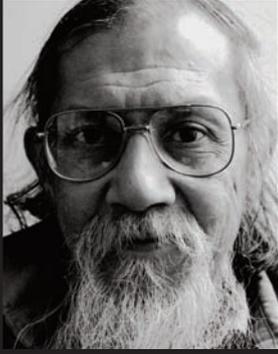


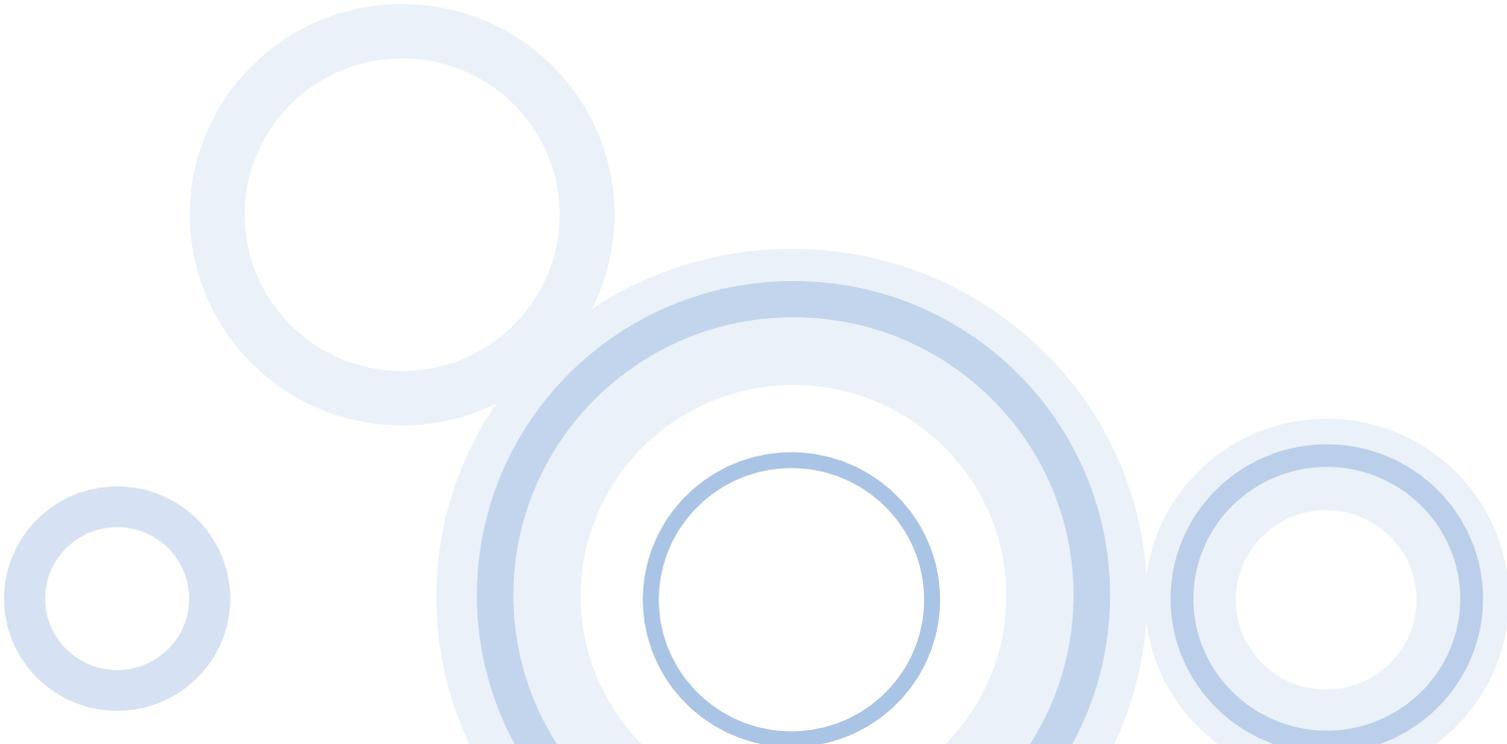
# RecoveryJourneys:

Stories of coping  
with mental health problems.



Edited by, Jerome Carson,  
Frank Holloway,  
Paul Wolfson and Michelle McNary.

