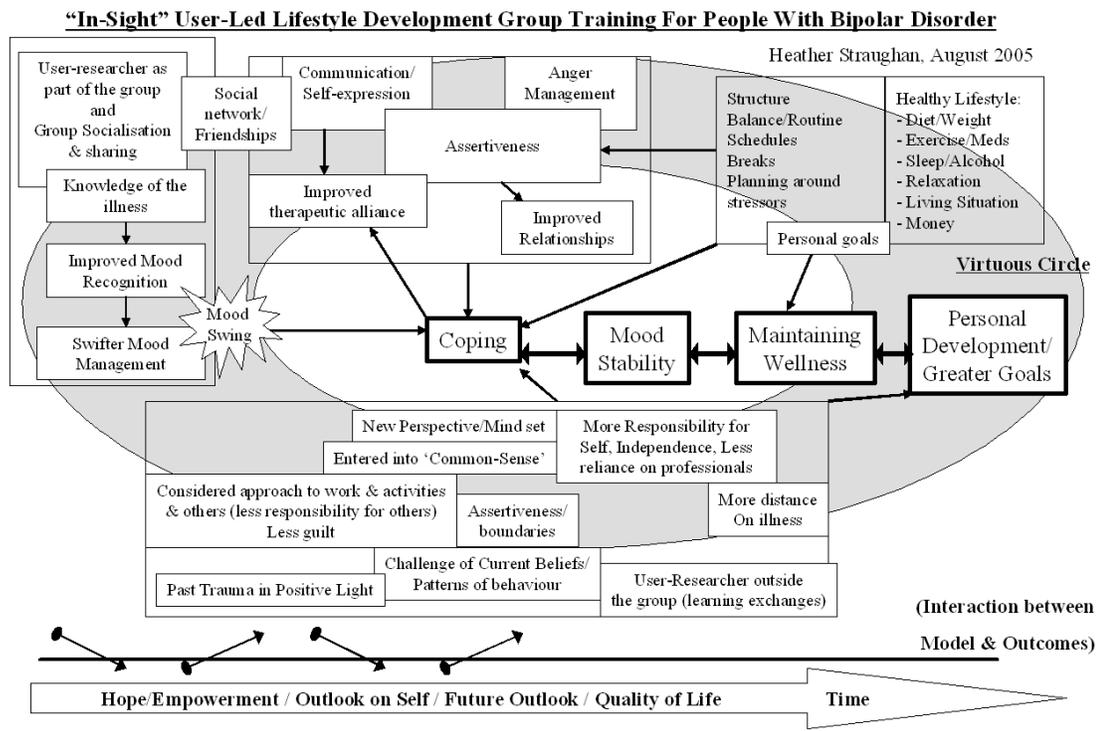
Through intellectual challenge, personal responsibility was incorporated into participants' own common-sense values which resulted in a change of perspective and a different 'mind set' was adopted. This new mind-set improved COPING strategies and helped develop participants' PERSONAL DEVELOPMENT and GREATER GOALS.

This PERSONAL DEVELOPMENT was also as a result of increased WELLNESS which drew from increasing MOOD STABILITY.



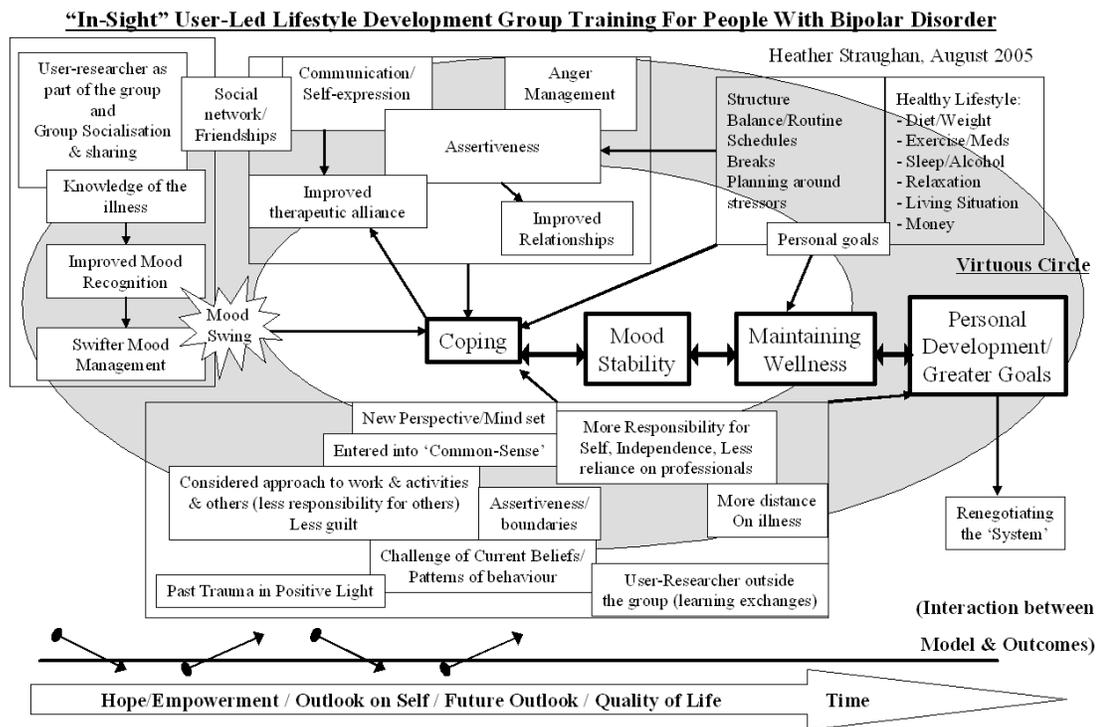
## Part EIGHT:

Throughout the process, outcomes from the combination of COPING improvements resulted in greater hope, improved outlook on self and the future, greater empowerment and improved quality of life.



**Part NINE:**

COPING in all its different facets led to MOOD STABILITY, which led to MAINTAINING WELLNESS and then to PERSONAL DEVELOPMENT which resulted in participants having to renegotiate their own mental health ‘system’ to move forward towards greater personal development.



## **Central theme: COPING**

Each part of the course - whether to do with improved mood management, or skills development, lifestyle components, or the intellectual development of participants all impacted upon and enhanced participants' COPING strategies, either directly or indirectly.

The longer participants maintained wellness, the more likelihood of personal development (which included reviewing the type of work and unhealthy relationships that participants were experiencing) and resulted in greater life changes.

### **Improved COPING is considered as a first level outcome:**

It is considered that without enhanced coping, other areas of development although able to be achieved in part, are not on a firm footing for longer-term benefits. If mood instability results, then the focus reverts back to coping, rather than high developmental areas such as maintaining wellness or personal development. Coping is considered the foundation from which other developments spring.

### **PERSONAL DEVELOPMENT is considered as second level outcome:**

It is only when coping is firmly rooted over time that mood stability results and the focus then becomes one of maintaining longer term wellness. This turns attention to major changes in participants' lives in their own individual context; these include job changes, house moves, goal-setting of new projects or the realisation of dreams or engaging in new relationships. Personal developmental changes are also those which may have been arrested as the illness onset

occurred in adolescence. Whilst coping is part of personal development, this second level outcome of major change in personal development and sustaining this personal development is only possible through long-term coping, mood stability and maintaining wellness. If a mood swing occurs, energies and focus revert back to coping, impacting negatively upon these new life developments as immediate attention is drawn away from them.

MAINTAINING WELLNESS impacts in turn - like a virtuous loop - back into the skills components, the healthier lifestyle, improved mood management and enhanced change of perspective or mind-set, as reinforcing the connections between these.

### **Managing the mood swing**

The 'joker' or 'wild card' in the model is the mood swing - this happened to all participants during delivery of the training or during the follow up period, directly drawing from mood recognition and mood management skills, although this was also aided indirectly from skills improvements, improved life structure and healthy lifestyle and a changed mind-set towards the illness.

Participants' successful COPING impacted upon their on-going MOOD STABILITY. Not only were the mood management components vital for coping with a mood swing, but also the skills, healthier lifestyle and intellectual components were important as they fed into and reinforced COPING.

It was vital that the participant managed this 'joker' successfully, and emerged from this experience as having coped well with it, as this then reinforced the knowledge base in that the whole content of the course was helpful at different stages of the illness, as different skills were needed to cope. All participants who experienced a mood swing during the training coped with it successfully.

This was due to group support and putting into practice new skills which the researcher aided participants to master. Mood swings reported during the six months follow-up were also dealt with successfully. Successful management of the mood swing impacted positively upon a participant's sense of empowerment and control over the illness, sense of hope, added to their self-esteem and confidence, future outlook and enhanced a continually increasing quality of life.

### **Assertiveness**

Above all, the skill of assertiveness was vital to ensure that participants were able to put into practice their new skills, new healthier lifestyle and structure and were able to express themselves and communicate their needs with others, impacting upon improved relationships with others, inside and outside of their mental health sphere or 'system'.

Assertiveness was necessary in order to change deeply ingrained patterns of behaviour and to achieve a new mind-set, put into place new structures and healthier lifestyles in participants' lives and to be able to express feelings and manage anger assertively, thereby leading to improved relationships with others outside of the group.

### **Accessing the model**

Different degrees of this model were at different stages of advancement for the different participants who engaged in the study, depending upon their level of need and willingness to engage and learn and change, their mood state at the beginning of the course and as the course progressed and their level of advancement in this process of learning or lacunae at the start.

It could have been that communication skills were good, but that these did not translate well nor were used assertively outside the group context in a family or work environment.

It could have been that the challenge for some participants lay in an intellectual change, as they dealt with a challenge to and questioned their own deep-seated beliefs and ingrained patterns of behaviour and the thinking and beliefs that lay behind these behaviours, before the participant realised that the practice of other behavioural components were useful for COPING. This represented a major cognitive change first, before more behavioural course components were integrated, for example, improved structure, balance and healthier lifestyle.

It could have been that a change in behaviour was within the initial grasp of a participant, for example, for participants who were less adept at the more cognitively challenging aspects of the course. Behaviour, such as adopting a healthier lifestyle or improved skills, i.e. the tangibles changed before any intellectual change in mind-set was observed. It was through these more behavioural changes that the intellectual change took place in that in experiencing for themselves the effects of their changed behaviour and how this impacted positively on their mood, a changing intellectual perspective was able to form.

In this way, the virtuous circle impact of the training established itself. The behavioural aspects were more readily accessible to some; the cognitive or intellectual challenges necessary initially for others to fully engage with the training; however the one compounded the application and development of the other as both impacted directly upon their own personal experience of mood improvement, thus consolidating and compounding the whole training as helpful as participants were more willing to engage with the material and it was more readily applied.

It was vital that all participants assimilate the elements in the mood management field; however to progress it was necessary for them to assimilate and practice change in the other fields, such as healthier lifestyle or skills development as these areas impinged indirectly upon coping. The progress in the intellectual field was at a varying pace but was necessary for participants to achieve some distance from the illness, and stand back from it distinguishing the illness from themselves, for the training to be fully useful.

### **Final outcomes of the training**

All the while the model was progressing with each field taught, participants became more and more hopeful, self-confident and empowered. Empowerment and sense of being in control resulted in an enhanced feeling of well-being, which also increased with time. Further impacts from the course assimilation over time included: improved outlook on self and better future outlook that were strengthened as the course was assimilated.

As the course was assimilated, to a lesser or greater degree by the different participants, there was an interaction between empowerment, well-being, outlooks on self and the future and the whole In-Sight training content. The more the whole course was assimilated, and the benefits were derived from it, as perceived by the participants themselves in relation to their application of it, the greater their empowerment and improved outlook on themselves and their future became. These positive benefits fed back into and strengthened the applications of the course and its different elements regarding COPING with the illness as a whole. For example, if two elements of the course were applied and positive benefit derived as perceived by a participant, then feelings of empowerment and improved outlook resulted; if many more elements of the course were applied, these resultant benefits were much greater.

## **Personal Responsibility of participants**

From the outset of presenting the course to participants at the very first teaching session and in the introductory letter in the course manual, personal responsibility was promoted. It was pointed out to clients that this was their course, and course manual, and what they would get out of the course would depend upon what they themselves put in as regards time and application and willingness to engage with it. The researcher presented herself as simply the facilitator.

The onus of responsibility was reiterated throughout the delivery of the course. Whilst some participants took this personal responsibility to mean that they could chose not to engage with the material and hence heated ‘learning exchanges’ resulted in which the benefits were pointed out by the researcher and other group members; others understood this as being their opportunity to make real and lasting changes in their lives which they had hitherto not been able or willing to make and hence full engagement resulted with consequent full benefit.

As the training progressed, and at the end of the study period, all participants showed that they had engaged with the course material and were applying it, to a lesser or greater extent in their now changed lives. What had commenced as a teaching that had been delivered, was, at six months post-course, now being represented back to the researcher as having entered the common sense of the participants as they had changed their mind-set towards the illness and what they had applied to their lives from the teachings. At the end of the study period, participants were taking more responsibility for themselves, less dependent upon mental health services, and less responsible for others from whom they had hitherto sought approval.

## **Different and changing needs of the participants**

While all the fields were taught, participants differed in their needs at the start of the course and their needs varied as their moods became more stable and developments were made.

Two examples are given:

- (a) Similarly to the section on “Accessing the Model”, if a participant was experiencing a low mood swing at the start of the course, it was aspects of the training and group support and facilitator guidance on mood management that were important initially. As the participant’s mood became more stable by applying these COPING strategies, it was possible to engage in other areas of the course, for example, self-expression and assertiveness that would enhance the improvement of relationships thus alleviating a low mood swing at a future date or addressing a healthy structure planning around stressors thus alleviating a high mood swing at a future time.
  
- (b) If a participant commenced the training with issues of conflict relating to past trauma or ingrained patterns of behaviour, the intellectual working through of these issues and how they related to present-day circumstances were illuminated so that the participant could then progress to practising their new skills, such as self-expression and assertiveness, in order to make more positive changes to their life.

## **Individual measures in the qualitative interviews**

Following on from this individualised set of circumstances and changing needs that each participant brought with them to the group training, participants were interviewed at pre-course with a standardised semi-structured interview schedule (see Appendices).

However, at post-course and at six months post-course, these semi-structured interview schedules for each participant became more individualised.

The two examples, used in the previous section, are illustrative of how interview schedule became more personal to individual contexts:

- (a) One participant who commenced the training with a post-manic depression, which was brought about by a work-related incident in which he had not been able to express himself and was unlikely to be able to express himself if a similar incident occurred in the future, also had a pattern of persistent low mood without feeling he was able to change this as it stemmed from childhood. During interviews, it was not only the management of this low mood swing that was followed but also any improvements in his self-expression, communication skills and use of assertiveness, together with his drawing up of a schedule so as to achieve a balanced lifestyle. Taken together these elements would alleviate a future mood swing and were followed closely. If this same participant had to go through a major change in mind-set due to a lengthy time with the illness, in order for him to be able to realise the benefits of applying these new skills and healthy lifestyle changes, this change was also considered important to monitor closely in his individual interviews post course and six months post-course (main study participant no. 11)

(b) If a participant commenced in a euthymic mood, but had experienced a persistent low mood due to childhood experiences (main study participant no. 12) or unstable mood due to a distant incident (pilot participant no. 4), then likewise a number of issues were followed in interviews: their intellectual development, addressing of past trauma and challenge to their ingrained patterns of behaviour in addition to their assertiveness with significant others and mood management techniques, so as to alleviate a future low mood. All these elements formed part of these participants' individual post- and six months post-course interview schedules.

Changes were measured in the individual according to their personal start point compared to their own personal end point, immediately after and six months after the course was completed.

### **Learning Exchanges: researcher-facilitator both inside and outside the group**

The nature of the group sessions, user-led, were vital to the impact of the fields on the individuals as the sessions were not only didactic but also group therapies in which individuals situations were shared and discussed in relation to the previous weeks and the course material.

It was a chance to offload long-term situations, examine intellectual approaches and different coping strategies, swap ideas and exchange on painful situations and grow. Debate and heated learning exchanges were sometimes needed to challenge difficult participants who were resistant to change. Other participants lent weight to the researcher's teachings. The group was both self-supporting and acted as a microcosm of the individual's larger world, a cathartic safe space, a time for self and one that was missed when the course ended.

Growth was also present for the co-trainer and researcher, as arguments were defended and course reminders served to strengthen the belief in the course material and impacted upon its continued use.

The researcher-facilitator in these group sharing and learning experiences was considered as part of the group, as a ‘similar other’ having experienced the illness herself. However, when there was resistance to change and challenge of ingrained patterns of behaviour, the researcher stood outside the group. This was necessary in order to continue learning for the whole group. At these moments, given the didactic nature of the course, and to maintain authority as group leader, the researcher was supported by the group as participants were by that time experiencing their own benefits from the course and so lent weight to the challenges put forward by other group members.

### **Drawing it all together - A synthesis of the Model**

Whilst theoretically, a model has been presented to show how each different therapy and technique have been drawn upon to create hypothesis of outcomes (c.f. Hypothetical Model), the emergent themes and the synthesis of how the training impacted upon participants in comparison with controls is illustrated by the section on Building the Model.

The Main Model (detailed) has been built up, from the thematic analysis through nine different but overlapping stages, to construct the full model.

It has been illustrated that whilst the major theme resulting from the training has been that of improved COPING strategies, these included improved mood management and mood recognition, situated within the user-led self-help group format, improved mood management techniques and ability to cope with a

mood swing, the development of a number of life skills, of a healthier lifestyle and structure, and the improvements in intellectual perspective or mind-set towards coping with the illness and increased responsibility of self .

Together these contributory themes compounded in a virtuous circle to increase and enhance a participant's overall COPING techniques with the illness either directly or indirectly.

Improved COPING led to increased MOOD STABILITY.

Increasing MOOD STABILITY allowed participants to continue to MAINTAIN WELLNESS.

MAINTAINING WELLNESS resulted in greater PERSONAL DEVELOPMENT and enabled participants to renegotiate their place within the context of their developing mental health system.

Additional outcomes of this process were found not only in the various course components per se as participants practised these (e.g. increased skills, healthier lifestyle, mood management) but also in their increasing EMPOWERMENT, better OUTLOOKS (on themselves and their future) and an improved QUALITY OF LIFE and an ever-growing new mind-set towards the illness that had previously challenged their belief systems.

There was an intrinsic linking in of each contributory theme to form the major tenet of COPING and an interrelationship between each contributory theme. The group provided the 'nucleus' in which participants explored their understandings and new skills, and the group served as the springboard towards integrating these new ways of being into their own lives.

## **9 Summary of Main Findings**

## **9 SUMMARY OF MAIN FINDINGS:**

- (1) The primary hypothesis was that participating in the user-led lifestyle development group training “In-Sight” would result in trends in improved mood, coping, empowerment and quality of life in comparison with controls, as reported in the self-report questionnaires. There is support for this hypothesis:

Participants reported trends in a continually more stable mood during the study period; trends in a reduction in overall symptom severity which were sustained or reduced further at the end of the study period; trends in immediately decreasing and further decreasing the use of bad coping strategies at the end of the study period; trends in immediately increasing their use of good coping strategies with variability at the end of the study period; trends in a sustained increase in empowerment during the study period. Trends in quality of life showed improvement immediately and continued to improve at the end of the study period.

In contrast, however, controls reported trends in mood fluctuations indicating Winter depressed and Summer hypomanic or manic moods; trends in a general worsening or variability in their overall symptom severity; trends in an immediate reduction in the use of bad coping strategies with variability at the end of the study period indicating maintenance of pre-course levels; trends in an immediate reduction in the use of good coping strategies with an overall continuing decrease in good coping at the end of the study period; trends in a reduction in empowerment post-course (Winter) with increased empowerment at the end of the study period (Summer). Trends in quality of life were reported as variable during the study period.