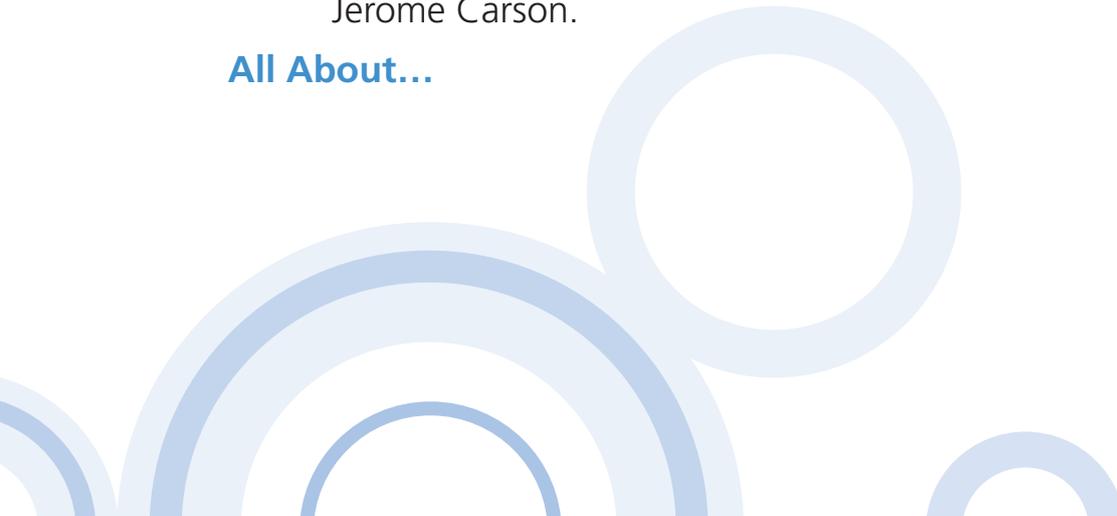
South London and Maudsley   
NHS Foundation Trust



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Stuart Bell



Dan Charlton



Jill Lockett



Patrick Gillespie



Godfried Attafua

## Forewords

### **Stuart Bell.**

When Henry Maudsley set up the Maudsley Hospital, one of his ambitions was to create an organisation which was concerned to help people with mental illness get better, rather than simply create an “asylum,” where they could be kept away from the rest of society. One hundred years on, our concept of Recovery is much broader and is rooted more in the notion of a fulfilling and active way of life, as opposed to the treatment of an illness by itself. It is also a process which we now recognise must be led as much by service users and carers, as by professionals. Nevertheless, it still shares the same basic premise of an optimistic and positive approach, and so I am sure that if he were around today, Maudsley would want to join with me in offering his strong support for this booklet.

**Chief Executive, South London and Maudsley NHS Foundation Trust.**

### **Patrick Gillespie.**

The Lambeth Integrated Mental Health Services have been promoting Recovery-focussed working practices within mental health teams across the Borough. We have been supporting teams by providing training to staff on what Recovery means and to date, nearly 400 staff have been trained in the approach. Working within a Recovery framework, means that goals are service user defined and therefore individual. These are sometimes challenging for staff to work with, as they are not staff defined. This gives the service users choice in the care and treatment that they receive, and promotes independence. I strongly support this booklet and look forward to the release of the film.

**Borough Director, Lambeth Directorate.**

**Jill Lockett.**

A year last Summer (2007) I was launching the Business Development Framework for the South London and Maudsley NHS FT. It was quite hard going, with a real sense that new areas of business were realised only through complex tender responses.

Then the call came... a date for coffee made .....a service user with a Masters in Film Making wanted to make a film....about recovery.....supported by clinicians ...but in the voice of other service users.

Rapidly a deep sense of something quite exciting; the opportunity to help users tell their story, not in NHS language, through clinical reports or audit, but in their words. We didn't have a budget, track record or business case but when there's enough commitment these can be realised quite quickly.

I am very proud of the film and the hard work from Michelle, Jerome and co. that has achieved such a great product. I hope it helps others – staff, carers, families, patients and the public understand the real possibilities of recovery, how every person's recovery is so individual to them and reduces the stigma of mental illness that continues today.