In comparison with the bipolar participants as a separate analysis, the pilot group, of which three participants were non-bipolars, generally reported trends in improvements to a lesser degree and of less sustainability; however, in comparison with controls, they reported trends in benefit after the course and trends that were sustained at six months post-course. Seasonal mood fluctuations – depressed Winter and hypomanic Summer moods – may possibly explain decreased Winter empowerment and increased Summer empowerment scores in controls.

(2) The secondary hypothesis was that participants would enhance their general ‘coping’ skills and be able to develop their lifestyle within their own individual and specific contexts compared to controls, as rendered by participant interviews, mental health professional interviews, medical note analysis and participant observations in the thematic analysis of these texts. This is support for this hypothesis:

The user-led training within a group format appeared to enhance the learning of the course material and enabled participants to improve their coping strategies. Trends in improved communication skills led to improved relationships including those with mental health professionals and impacted upon trends in improved coping. Trends in the adoption of a healthier lifestyle and improved structure impacted upon improved coping and helped maintain wellness. Trends in the increased practice of assertiveness and anger management skills improved trends in coping strategies. Addressing past traumas and ingrained patterns of behaviour within group exchanges resulted in trends in increased assertiveness and improved coping. Intellectual challenge of deep-seated beliefs led to trends towards a change of perspective and increased personal responsibility that impacted upon coping. Trends in improved coping with a mood swing impacted upon general coping skills and enhanced mood stability. Through intellectual challenge and personal responsibility a different ‘mind set’

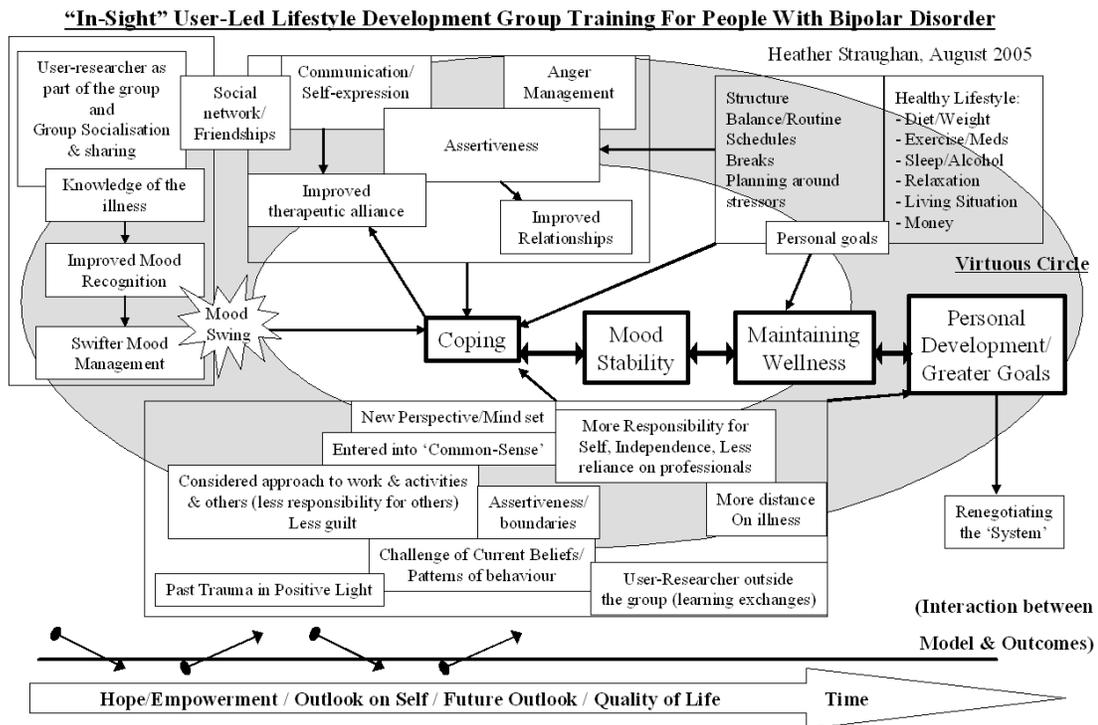
was adopted which enabled improved coping strategies and aided personal development. A variety of lifestyle improvements were derived through enhanced general coping skills: improved outlook on self and the future, greater empowerment and improved quality of life. Coping, in all its different facets, led to trends in greater mood stability, maintaining wellness and greater personal development, which resulted in renegotiating the mental health 'system' to move forward.

Controls however showed none of these trends in improvements. Four out of the six controls continued in their unhealthy lifestyles and their general coping deteriorated with resultant mood instability. For two of these controls relapses were noted (clinical depressions with psychosis) requiring additional support from their mental health professional team. A third control, after undergoing concurrent therapy, still showed vulnerability to future relapse. The remaining two controls showed trends of gradual improvement although with some variability, one of whom had undertaken several previous therapies.

## PRINCIPLES & RELATIONSHIPS ESTABLISHED

Drawing from the themes that emerged from textual data, it is possible to construct a model to clarify how these themes link and lead to one another.

The model presented here is fully developed in the chapter on The Model – How it Works.



It is plausible, when referring back to the Hypothetical Model (c.f. Methodology), that in drawing from the different therapies used in bipolar psychosocial interventions and recovery-based foundations of the training, user-led within a self-help group format, that these many and varied trends in outcome emerged.

## **10 Discussion**

## **10 DISCUSSION**

### **Initial concerns abated**

The training was welcomed by both participants and professionals and confirms evidence that combined therapies receive approval by service users (Seligman, 1995). There were also concerns expressed by professionals about how the user-led training might interfere with treatment (Salzer et al., 2001; Chinman et al., 2002). However, these concerns dissipated as the study progressed. The participants were observed by mental health professionals as deriving benefits from the training; in turn mental health professionals benefited indirectly through their participants' progress. Support for the study increased as mental health professionals noted that their consultations with participating clients were later more straightforward with more knowledgeable, more responsible and more articulate outpatients who were more responsive to medication and its benefits and that the training included recognized clinical therapies. Concerns abated also when it was recognised that within coping strategies in the training, medication adherence and contact with the mental health professional team were advocated.

Concerns were noted from consultant psychiatrists that their participants might be demonstrating 'symptom centric' tendencies immediately after the course; however these dissipated at six months post-course when this new information on illness recognition and management had been integrated into participants' personal knowledge base and issues had time to settle. This was more

noticeable for participants with a secondary disorder such as anxiety or panic. At six months post-course, however, these participants became more centred and self-assured. This is in line with Van Gent & Zwart's (1991) findings that psycho-education in families increased anxiety during the initial stages of the therapy, although resulted in increased well-being later on.

### **Season fluctuations: questioning the measurement tools**

Quantitative data indicate trends in greater mood stability and fewer symptoms during the study period for participants compared to trends in worsening mood and symptom severity for controls, which illustrates that seasonal fluctuations are present in bipolar disorder. There is some evidence in interview data that Winter depressions and Spring/Summer high moods were evident in participants before they followed the training and for controls these fluctuations persisted, resulting in two controls experiencing major episodes during the study.

Trends in improved and sustained empowerment for participants during the study period compared to trends in decreased empowerment in Winter and increased empowerment in Summer in controls also indicate that seasonal fluctuations are present in empowerment, as measured by the self-report questionnaires. Empowerment fluctuations are possibly associated with fluctuations in mood and hence prone to seasonal variability.

Interview data indicate that it is rather a continued decrease in empowerment in controls that emerges during the study, not the increase that is identified through self-report questionnaires at six months post-course.

When examining the five concepts employed to measure empowerment in the Rogers et al. (1997) self-report scale: self-efficacy/self-esteem,

power/powerlessness, community activism, righteous anger and control over the future/optimism are included. The scale was derived from work undertaken by Rogers et al. (1997) with leaders of the American self-help movement and validated with participants from six user-run programmes in six different American states. It was validated a second time in further work undertaken on an outpatient population receiving mental health services in South Carolina (Wowra & McCarter, 1999). However, validation was not verified on a group of people with bipolar disorder, only mental health generic populations using these services. This measurement tool, as defined by mental health service users, was considered the best on offer albeit with further testing on certain populations still remaining to be done.

It must be questioned whether this scale is a valid one when applied to people with bipolar disorder, as, on reflection given the discrepancy between the qualitative and quantitative findings regarding empowerment in this study, several of these concepts could be viewed as mood dependent and hence may fluctuate according to mood state. For example, in a low mood, it is plausible that a person feels they have little control over their future or has poor self-esteem; conversely in a high mood, it is plausible that a person's possibly unrealistic optimism has increased or they feel more powerful and are more expressive about their anger.

Employing an empowerment scale that stands alone, without being associated to stable mood as indicated by another scale, or without a mood component within the empowerment scale, may not be a valid indicator in bipolar studies.

Further, it is of concern that the empowerment scale used in this study has also been considered a scale useful to measure the same concepts present in 'recovery' (Allott et al., 2002). Likewise, one must be careful to associate recovery scales with mood stability for this bipolar population, as euthymia is

inherent in recovery although perhaps not the essential focus of it, as is appropriate empowerment, else we might find that we measure the success of an intervention through increased numbers of participants having ‘recovered’ and greatly ‘empowered’, albeit hypomanic or manic. Further studies on this Empowerment scale with a bipolar population are recommended.

### **Participants coped better – Whatever that meant to them**

Data indicated trends that participants increased their good coping strategies and decreased their bad coping strategies that were sustained changes at six months post-course. This contrasts with trends for controls who, although aware of what constituted good and bad coping appeared powerless or unmotivated to change and who continued with their ‘usual’ coping style. This resulted in continued unhealthy coping for four controls, of whom two relapsed during the study.

Coping is dealt with in some detail in the qualitative findings (Part 6, Section 6) and is defined as the central tenet in the hypothesis (Part 4). Coping in this study is defined by the researcher as being the sum of all the techniques that are needed to live with and despite the illness, not simply illness management at times of crisis. Good coping is likened to recovery. Good coping is the amalgam of what is needed not to have to reach the later stage of illness management but also includes successful illness management.