**Service Director – National Division and Neurodevelopment.**

**Dan Charlton.**

Anyone who had ever had a health problem, or who has been worried about the health of someone they care about, knows the value of clear, reliable, up-to-date information about what help is available, how to access it and the chances of recovery.

Good information from health and social care about clinical services and treatments has the power to reassure, educate and empower. It can bring relief to people at a difficult and worrying time in their life. By the same token, poor information - or the absence of information - can cause frustration, distress and anger.

Some of this is about what we say to people – language that may be familiar to those of us who work in health and social care can come across as technical, bureaucratic and impenetrable to those who don't.

It is also about how we provide people with information. This includes ensuring that the people who use services have clear, written care plans. It involves producing information leaflets that are

helpful and easy to read and working with the media to promote positive messages about how people can look after their own health and well-being. It also means being alert to new communication opportunities, such as the emergence of social networking web sites.

I think the recovery film project is an excellent attempt to provide people with information about what it is like to experience a mental health problem – and to deliver a message of hope and inspiration about recovery. Producing films about the work of the Trust, and about mental health in general, is a great way of engaging people – especially when they involve people who have direct, personal experience of mental health problems.

**Head of Communications, SLaM.**

**Godfried Attafua.**

I have been quite impressed and reassured by how mental health professionals in recent times have embraced the Recovery model. I, like many others within the mental and social healthcare profession have taken a while to develop a clearer understanding of the principles of the Recovery model and how this would impact on service users in our local communities.

It is quite refreshing to note that as a Directorate, Lambeth have invested in providing Recovery focussed training to a number of its staff and that some of the concepts key to the model are being operationalised within the locality teams.

When I was first approached about the development of a film project which entailed making a film depicting stories of service users at different stages of the Recovery process, I had no hesitation giving this my full support. I found the idea of this initiative quite appealing in that it offered service users the opportunity to share their personal and individual experiences with others.

I have had the unenviable task of managing the budget for this project which I must say has so far gone smoothly without any problems. I am pleased to have contributed in a small way to this worthwhile project and do look forward to the film being released.

**General Manager North Lambeth, St.Thomas' Hospital and HMP Brixton Healthcare Services.**

### Introduction and Acknowledgements.

The Recovery Film, is one of the most exciting projects that each of us has been involved with. The project aimed to produce a film about Recovery from mental illness, made by a service user and featuring service users themselves. The choice to include service users and not mental health professionals, was deliberate. As a recent set of discussion papers from the Social Perspectives network asks, **“Whose Recovery is it Anyway?”** It is of course the service users’. Who better to make a film about Recovery, than a service user, Michelle?

The Recovery Film project, and this accompanying Recovery Journeys booklet, have both been made possible through the **financial generosity of the Charitable Trustees of the South London and Maudsley (SLaM) NHS Foundation Trust**. We are grateful to the Trustees for supporting both ventures. We are also grateful to Oxleas NHS Foundation Trust, for allowing Dr Wolfson to collaborate with us on this project.

From the outset, the Recovery Film and the Recovery Journeys booklet, have been supported by a number of senior managers within SLaM. The original idea for the project was conceived by Michelle McNary and Jerome Carson. Frank Holloway and Paul Wolfson then joined a small project team, which further developed the idea. We next took the idea to Jill Lockett, then Trust Business Manager and to Dan Charlton, Head of Communications. It was they who suggested we make a 20 minute film, which could then be downloadable free from the Trust website. Jill gained support for this plan from Zoe Reed and Stuart Bell.

Within the Lambeth Directorate, where Michelle and I were based, the idea gained the support of Patrick Gillespie, the Borough Director. Godfried Attafua, the local clinical co-ordinator helped manage all the finances. Additional support came from Dr Nicola Byrne, Claudette Miller, Sam Holmes and Mary O’Connor, as well as numerous other colleagues. Other service users have also been very encouraging. We are grateful to all these individuals and many others, not named, for all their help with both projects.

There has of course been a separate group of individuals working on the Recovery Film, from Gilly Sykes the Production Manager, to cameramen and sound recordists and other technical experts who Michelle has consulted.