Whilst changes in the use of good and the avoidance or minimisation of bad coping strategies are apparent in the trends for participants, what emerges from the data are the wealth and variety of coping techniques used by participants, depending upon their mood state, their skills deficits, the lack of structure in

their lives, their unhealthy lifestyle, their limited social circle and how intellectually ready they are to embrace fundamental change in their lives. The trends in data showed that all these various coping techniques were used by participants.

The study supports the research on how a self-help group of similar others can promote wellness and problem-centred coping (Ah-Mane, 1999) and that being in a group of others sharing similar experiences can be helpful for group members to feel more understood, less isolated, achieve greater empowerment and increase their coping strategies (Helgeson & Gottlieb, 2000).

In using a variety of techniques to cope, the findings also support previous evidence of the importance and the use of a variety of non-medical aspects (Baker, 2002) which are not accorded importance by mental health professionals, however impinge upon coping with the illness. This is borne out by the emphasis accorded by the consultant psychiatrist who followed P1 for 18 months in this study and by the emphasis accorded by the research assistant in her analysis of qualitative data for this participant (c.f. Analysis section in the Methodology). In their use of a number of current professionally-derived techniques present in cognitive behavioural therapy, interpersonal and social rhythm therapy and family interaction styles, participants confirmed the importance that this range of current therapies is needed for recovery from bipolar disorder. Firstly, let us deal with the importance of the group.

### **The group – more than the sum of its parts**

Participants appeared to benefit from the opportunity to share similar experiences and learn from each other. No participant had previously benefited from this self-help format. Participants found the catharsis of self-help extremely positive to be able to deal with different kinds of loss engendered by the illness. This supports Solomon et al.'s (1995) findings of the usefulness of self-help groups in being able to deal with loss. For participants, it may have been lost hopes of future careers, or redundancies due to episodes, or loss through difficult childhood experiences that had resulted in set patterns of interacting with family or friends. Participants were able to use the group to revisit their lifestyles and events leading up to an episode.

The 'safe space' environment of the group appeared to offer participants the much-needed time to offload and grieve whilst working towards ways of resolving a variety of life issues in a positive way. Some had deep-rooted family or interpersonal issues that had remained unresolved; some remained traumatized about past episodes. The weekly sessions provided a safe holding environment to review expectations and life goals and work towards taking back responsibility and control over the illness. Participants widened their horizons, although in a more rational and grounded way, rather than lowering their sights or future plans, which contrasts with the findings on downward adjustment of expectations by Mason (1998) and Wahl (1999).

Rather what emerged from the findings appeared to be that whilst previously held expectations were grieved over, what remained after the training was 'making the best' of the situation they now found themselves in. In times of low mood participants did not reinforce their previously held high expectations and so prevented self-criticalness thus reinforcing a low mood. In times of euthymia, and guarding against a high mood, participants practised balanced structures that sought to limit focus although still set and pursued their goals.

Participants demonstrated that goals were within their reach where previously they had not thought this possible, albeit now framed in a more realistic way.

The group format aided participants to explore their experiences of stigma and discrimination. They became more honest with themselves and open with others about their illness, especially with new employers, and hence increased their feelings of self-esteem and hopefulness (in contrast with the difficulties found in the work by Jameson, 1998 and Wahl 1999 although confirming the conclusions drawn by Morris et al., (2005) that providing care that maximises client hope is important). Participants used the group as a supportive sounding board, a point of solidarity and gained strength from other group members' experiences and comments on their own situations, learning how they would deal with issues of stigma when they arose in future, rather than keep these repressed and burden themselves with these painful feelings. Participants reported having missed this group time of support and additional social circle when the study concluded confirming work by Johnson (2003) on the importance of social support.

### **User-led training – an effective message**

Participants and mental health professionals reported trends which confirmed that having similar others to deliver the training was helpful in strengthening the actual training content taught. Having the knowledge of the illness and the sensation of it were considered important especially where participants resisted change. This would confirm findings by Dion & Pollack (1992) regarding similar others being able to challenge others in denial and being able to offer credible explanations and reasons for behavioural and cognitive change, especially for those recently diagnosed or having experienced the illness for many years. This is reflected in the 'heated exchanges' (in Section 5 of the

Qualitative Findings) that occasionally took place during delivery of the training and later resulted in major changes in participants.

The user-led element of the training appeared to enhance the therapeutic alliance between the participants and the para-professional facilitators. This understanding reinforced the self-help group format impacting more strongly upon the techniques of illness management. Learning was enhanced by the lived experiences of the facilitators. Trust was not an issue to be worked at; it was an underlying foundation from the start of the group training. The “more than the sum of the individuals” resource-pooling of a self-help group format and enhanced socialisation during and after the group training served to reinforce the training content and create a social support system.

As communication was often a difficulty for participants when they commenced the training, having a similar other delivering the training provided this common language and established a trusting relationship besides living, not just teaching, a more positive lifestyle confirming work undertaken by Abdul-Quader (1992) on the benefits of employing service user role models.

The co-facilitator, formerly a pilot participant, demonstrated that in delivering the training one year later, he could effectively model a better life. This confirms the work done by Ward & Brown (2003) and confirms Wilson & Leary’s work (1980) in illustrating how this modelling then had a beneficial effect on the co-facilitator’s self-esteem and his status within his peer group. The co-facilitator demonstrated promising evidence that he had continued to further his own recovery whilst delivering the training and until his final follow-up interview at post 18 months. He had strengthened his own prestige and at the end of the study period was progressing the independence of his own social group he had founded through his awareness of his own need for a social support system and how others would also benefit from this group support.

Given the impact of this commonality of language, understanding of the illness and shared experiences giving rise to a more easily achieved therapeutic alliance between user-facilitators and participants, and equity of efficacy between professional and para-professionally-led interventions (Bright, Baker & Neimayer, 1999), it might be interesting to pursue a comparison of training delivery between professionals in comparison with bipolar diagnosed trainers in a later study.

### **Coping is not just illness management**

Participants demonstrated trends in successfully coping with both high and low moods. Their trends in resultant mood were more stable in comparison with trends in deteriorating mood for controls. This is in line with findings by Colom et al. (2003) which showed that significantly more participants receiving psycho-education remained well after a two-year follow-up compared to controls, in that they experienced fewer hypomanic, mixed and depressive relapses and days hospitalised. These findings are also in line with individual psycho-education delivered by Perry et al. (1999) in that participants in this study also experienced fewer manic relapses.

Participants in this study demonstrated promising evidence that they were more responsible towards and more responsive about taking medication, and about changing medication when their mood state required this. A few participants showed that they were later able to self-manage their medication in times of crisis, within pre-agreed limits and with the support of their psychiatrist, which avoided a relapse and hospitalisation. These findings are in line with other studies that showed that psycho-educational approaches improve medication

adherence (Clarkin et al., 1998; Colom et al., 2003a; Colom et al., 2005; De Andre et al., 2006).

Participants demonstrated promising evidence for the necessity and effectiveness of structured illness-specific therapy for people with bipolar disorder (Colom et al., 2003). However, whilst illness-specific therapy is incorporated into the only other British user-led approach established by the Manic Depression Fellowship, coping with the illness was demonstrated in this present study as being much more than the use of selected illness management techniques alone.

However, trends in better mood recognition and swifter mood management, although successful, only contributed to one part of coping with the illness from the perspective of participants, whereas illness management was equated wholly with coping from the perspective of professionals. What emerges from the data is that whilst illness management appears to be essential to maintaining mood stability, there is more to coping, and therefore more to mood stability, than illness management per se.

From the section on the Model and how it works, derived from what emerges in each of the nine sections in the qualitative data, all of the techniques and support that were used by participants were instrumental, directly or indirectly, towards establishing trends of enhanced coping. These cover the self-help group format, the user-delivery of the training, together with improvement in social skills, structure and balance, healthier lifestyle, goal-setting, intellectual change of perspective and illness management. All of these together contributed to trends in improving participants' coping strategies.

These findings are in line with work undertaken on group psycho-education (Colom et al., 2003, 2005), cognitive-behavioural therapy and the Sense of

Hyper Positive Self (Lam, 2005), the Life Goals Programme (Bauer, 1998, 2001) and Social Rhythm Therapy (Frank et al., 1997, 1999, 2000) which point towards all of these individual elements contributing to successful coping with bipolar disorder. The findings from this study are also in line with the group as a social support (Johnson, 2003) and the satisfaction emanating from group interaction (De Andre et al., 2006).

For mental health professionals, their focus resided in whether the mood was stable and whether this stability was sustained in maintaining wellness, ie. the outcome of improved coping, not effectively whether the person was coping well. This only became an issue when the person's mood was unstable ie. that a person was not coping well. This resulted in professional concern that the mood may deteriorate further and interest as to possible causes for this deterioration. It resulted in immediate referral to their treating psychiatrist, additional outpatient appointments and increased support by the whole professional team engaged with the participant. This was noticeable in the two controls who relapsed who increased their contact with their mental health professional team to weekly and then fortnightly contact, with on-going support during the week if necessary, which was sustained until the mood stabilised.

For participants, however, this help-seeking behaviour at an earlier time than previously for high moods resulted in their being reassured as managing their illness well and their being 'prompted' and encouraged by their mental health professionals to maintain mood stability without the need for additional professional appointments. For some mental health professionals this earlier help-seeking behaviour was considered unnecessary, as the mood appeared stable enough not to warrant attention. Participants became more open with their mental health professionals about how they were coping and what factors were contributing to their good health and what they felt were underlying unresolved issues that may point to on-going stressors, with the purpose of

improving their coping of these issues. For example, on-going ways of interrelating that had, in the past, provoked a mood swing that they now wished to explore.

Participants, whilst distinguishing what appeared to be the principle focus of concern for mental health professionals, especially consultant psychiatrists, ie. mood stability, were more discerning as to issues that they themselves considered important but which they found were of less or no concern to mental health professionals. For example, the reasons behind their past medication non-adherence, or why they had in the past welcomed a high mood, or issues in their lives that had emerged whilst in a hypomanic or manic state. These were noted by participants as being outside the domain of psychiatry; however they were considered important for participants to explore for themselves within this domain to further improve their coping skills that impacted upon their sustained mood stability.

Nor did mental health professionals concern themselves with the further personal development of a participant's long-term maintenance of wellness which was sustained by good coping; this, like what actually contributed to good coping, remained unexplored until mood instability occurred, as this was likewise considered by some professionals as outside the domain of psychiatry, although indirectly impinging upon it.

In contrast, participants demonstrated that it was through their usage of every component in the In-Sight model that contributed to their mood stability, ie. improved coping employed by participants enabled them to successfully manage the illness at times of mood swing. However, participants also demonstrated that it was in their building up and application of these components that warded off the necessity to actually have to use this 'last line

of defence' to maintain a stable mood, ie. their use of illness management techniques.

It is possible to argue from these findings that, given the hypothetical model that consolidated known beneficial therapies and techniques with a holistic recovery base situated within a self-help user-led group format, trends in improvement are various and numerous. It is also possible to argue that participants, in comparison with controls, demonstrated trends in managing both high and low moods. Interestingly, what emerges is that whilst dealing with a mood swing was vital to maintaining mood stability, these various and numerous coping strategies were employed by participants to be able to avoid, attenuate or cope effectively when this occurred. Referring back to the literature might explain why this holistic training has demonstrated promising evidence of effectiveness in aiding participants.

### **Coping –the sum of the therapies and more**

It has been noted in the review of the literature that this complex illness requires a combined, integrated approach for illness management. Whilst Perry et al., (1999) found that their cognitive behavioural participants benefited from improvements in time to first manic relapse, improvements in time to depressive relapse were not established; however, help-seeking behaviour elicited from professionals defined improved time to relapse. In contrast, Scott et al. (2001) and Lam et al. (2003, 2005) found that cognitive behavioural techniques were useful for depressive but not manic relapses. Interpersonal and Social Rhythm Therapy and Family Focused therapy have been helpful with depressive, not manic, relapses (undertaken in several studies by Frank et al. 1997, 1999, 2000 and Miklowitz et al. 1996, Miklowitz & Simoneau, 2000 respectively).

Frank and Swartz (2004) in their instability model of relapse, adapted from Ehlers, Frank and Kupfer (1988) showed that besides biological vulnerability, several factors might indirectly provoke an episode - medication non-adherence, disrupted social rhythms and life events with personal meaning – mediated by factors such as coping strategies and social support.

However, the therapeutic components present in these therapies were each beneficial to ensuring good coping and hence greater mood stability in participants.

Confirming the work undertaken on Interpersonal and Social Rhythm Therapy (Frank et al., 1997, 1999, 2000), the data showed that participants demonstrated trends in improvements from enhanced structure to their schedules to obtain their necessary sleep quotas, balance, routine, goal-planning and breaks and that these helped to modulate environmental stress for participants. Healthier lifestyles taken up by participants aided them to gain more control over their physical selves and the illness and led to increased self-confidence. Getting in touch with their physical self was more accessible and helped participants to engage with changes in their mental self. The setting of personal goals by participants was often derived from the desire to change more readily attainable aims of a healthier lifestyle or structure.

In further confirmation of the work on IPSRT, the skills that participants demonstrated trends in using, and were confirmed as practising by professionals, aided them to modulate their environmental stress and invoke positive changes in their relationships with others. Both healthier lifestyle and structure and skills development, drawn from IPSRT, were enabled through participants' improved communication skills and assertiveness with others. Assertive self-expression took away the need for angry expression; a more relaxed approach was adopted; honesty of communication with others including

mental health professionals enabled participants to gain greater reward and authenticity, and in turn, improved their therapeutic alliance.

For example, being able to say “no” and getting the sleep or the rest required and avoid overtiring themselves, or being able to say “enough” and express themselves assertively with friends or family allowed them to break past patterns of behaviour that had once sealed them in to subsequent anger, resentment or disempowerment. Being able to say “enough” appeared to stop the mood from entering a low cycle, as participants no longer felt they had to get “trodden on” (p12) or try to please others in an impossible cycle. It was no longer their responsibility to find solutions for others’ problems; it was now up to others to take responsibility for themselves.

These indirect components appeared to contribute to the building up of a wider variety of choice of behaviour and approach to situations, thus helping to avoid or attenuate a mood swing. One participant described this as enabling her to have an “extra split second” (p12) to consider what choices she would prefer from a given situation; she later called her change in intellectual perspective towards her life with the illness as “stepping a different way” (p12).

Improved communication, stemming from the group format of similar others, appeared to enable participants to find the words to express themselves, firstly to themselves and then to others. Acting assertively dissipated the need to be angry with themselves or with others for not putting their needs across. Participants appeared to feel an enormous amount but found it hard to express these feelings hence maladaptive coping had resulted in mood instability as they had previously taken these feelings upon themselves.

Confirming the benefits of Interpersonal Therapy, in dealing with the loss of a healthy self, or the grieving over what a participant “might have been in those

moments” (p10) of high mood, others’ expectations, standards, ambitions or conduct rule book were expressed within the group discussions. Participants assessed their own area of core interpersonal deficit. Often disputes with others and skills deficits were evident as participants did not initially have the range of skills which were instrumental in successfully dealing with others. Deficits were long-standing as participants had fallen into set patterns of behaving towards significant others and had, until then, been unable to break these patterns.

Participants demonstrated trends in improved communication skills and became better at “emotional exchanges” (p11) where they too felt that they “were worth” (p10, p11, p12) the same self-expression that they allowed others but had hitherto not put into practice. These double standards of not allowing themselves, but allowing others, became more authentic.

Desires to achieve to high standards, driven by goal attainment and anti-dependency of participants, were also noticeable in this study. Lam et al. (2003, 2005) concluded that the reason for therapies not improving time to manic relapse, only depressive relapse, might be explained by these values.

### **Intellectual challenge – changing the belief system**

The intellectual change of perspective resulting from participating in the training included challenging unrealistic standards and goal-driven behaviour and a singular almost extreme self-sufficiency, similar to that found by Lam et al. (2005). It was also interesting that whilst hypothetically, all other outcomes were envisaged, it was this intellectual development that was not expected to this extent by the researcher in this study, nor was this way of functioning considered so necessary to change in order to reinforce the benefits of the other components of the training derived from IPSRT, various group therapies or the

Life Goals approach (Bauer & McBride, 1998) or even to apply the illness management techniques.

It is interesting to note that, whilst non-adherence to medication due to the side-effects was cited by less than 5% of patients, the uncomfortable feelings associated with 'feeling dependent' or 'feeling that medication is slavery' or 'feeling ashamed or afraid' due to taking medication were more often cited (taken from Colom & Lam (2005). Whilst giving information may not be enough to secure medication adherence, as if leading a horse to water was sufficient to make it drink, there are mechanisms in the psycho-educational component that enhance adherence.

However, putting these two recent studies (from Colom & Lam, 2005 and Lam et al., 2004) together, if 44.2% of a bipolar participant's total variance of personality traits are accounted for by an extreme independence, goal attainment and achievement needs, it might be proposed that the perceived dependency upon medication, the slavery, the resultant shame and the fear are in direct opposition to a bipolar participant's possibly dysfunctional desire for independence from medication and their striving for this independence from medication.

It was also noted in this study that participants could range from excessively dependent passive behaviours common in a low mood, to fiercely independent behaviours when euthymic and especially in times of high mood, which resulted in perceptions of interference towards others. Participants' behaviours ranged from complete self-blame for incidents that were not in their control for which they felt totally responsible and which kept them in ingrained unhealthy patterns of interacting, to complete blame placed on others for events to which they had contributed. Denial was frequently a first-line defence. Passive-aggression was commonly preferred to assertive communication. Displays of vulnerability or

feelings were not common despite having an enormous depth of emotional feeling. This would confirm Lam et al.'s (2004) findings that indicated that the concept of control over feelings is inherent in the goal-attainment component.

It is unclear which elements of the above may or may not be attributed to secondary developmental issues that may also be considered as secondary personality disorders. However, it has been noted that psycho-education may be helpful for bipolar participants with a co-morbid personality disorder (Colom et al., 2005). It is clear however that participants were not all-accepting passive recipients; they questioned in depth the whys and the wherefores of the training as it was delivered and they discussed these aspects amongst themselves in the group and the post-group meals. The nature of the self-help group format and user-led delivery of the training encouraged them to explore issues that they had difficulty accepting so that these were resolved satisfactorily from their own perspective, not from perhaps the perspective of receiving others' wisdom, albeit drawn from the research and delivered by a similar other.

Participants underwent this process of questioning the teachings for them to be fully integrated into their own lives, become part of their own reflexes and part of their own commonsense values. This was instrumental in developing a new 'mind set'. The group format enabled participants to gauge themselves in this cognitive development in comparison with others in the group. What might have been considered as a homogeneous group of bipolar disorder diagnosed individuals at times during the case study, was equally heterogeneous in intellectual development towards adopting a new mindset, ie. approach to changing how they would henceforth live with the illness.

By practising communication and assertiveness skills, being comfortable in asking for help rather than feel that they had to be "super-human" (p12) to resolve their own and other' problems on their own and with group feedback

and support, participants were able to frame more realistic expectations of themselves and renegotiate the expectations set by others which had hitherto been introjected. It was a learning of putting themselves, not others, first. This meant that they only had their own standards, not “where the others drew the line” (p10, p12).

From the data establishing the model, participants demonstrated trends of traversing this change in their intellectual perspective towards the illness and were able to take on the responsibility of managing the illness in a healthier way. This distance they appeared to have from the illness, this space given over to the process of grieving, and relinquishing “those moments when I can be all I can be” (p10) ie. high moods, were replaced by the reasoning through in their own minds that “That’s not the way. No” (p10, p13). Participants effectively changed their underlying beliefs that would drive their changed future behaviour.