The Recovery Journeys booklet has been produced by SRA, a charity that provides intermediate employment to individuals with mental health problems. Paul Richards, the printer at SRA, has been involved with the project from the outset. Jane Fradgley, has taken all the photographs for the booklet.

The Recovery Journeys booklet follows the film in that the four central accounts are written by the four service users who appear in the film. These are Dolly Sen, Gordon McManus, James Bellamy and Ben Haydon. We are grateful to them and to their carers for their courage in sharing their stories. Michelle has written an account of what it was like to make the film, from her Director’s perspective and Paul Wolfson describes how they conducted auditions for the film. Frank Holloway talks about the historical development of the Recovery concept, while Jerome Carson talks about future developments in Recovery. The booklet ends with a list of useful websites for those wishing to learn more about Recovery.

The Recovery Film will be released early in 2009, and is currently in the “post-production” phase. We hope that you will enjoy the Recovery Journeys booklet and that it will “wet your appetite” for the main course to follow!

**Jerome Carson, Frank Holloway, Paul Wolfson and Michelle McNary.**

## Paper 1. Recovery: Where does it all come from?

Mental health service providers, users and carers hear a lot nowadays about “Recovery”. As a term it is capable of being used in many ways. There are now literally thousands of publications available on the subject: I have chosen a few texts that illustrate the richness and complexity surrounding the concept.

### **Description of the Retreat (Tuke, 1813)**

It is often stated that until recently mental illness was felt to be incurable. This is quite wrong – what has happened is that views about how care and cure should be provided have changed. The cutting-edge technology of the late 18th Century, was care in an asylum. The York Retreat (which is still open) offered humane treatment in homely circumstances where people were offered hope, were supported in maintaining activities, building on their strengths and encouraged in self-management without recourse to the use of “mechanical restraint” and ineffective medical treatments. Early asylums reported impressive rates of recovery.

### **On Our Own: Patient Controlled Alternatives to the Mental Health System (Chamberlain 1978)**

The later failures of the asylum system are well documented. Reform came slowly but from the 1950s onwards there was a move towards community care in parallel with the introduction of effective treatments for mental illness. America in particular saw the development of consumer-led services as an alternative to a professionally-led system that was seen to have been abusive. These consumer-led services often rejected the concepts of mental illness underlying official psychiatric care. They drew much of their energy from the evident successes of the civil rights and disability rights movements.

### **Recovery from Schizophrenia: Psychiatry and Political Economy (Warner, 1985)**

In a provocative book first published over 20 years ago (and now in its third edition) the psychiatrist and anthropologist Richard Warner drew together the evidence on rates of recovery from one particular mental illness, schizophrenia, over time and across cultures. He noted both how common recovery, as conventionally defined, was and how rates of recovery were related to prevailing social and cultural conditions. In a richly argued work

Warner identified many ways in which recovery could be promoted, from optimal professional treatment, through user-led services to large-scale change in society that would lead to the desegregation of people with a mental illness.

### **Sense of Self in recovery from severe mental illness (Davidson and Strauss, 1992)**

In a seminal study two eminent researchers, Larry Davidson and John Strauss, moved beyond quantitative statistical analysis of the long-term outcomes of people receiving a diagnosis of schizophrenia to look in depth at the stories of the people themselves. They found that key to recovery was the person’s rediscovery of a “sense of self as an active and responsible agent” leading them to recommend that services foster “a more active and collaborative role for the person”. Davidson has gone on to develop a sophisticated model of how people with a mental illness can break a vicious cycle of despair by discovering a sense of belonging and hope that leads to experiencing successes and pleasure, an increasing sense of agency and increasing community involvement.

### **Recovery as a Journey of the Heart (Patricia Deegan 1996)**

The importance of people’ stories and the very individual nature of recovery comes through loud and clear from the writings of service users and “survivors”. Patricia Deegan is an outstanding contributor to this literature and has memorably described recovery as “a journey of the heart”. For her “The goal of the recovery process is not to become normal. The goal is to embrace our human vocation of becoming more deeply, more fully human... The goal is to become the unique, awesome, never to be repeated human being that we are called to be.”