Whereas previously, participants had embraced periods of high mood as a welcome escape from long depressions, they now appeared to practise good illness management that prevented or alleviated high moods. Participants were less critical of themselves and they did not feel they had to be happy all the time, aiming for being ‘content’ (p1) and ‘in that stable area’ (p11) rather than using others to hype their mood up further, possibly into hypomania. They appeared to seek help sooner from mental health professionals, they took additional medication and they called upon their social circle indicating that they were able to mitigate their anti-dependency needs (Lam et al., 2004). Participants expressed their needs with significant others by putting themselves first, they took breaks, put up boundaries to ensure healthy sleep quotas and generally called upon the complete range of skills that they had learned from the training to “cope”. This indicated that participants were able to mitigate this dysfunctional belief to have to control their feelings (Lam et al., 2004) by being

able to express their feelings and by being assertive with others, without the need to become angry or resentful for not having done so.

High standards were challenged in the training, taking these to their logical conclusions of relapse, either extreme focus leading to high moods or failure to achieve resulting in low moods and self-criticalness. At the end of the study, participants generally became more realistic in their attitude to their own high standards, realising that perfectionism was impossible, but for some these high standards and need to achieve remained; however, within firm structures offered by IPSRT and the Life Goals programme (Bauer, 2001), participants were able to restrict these and ground these to the mundane making these more realistic.

Participants, through learning exchanges and discussions, were able to take another slant on themselves with regards to the illness; they were able to stand back and question their own behaviours; they were able to make changes that were sustained and continued improving at six months post-course. It remains to be seen whether these continue at one or two years and align with Lam et al.'s findings (2005) where no significance is found in manic, only time to depressive, relapses. However, the promising findings in this study demonstrate that this fundamental intellectual change had taken place that would guide the participants in their mood management at a later date.

What was noted in the data was that participants had to be willing and ready to change. The more readily they engaged in change, the more benefit they derived. It was not a pure intellectual argument per se, removed from how they then lived their lives, it was a transformed cognitive perspective firmly residing in lifestyle changes, and being reinforced by these. Goals were vital for direction especially in low mood; however situated within a realistic framework that challenged perfectionism, contained these, gave them balance and a firm

schedule that kept a participant rooted. It enabled participants to experience a freedom for focus as not in complete opposition to their possible dysfunctional beliefs and needs to achieve, but the firm structure of the more mundane to enable them to remain grounded and balanced.

As this training taught self-responsibility, it may be questioned as to whether it also reinforced the dysfunctional belief of independence? However, this was not the case. Data suggested that social circles were increased, friendships established, social or self-help groups were joined and in one instance, one participant established his own social group (P1). Rather than isolated, participants became connected to others and more adept at emotional exchanges and displays of their feelings and opinions. Participants came to view having a social circle and being able to call upon this as an acceptable coping strategy, not viewed as being dependent or vulnerable through a perceived weakness of not being able to problem-solve on their own. This was enabled through a group of similar others.

It was possible within the group for participants to examine where these high standards and goal-driven behaviours had first emerged, often through childhood, and then gain distance on them. They were able to realise that “they did not want to do this anymore” (p10) in repeating set patterns of behaviour and that by changing set schemas they had actually given themselves another way out, no longer trapped or “caught in the spider’s web” (p12) of their own actions and consequences of them. It was no longer “where anyone else drew the line” (p10, p12), only themselves, and participants were aware they could change this.

### **An individual training – with secondary family benefit**

Family Focused Therapy elements appeared to be helpful to participants and confirm the usefulness of this approach (Miklowitz et al., 1996, 2000). Participants demonstrated trends that their improved self-expression and assertiveness were helpful in creating new patterns of relating to family members and close friends. Ingrained patterns of relating to family members were often the final domains that participants felt comfortable in approaching to change. Often, they achieved initial success with those not known to them well, at work or with friends, before feeling confident enough to assert themselves in the family milieu.

Participants appeared to realise the benefits of restructuring these relationships with family members although were conscious that changes in themselves might mean challenging hitherto stable patterns and disrupting the status quo, even though they knew these not to be healthy. They were often fearful of the outcome, and of close family members thinking badly of them for making changes or of fearing the loss of this relationship altogether. However, with subtle differences, participants realised that no one “thought badly of them” and that “they had all survived” this experience of change within the family (p12) and that the guilt that they might initially experience through establishing themselves, rather than putting others first, did dissipate as new patterns were formed. Participants demonstrated trends that they were aware of how these initially formed patterns of interacting had led to their current ways of inter-relating with family members, and how these had played a part in their mood state.

Comments from family members reported through participants and professionals, although not directly solicited, demonstrated trends that the training was welcomed and that they too had benefited, albeit with some challenge on occasions to long-standing relationships.

## **How did a recovery approach and a holistic training help participants?**

Coping, as with recovery, was seen as a personal issue. Participants appeared to employ different aspects of the training at different times according to their need, focused on areas that they themselves wished to improve and employed the skills learned to make changes. Participants felt as if they had been given “guidelines” (p2) within which they had latitude to act; not a strict rulebook. Material was didactic but allowed participants to adapt this to their own personal situation. This allowed them to find their own way within the training content, and what they needed from the group discussions and support.

Recovery, as demonstrated by trends in improvement in participants, was not a set of procedures rather tools to enable them to find their way. Recovery was a “burrow of silly little things” (p12) that together made a huge difference. It was “the whole (emphasis) overall lifestyle” (p9) that had made this difference. For participants to explore their own unique process, to find new meanings, to explore new behaviour and feel better in themselves about this new way of interrelating, they needed time to assimilate the skills, put them into practice, see the benefits for themselves according to how they judged them to be, and often work through residual guilt from now putting themselves and not others first. Similarly, their double standards became more authentic although working through the guilt took time.

For some participants, this was a gradual process during the training; for some it came from ‘light bulb’ moments of sudden insight when they “would mark that day” (p7); for others through intellectual heated exchanges. For some, it was quite an emotional experience. For participants, recovery involved doing things differently and feeling differently about them. In coping with mood swings that

they experienced during the study, it was through a different perspective they later dealt with these. For example, those who experienced high moods during the study coped well as they had changed their attitude towards how this was only the illness and not significant of themselves. They had the tools to cope and took responsibility “in a logical and linear way” (p10) but had worked through issues that previously would have distracted them; they kept focused and grounded to the mundane. Some changes participants were unaware of at the end of the study but on reflection could remark that they were now, in their own ways, “stepping a different way” (p12).

The hope, optimism and belief that the researcher had invested in participants in their ability to cope was reported back by participants in their own growing hope and self-belief. Participants reported trends in greater confidence, a brighter outlook on themselves and their future and a growing empowerment. Empathy and non-judgemental treatment by the researcher towards participants who experienced mood instability during the training was returned by participants in their own decreased stigma associated with the illness, and their ability to distinguish what was symptomatic of the illness from themselves as individuals. What emerged was that participants were simply managing their illness in a more “logical and linear way” (p10), not attempting to deal with all the other issues that they previously could not dissociate from the mood swing. What had been previously a “spirit-breaking” time (Deegan, 1990) or break down had transformed into a “break through”.

Throughout the data, it emerged that participants appeared to traverse the six steps used by Ralph (1999) to describe the process of recovery: from initial anguish and hopelessness, victims of repetitive interrelationships in which they have been “trodden on” (p12), unable to express themselves, participants awoke to the realisation that they were learning new tools from which they could benefit and that “no one can come to any harm” (p12) by them using these.

Insight, the third stage, was gained throughout this process as participants were able to distance themselves and distinguish themselves from the illness and in gaining benefit from what they practised. Participants set goals, established action plans and became more determined to become and stay well, whereas previously they would not have known how to deal with a low mood, nor wanted to curtail a high mood. The final stage in recovery is seen as that of well-being or empowerment, which I have considered as the final outcome in this study, not the lesser or intermediary outcomes.

Whilst it has been noted that the only user-led self-management intervention for people with bipolar disorder run by the Manic Depression Fellowship does not incorporate such useful coping components, it is also noted that recovery programmes that are user-delivered, such as the generic Experts Patient Programme or the Wellness Recovery Action Plan do not contain vital illness specific components for bipolar disorder that are more useful than self-help alone (Colom et al., 2003). It is doubtful therefore whether the effectiveness of these programmes would result in full recovery for this client population.

### **Final and second-level outcomes**

Participants demonstrated promising evidence that they grew in hope, became more empowered, had more self-confidence, a better outlook on themselves and their future and an improved and improving quality of life at the end of the study. They had effectively moved themselves on. These promising findings confirm those in the work of Mueser et al. (2002), which related similar experiences associated with recovery.

In coping well and benefiting from these final outcomes, participants appeared to be able to simply 'enjoy life more' (p1) and focus on their longer-term projects and goals. This focus on taking responsibility for themselves and self-efficacy overlaps with some therapies which enable participants to spend more time formulating the future, rather than having their lives disrupted by the illness (Mueser et al., 2002).

These longer-term outcomes are also likened to greater personal development, or second level outcomes in this study, when mood stability for longer periods appeared to enable participants to make even greater changes to their lives.

Participants made decisions to look for work, became more independent in their living styles, changed jobs for more rewarding ones in which they were more open with new employers about having experienced mental ill health, terminated unhealthy close relationships and renegotiated long-standing business or close relationships, realised their dreams, and occasionally made what was lacking in their lives a strong point by enabling others to find greater social support.

## **11 Evaluation of the case study**

## **11 EVALUATION OF THE CASE STUDY**

The findings from this case study were drawn from a limited number of participants. The quantitative data is therefore open to type I error in that the null hypothesis has not been rejected when it could be true that no change has taken place in participants following participating in the training. Replicating the study so as to analyse completed data for a minimum of 50 participants and 50 controls would render a more precise measure of benefit and clarify whether the trends demonstrated in this study might be generalised to a larger population.

The replication logic used in this case study, with 13 participants and six controls to saturation of data analysis, might thus allow a sampling logic to be later applied in a larger study sample. Whilst the case study was undertaken in only one day centre in one town, albeit with an experimental design utilised to offset this small sample, a larger sample might be drawn from several towns in different parts of the country and in several different study settings also employing an experimental design to clarify effectiveness.

The analytic generalisation used in the case study, whilst explicitly linking data to theory and demonstrating robust construct and internal validity (c.f. Analysis section in the Methodology), demonstrated trends in improvement for participants in comparison with trends in deterioration for controls; however, a larger sample would allow for the use of statistical generalisation to replicate outcomes.

At the outset of this study, it was difficult to gauge what data sources would provide richer sources of information for the time that was invested in obtaining access to, in recording and in analysing these. The use of both quantitative and qualitative data collection methods and the analysis of a wealth of texts in this case study (some 160 for the 19 participants) would involve re-evaluating and honing down the data sources in a later study on a larger sample. The use of medical notes, whilst helpful to establish time lines and possible reasons for past episodes, and despite participants' signed consent forms indicating permission to access to these, were accessed with some difficulty by a user-researcher wishing to make notes from another service user's medical file. These files may be briefly summarised or put aside altogether, and time and difficulty to access by service users undertaking research must be considered.

The self-report scale measuring empowerment, identified in the Discussion as one that must be linked to a mood scale indicating stability, might be better clarified through interview analysis. Participant observations undertaken at the day centre between the weekly course sessions, whilst informative, did not warrant the time invested; however, telephone contact by participants with the researcher, initially envisaged as a 'helpline' in case of an emergency, rendered more useful information. In a future study, in order to preserve the comprehensive methodology of a multiple case study within which an experimental design, a team of coordinated researchers would be needed to deliver the training, and collect and analyse the plethora of a wide range of data. One recording of the delivery of the main study training with a visible centralised microphone proved too inhibiting for participants in their group learning and sharing, and hence this microphone was abandoned, as the quality of the data thus obtained was poor given its perceived invasiveness.

The day centre proved a welcoming, supportive and familiar environment in which to undertake the case study, the user-researcher having volunteered there

for a number of years prior to commencing the research. However, whilst the pilot study was run at the day centre, the later main study was run at a nearby church hall as this removed the training from a community mental health environment to clarify effectiveness of the training as distinct from this usual supportive environment, and also removed the general organisation of training delivery from the, at times, conflicting expectations the day centre staff held about the delivery of such interventions in their day centre. It was concluded that a venue even more remote from community mental health services, for example, a school or university environment, would clarify effectiveness further with a larger sample. It was also noted that some independence in organisation of training delivery and final decision-making on some aspects of this study were not always within the control of the user-researcher which led to some confusion which the user-researcher had the responsibility of later clarifying with participants and which could have been avoided.

One example was that the day centre staff promoted the research to their clients as “being able to take part in the training group”, whereas, as participants were randomised to either the training or the control groups, this was not the case. However, as with all the other group activities at the day centre, any client who expressed a wish to join certain groups was enabled, hence this confusion arose. Another example was that the day centre staff advertised the training as being suitable for clients with “mood swings”; however, this study was aimed at people with a diagnosis of bipolar disorder. Hence three non-bipolar diagnosed clients were recruited into the pilot study and were later maintained as to exclude them would have been contrary to the inclusive policy of the day centre (c.f. Ethical issues in the Methodology). As the user-researcher underwent a change from volunteer to PhD user-researcher, some staff did not welcome this change as easily as others which led to some resistance in their willingness to help recruit study participants among their clients, or their lack of availability for interview regarding their clients later enrolled in the training. Despite these

challenges in researching at the day centre, the researcher welcomed being able to deliver the pilot study on the premises, as this afforded support from other staff members who were on site, especially during periods of illness experienced by some participants. Whilst some considerable time was spent at the day centre during the pilot study, this was as much to build up positive working relationships and acceptance from some staff towards a service user now undertaking research, as to afford opportunities for observations of participants enrolled in the study.

Whilst the perspectives of a research assistant and consultant psychiatrist of one participant evaluated for 18 months (P1) also informed the qualitative aspects of the case study, and the quantitative data were verified by independent sources (East of England Research and Development Support), this study was undertaken by a lone researcher who delivered the training and analysed the data. It is noted that there were many advantages of being immersed in the data to this extent and depth, and possessing the perspective of a “similar other” in that the researcher is also diagnosed with bipolar disorder, as these factors were extremely helpful in making sense of the participants’ views on changes in their lives in a more meaningful way. However, there was tension between, on the one hand, the need for objectivity and distance in maintaining boundaries with study participants and in undertaking the analysis of the qualitative data to render an accurate account and, on the other hand, in contrast, the subjectivity of the researcher’s own perceptions, but whose personal understanding of the participants and own lived experience enabled such a deep and meaningful interpretation to emerge.

It is worth recording that for participants the user-researcher undertaking this study was considered a “researcher” or in some cases a “mental health professional”, and for mental health professionals taking part in the study was considered a “service user”, so the distinction made by both groups ensured that

the user-researcher felt sufficiently removed from both groups taking part, and hence boundaries and objectivity were maintained, in so far as researchers can ever be entirely removed from the people they have chosen to study, especially if they are drawn from study samples having similar experiences.

In the case of mood swings experienced by some participants during the pilot study at the day centre, the user-researcher was treated as an extended part of the mental health team and a person to be confided in and questioned for further information regarding the team's concerns about a participant's health. This inclusion as part of a team, which had hitherto excluded the researcher, proved a challenging time as, whilst these participants were aware of the need for the researcher to break the confidentiality rule and enable the participants to increase support to manage these difficult times, it was necessary for the researcher to ensure that only the information that the participant had previously agreed to be disclosed, was disclosed. This ensured that the safe space of learning and support of the whole group and trust towards the researcher were maintained during the study. Whilst this situation was likened to having a 'duty of care' towards participants, this change in how the user-researcher was viewed served to reinforce the situation of the user-researcher being neither part of the mental health team (as not all details were disclosed at the request of the participants), nor a user as considered by the participants (as direct links were evident between the user-researcher and the team to ensure that participants managed the more acute phase of the illness). The user-researcher likened this experience of being neither user nor mental health professional as viewed by others as being "in a (lonely) group of one" which helped to maintain distance but also increased personal isolation in what were difficult situations for a user-researcher to navigate successfully with all concerned.

In a larger sample in a later study, it may help to increase objectivity and hence clarify effectiveness to separate out the training delivery component from the

data analysis component; however, it would also be important to include through interview these same user-trainers' perspectives on changes participants had reported during the training delivery as it would be important that user-researchers diagnosed with bipolar disorder undertake elements of the analysis for a more meaningful and rich overview of effectiveness from the perspective of a 'similar other'. It would not be recommended to divorce the user perspective completely from the data analysis as any likely increased 'objectivity' afforded by non user-researchers might negate the very richness and understanding that bipolar user-researchers might offer and result in a limited quality outcome (c.f. Analysis section in the Methodology, regarding the non-user researchers analysis in this case study). As a lone researcher undertook this case study, in a later study with a larger sample, it may be constructive for more than one bipolar user-researcher to compare data analysis for inter-rater reliability and researcher triangulation.

The delivery of the training over 12 weeks, with follow-up booster session one month later produced promising evidence of effectiveness that was sustained at six months post-training. However, it remains to be seen whether these promising trends of coping with both high and low moods are sustainable for a longer period. Following up after one and two years with larger samples would enable this to be clarified.

Whilst one participant was followed for 18 months, his continued progression was facilitated through his becoming a training facilitator that served to reinforce his learning experience as a role model for others. A longer-follow up period would clarify for how long these reinforced benefits might remain.

Monthly booster sessions and continued social support for participants were lacking in this study. However, these sessions were advocated as helpful by participants and professionals. The study has given impetus to the creation of

local bipolar disorder self-help group that might provide one route to continued application of the training and its derived benefits.

The ‘family and significant others’ psycho-educational component was lacking in this study due to the time constraints on a single researcher. A leaflet on bipolar disorder for families was given to participants for them to share with their family and friends that was reported as being of benefit. Participants often shared their course material with family members and friends. However, in future studies these additional workshops for ‘family and significant others’ are advocated as a separate but concurrent element to boost the effectiveness of the group training for participants and to offer benefits to their closer social circle.

The optimum timing for the delivery of the training is unclear; however, participants and mental health professionals involved in this project concur that the sooner the better after first episode and a diagnosis of bipolar disorder. Whether participants need to have been mood stable for a minimum of six months is unclear, however less time than this may indicate returning to ‘normal’ mood after an episode, rather than therapeutic effectiveness of the training. Several participants experienced psychosis or hypomania during the training, stabilised and derived benefit. It is considered that each participant would derive benefit from the training as the ‘hot issues’ would be initially considered more pressing, such as illness management to stabilise mood; however other components such as skills training, structure and intellectual development, as has been outlined, are also implicit in mood management and would be learned as the training progressed.

Extreme mood states, for example, commencing the training with a hypomanic mood verging on mania or an extremely depressed mood, are exclusion criteria. Interestingly, the only two participants who dropped out of the study had either of these extreme mood states.

Interestingly, the training indicated some trends of benefit for diagnoses of schizophrenia and schizoaffective disorder in comparison with controls; however these benefits did not reach the levels of trends in improvement derived for bipolar participants, nor were they as sustainable at six months post course. More precise diagnostic clarity would be helpful so that only primary bipolar diagnoses are included in a future study to optimise outcomes from this training.

However, given that some trends in benefit have been demonstrated for participants with schizophrenia and schizoaffective disorder, it may be worthwhile in a future study to clarify the illness management elements that were found wanting for these client groups and incorporate these into a new training manual for these diagnoses.

Secondary diagnoses of a personality disorder are common with primary bipolar disorder. Certain more challenging personality styles have been noted in participants in the Discussion. People with personality disorder and a secondary bipolar disorder may benefit from such a training; however, group learning as delivered by the researcher in this study was insufficient to be able to support the needs of this participant, who was later withdrawn.

Data were not collected on three participants who dropped out of the study. It was not the intention to treat people who did not have primary bipolar disorder; however, three non-bipolar participants remained in the pilot study. Diagnostic clarity and more precise exclusion criteria as to base line mood status would remove these challenges. After withdrawal, it was extremely difficult to engage withdrawing participants due to their decision not to pursue their involvement in the study and their mood status. The researcher also considered it would be harmful to persist.