### **The myth of recovery from mental illness (Whitwell 1999)**

Recovery is not without its critics, particularly from within services. In part this is because the experiences of professionals are inevitably dominated by contact with people who have continuing difficulties and cannot be said to have “recovered” in any conventional sense. There is a genuine (and possibly realistic) fear that the rhetoric of recovery could be used as an excuse for dismantling effective and valued services. Others

### Paper 1. Recovery: Where does it all come from?

may be concerned about the potential threats to cherished professional roles in a world where the watchwords are “empowerment” and “self-determination” and staff have to move from “doing to” to “working with” or even “working for”.

#### **Recovery Competencies for New Zealand Health Workers (O'Hagan 2001)**

Service users have begun to move into positions of influence within mental health services. Mary O'Hagan, a former Mental Health Commissioner in New Zealand, elaborated a set of recovery competencies for staff which demand, above all, a capacity to understand and respond to the individual needs of service users. For O'Hagan “recovery is defined ... as the ability to live well in the presence or absence of ones mental illness (or whatever people choose to name their experience). Each person with mental illness needs to define for themselves what living well means to them. The definition is purposefully a broad one, because the experience of recovery is different for everyone and a range of service models could potentially support recovery.”

#### **Social Inclusion and Recovery (Repper and Perkins 2003)**

People living with severe mental illness currently experience dramatically worse life-chances than their peers and, as a group, can reasonably be described as socially excluded. The causes of this social exclusion are both complex and controversial but there is no doubt that discrimination and stigma play a very significant part (there is incidentally abundant evidence of the corrosive effects of self-stigmatisation). Julie Repper and Rachel Perkins (who has successfully combined a role as service user with that of a senior clinician and service manager) have set out some practical steps for promoting social inclusion and recovery centred round a triad of fostering hope, giving people a sense of control over their lives and offering people opportunities to access roles relationship and activities that are important to them.

#### **A common purpose: Recovery in future mental health services (CSIP, 2007)**

Recovery has now entered the mainstream and is, indeed, a central plank of mental health policy in England and throughout the world. There is however no single “Recovery Model” that emerges from the literature, which often uses the metaphor of recovery as a journey and is rich in stories. Each story is unique. Each story can increase our understanding of what it is to live with and “recover” from mental illness.



**Dr Frank Holloway.**

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## Paper 2. Making the Recovery Film: Michelle's Story



**Michelle McNary**

When I first met Jerome Carson for therapy, I could not have imagined that I would be making a documentary about Recovery. We talked about how useful a film from the service user perspective would be for health professionals, families, friends and the general public.

I wrote a synopsis and budget for the film, and sent it to a woman called Jill Lockett. (Director of the National Division). Within a month or so we set up a meeting. I think Jerome may have sensed that I was nervous, as he was very supportive. Jill asked me to make the film 20mins long, and for the film to be shown on the South London and Maudsley (SLaM) website. The meeting went very well and Jill seemed to be genuinely interested in gaining finance.

At this point I was hopeful, excited, but aware that no individual had gained this kind of investment from SLaM before. However, Jill exuded both a quiet confidence and professionalism that put any fears I had at bay.

Jerome and I had talked about a book to accompany the film. He had also discussed this with two doctors within the field, Dr Wolfson and Dr Holloway. Dr Wolfson had been a scriptwriter for Derek Jarman, the filmmaker, which really impressed me. We talked about my ideas for the film and it was clear that Dr Wolfson understood what I wanted to achieve. We decided that Dr Wolfson would assist me in recruiting service users for the film. He also offered his help in compiling questions.

At the meeting, Jill said that I would have feedback by Easter. However, Easter passed and still no green light. I had not raised money for a creative endeavour such as this before. I was aware that maybe the budget was too high or maybe the people in SLaM were worried about my ability to make the film. I sent Jill an email and waited. I received an email saying not to worry, as I had the green light!

“When I first met Jerome Carson for therapy, I could not have imagined that I would be making a documentary about Recovery...many people did not want to be on film. Many service users keep their condition a secret...I am pleased with the content of the film. The interviewees were very responsive to my questions. Listening to their stories made me feel a great sense of HOPE.”

Jerome and I talked about ways of encouraging service users to take part in the film. We advertised on the SLaM website, The SLaM newsletter and Lambeth Mind. Jerome and Dr Wolfson, also spread the word. The response was slow for many months.