The training is in manual form, with clear exercises, homework sessions and objectives set for each session. It is worked through methodically. It can be said to be a step towards a more formal and robust programme for mental health, as advocated by Davidson (2005). However, as the pilot was delivered by the researcher and the main study delivered by the researcher and co-facilitator who had previously been a pilot group participant, guidelines for training deliver (ie. trainers' notes) were general and taught during coaching sessions, rather than a didactic 'training for trainers' teaching session. Formal trainers' notes, more explicit time lines for delivery of each session and time allocated to discussion periods would make objectives clear and enable the training delivery to be replicated as far as possible. This additional material is currently being explored with a publisher with a view to publishing the full course manual. However, whilst these time lines would structure the sessions more clearly, some leeway would be necessary to pursue group interest in certain topics or personal situations as these occur and need to be addressed. Referrals of these topics to the post-session mealtimes were helpful in this case study, as an additional discussion forum.

It had been envisaged in this study to recruit and train service user co-facilitators who would deliver the main study training; however, due to poor uptake this was not possible. Training others to deliver the group training would clarify whether the benefits derived for participants were consistent with those resulting from the present researcher having delivered the training. In a later study, this would clarify whether results were dependent upon the effect of the therapist or the effect of the therapy. Whilst it was not the aim to recruit trainers from the pilot group, poor uptake and a growing interest in 'cascade training' together with trends in improvement made by this pilot participant since participating in the pilot study, meant that co-facilitating the main study

training, whilst continuing to remain a study participant, enabled the researcher to extend follow-up to 18 months on P1.

It was not envisaged in this study to compare the effectiveness of the training delivered by a service user in comparison with that delivered by a mental health professional. However, in a future study, this comparison may clarify if there are any additional benefits for participants derived from a user-delivered training.

The course manual is in English and requires a good grasp of the language. An interpreter present would be one way of enabling non-English speakers to access the material; however this would, at the very least, stilt and slow down the training sessions and undoubtedly necessitate including non-mental health personnel which would more likely reduce the impact of the self-help group with an ‘outsider’ present. Translation of the manual would be another option. Ideally, it would be better if the manual could be translated and the training delivered by a person with bipolar disorder from a minority ethnic group, so that both the language and the delivery of the training could be more adequately geared to meet the needs of this population.

As to disconfirming evidence for the outcomes of the training, minor and occasional discrepancies in accounts arose when there were differences between testimonies rendered by participants and those rendered by their mental health professionals. These were few and arose from the knowledge to which the mental health professional had access about a participant’s situation, and what the participant had related directly or through participant-observations to the researcher. Mental health professionals who were in more frequent contact with their client participants gave a more cohesive account that was confirmed through participant testimonies.

As to alternative explanations, it might be ventured that outcomes from the training are merely due to medication changes that alone caused participants to derive trends in benefit. Alternatively, that the self-help group was alone responsible for these trends in improvement. Alternatively, that the attention that the researcher gave to the pilot and main study participants was sufficient to engender these trends in outcome. Alternatively, that other previously undertaken therapies were responsible for these trends in improvement. However, this is not the case.

There was no major change in medication for participants or controls prior to taking part in this study that would account for the trends in benefit derived for participants resulting from their medication adherence alone; nor would medication adherence account for why two controls experienced a relapse during the case study. The training taught the necessity of medication that a participant might need to remain well as being vital. This engendered in participants a more responsible and more responsive approach to their medication and to their mental health professional team after following the training. The therapeutic alliance was strengthened and participants derived more benefit from this relationship; likewise professionals felt that their relationship had progressed. Analysis of medical notes clarified medications given at hospitalisations and outpatient visits, previous medication non-adherence and relapses, and long-term dosages of mood stabilisers, and often long-term usage of anti-depressants with intermittent usage of anti-psychotics that pointed to medication being prescribed and adjusted dependent upon mood state. Medical notes indicated that participants and controls had had frequent mood disturbances resulting in changes to their medication. Interviews with consultants indicated an on-going pattern of the disorder with medication offering some basis for mood stability although no guarantee that it would prevent relapse or that a relapse had happened in the past even whilst participants were medication adherent.

Medication therefore did not play a significant role in explaining the positive trends in benefit for training participants in comparison with non-participatory adherent controls at six months post-course; nor was it sufficient to account for why two controls experienced a major depression with psychosis whilst medication adherent. The findings indicated however that participants were more responsive to having their medication changed, more able to engage with professionals in constructing a healthier therapeutic alliance and more responsible for changing their own medication as and when they needed to, to cope with a mood swing.

Was it simply the attention that the researcher invested in the participants, or the self-help nature of the group? Self-help is beneficial as previously noted. Non-specific effects are also helpful. However, bipolar disorder has been shown to need an illness-specific therapy component. Previous discussions of other therapies incorporated into this training have indicated that it is this variety of tools and techniques that together establish trends in good coping, and hence this research has shown that it is this panoply of such tools and techniques that account for such trends in beneficial outcomes.

Could these trends in benefit simply be attributed to participants having undergone other therapies? Two controls and one participant had undergone previous therapies. For one control, this had not improved his risk of relapse; he was still unmotivated to change, still alcohol-dependent and angry, with a propensity for violence (c6). For the second control (c2), who experienced some trend in improvement at the end of the study period, numerous references were made throughout her interviews as to the cognitive behavioural techniques she had previously learned to which she often referred. The participant who followed cognitive analytic therapy (p10) had benefited from the clarification of deep-rooted patterns of behaviour since childhood; however the group

training's trends in benefit were separated out from those derived through professional therapy. These elements were clarified both with her treating clinical psychologist and the participant through interviews; the clinical psychologist confirmed that the therapy and the training group's components were distinct.

Therefore it can be re-affirmed that this participant's (p10) successful coping with a mixed mood swing was a direct result of practising illness management techniques "in a logical and linear way"; engaging in healthy structures and a healthy lifestyle a direct result of no longer "twittering around", greater assertiveness in new employment due to "not taking any shit anymore", down-sizing her perfectionism to a more rational pursuit of her goals in a grounded structure, and the realisation that a number of issues she was pursuing in therapy were common within the group discussions in that "it was only where her mother places the line", all directly resulted from following the training and not the therapy.

The researcher considered that as the controls were weighted in favour of having followed previous therapy, this would clarify the effectiveness of the training. However, in future studies where possible, it might be advisable to select participants who had not undergone previous therapies.

Finally, on a personal note, it is also worth mentioning that the user-researcher underwent considerable personal change whilst undertaking this case study. As a self-development training, having delivered the course twice to two groups and coaching the co-facilitator who was measured until 18 months post-pilot training, this experience served to reinforce the application of the study materials, and to enable a certain confidence to emerge as a trainer in the subject area. This also confirmed the need for future trainers in the materials to remain adequately stable and for them to have previously worked through

sensitive issues, which might otherwise de-stabilise them if these issues have not been resolved. This also served to confirm that user-trainers are equally capable of delivering training in the right conditions, with the right motivators, and with appropriate and timely support, and the need to know the client group well in order to distinguish those participants a trainer can enable and teach, and those the trainer is ill-equipped to enable and with whom the trainer might feel out of his/her depth. These factors need to be borne in mind in a further study on a larger sample in which bipolar user-trainers and bipolar user-researchers would be engaged.

## **12 Implications and Recommendations**

## **12 IMPLICATIONS AND RECOMMENDATIONS**

There are a number of recommendations emanating from this case study.

Firstly, it appears that all roads lead to Rome. Since governmental policy is promoting whole life and recovery agendas and user-commissioned services, theoretical models indicate the necessity of multi-level complexity in the treatment of bipolar disorder, current research advocates multi-dimensional integrated therapies in a ‘full package’ for such a complex disorder that any single therapy could possibly hope to provide, and self-help as delivered by service users offers benefit and reaffirms a holistic approach, it would clearly be worthwhile pursuing research into the “In-Sight” training on a larger sample to determine if the trends of benefit found in this study can be replicated. This larger sample to demonstrate effectiveness is currently being explored.

Secondly, as the study indicates that the training offers trends of benefit for people with schizophrenia and schizoaffective disorder; it would be worthwhile pursuing how treatment outcomes might be improved for these groups, possibly looking towards Rethink’s current pilot of self-management for schizophrenia as a collaborative partner. This wider availability of the training programme is currently being explored with a publishing house.

Lastly, is cost. Treating a group is less costly than current individual therapy. The group can be self-supporting when the therapist terminates therapy. In the current financial climate, this may provide a real alternative to long waiting lists for therapy to find that the services themselves have been terminated. If greater benefits can be derived through learning and then later teaching the group training to others, with very little investment, the benefits could self-sustain.

Economic analysis is to be incorporated into the larger study sample being explored.

## **13 Conclusions**

## **13 CONCLUSIONS**

The case study as a whole provides promising evidence of the effectiveness of “In-Sight”, the user-led lifestyle development group training for people with bipolar disorder.

Conclusions indicate that this service user-led, recovery-based didactic lifestyle-development group training for people with bipolar disorder appears to be acceptable to participants. Trends in improvement in a variety of areas of participants’ lives have been observed. Trends indicate benefits for participants in comparison with trends in deterioration for controls. Trends of benefit have also been demonstrated for the participants’ mental health professional team.

Trends of benefit have also been demonstrated for participants with non-bipolar illnesses experiencing mood swings in comparison with controls, although to a lesser degree and of lesser sustainability than for participants diagnosed with bipolar disorder.

Whether in its current form for people with bipolar disorder, or in an adapted form for non-bipolar diagnosed individuals, further research on this training with a larger sample is clearly warranted and would be required to demonstrate effectiveness.

Further exploration of the promising evidence of the effectiveness of this training noted in this case study might provide a step forward towards valuing the experiences of service users in order to provide better NHS services in future (Sang, 1999). It might also shift the paradigm a little so that user need and user

outcomes direct what is required, although not currently available from services, by providing an advancement of them through user-led research.

It is hoped that this case study might be viewed not as an adjunct to current service provision or an alternative at odds with it, but as an advancement of mainstream services.

An advancement that might shift the paradigm slightly by greater therapeutic integration so as to provide more effective and more cost-effective treatment that is still wanting for this group of people: both the ‘baby’ of user focus on recovery and whole life and the ‘bath water’ of integrated current professional therapies for bipolar disorder are considered necessary to achieve this.