There was no deadline for the project, which meant I had time to do research and come up with a format for the film. I started by reading other service user accounts of their experience of recovery. I brainstormed the idea. I decided that I would interview four people, then use images and graphics with the interviews to explore the concept of “Recovery”.

Jerome and I set up a meeting with Dan Charlton, Head of Communications. He was now our point of contact. He offered his support with the film and is a very nice man to boot! Throughout the pre-production, Dan was in dialogue with my Production Manager, Gilly Sykes. Dan assisted with legal and other aspects of production. I look forward to working with Dan during the exhibition of the film.

I attended the local service user Recovery Group to scout for people to appear on the film. A woman called Dolly Sen, was giving a talk about her published book and experience of mental illness. She agreed to take part in the film.

I set a date for interviews with service users. Dr Wolfson was present and assisted with questions. Unfortunately, most of the people that attended were not suitable. Some had difficulty in answering my questions, which would cause a problem when the real filming began. Others did not want to talk about key issues that I needed to address.

I set up a second round of interviews with service users a few weeks later. Jerome suggested a man called James Bellamy, who appeared in documentary called “Edge of Madness” and a man called Gordon McManus. They both agreed to attend. After

### Making the Recovery Film: Michelle's Story

consultation with Dr Wolfson, I was still undecided. I thought that Gordon was too shy as he gave me very little eye contact during the interview and James seemed very anxious and uncomfortable.

That evening Dr Wolfson and I talked with Jerome. I expressed my doubts about Gordon and James. I decided that I would ask James to come along again. Dr Wolfson was very keen on Gordon. Jerome agreed and said that Gordon just needed warming up. I took their advice, although I still had nagging doubts. When James attended the second time he was more relaxed.

It became clear to me that I had no control over who would be interested in appearing in the film. Having come from a fiction background where you can choose actors, this made me feel insecure. The bottom line was that many people did not want to be on film. Many service users keep their condition a secret. I could empathise with this, but I was concerned that we would not get the fourth person in time for the shoot.

I received an email from Dolly who suggested I go along to "Bonkersfest," the festival celebrating madness on Camberwell Green. Dolly was showing some performance art. I arranged for crew and transport. I recruited a friend to hand out flyers and knew this would be a great opportunity to recruit service users. When we arrived it started raining, but by the time we started to film the sun came out for the rest of the day. I took this as a good omen.

I was hopeful of a good response with the flyers but did not receive any feedback. Fortunately, a few weeks later I got an email from a man called Ben Haydon, an artist, who was very keen to appear in the film. I now had the fourth person for the film.

I was also in recruitment for a Production Manager to start at the end of July. My workload was increasing and I was trying to juggle my commitments. I had less time to be creative and spent most of the time in administrative tasks. I expressed my concerns with Jerome, who sensed my frustration. I would have liked to employ a Production Manager as early during the pre-production, but the budget did not permit.

Setting up interviews for a Production Manager was very time consuming. I had eight people to interview and many already had other commitments. Luckily, I met a woman called Gilly Sykes, who was very experienced and was available for the duration of the shoot.

Gilly started at the end of July. The first thing we did

was look at the budget. Then Gilly started to find crew and equipment. I had already decided what locations I wanted for the interviews, but we had to convince people to let us use them. We had no money in the budget to pay for locations. In fact we were lucky to secure most the locations within a few weeks!

Gilly arranged for me to meet a Cameraman called Richard Gibb. We discussed the tone and mood of the film. We decided a Z7 would be best camera that we could afford. Richard asked if I wanted a mirror, which would create the effect that the person being interviewed is looking straight at you, but it would be something that had to be used consistently throughout the interviews. The rationale of the mirror is to empower the person being interviewed. However, I was undecided at this point.

We organized another meeting with Dan to meet Gilly. We gave him a rundown of our progress and he seemed pleased that we had the all the service users and most of the locations. I told him that we had a shoot date for September.

I started writing questions for the service users. I began with direct questions about their recovery and what had helped or impeded their journey. I also included questions about medication, hospitalisation, benefits and other factors that influenced their well-being and lifestyle. I showed them to Dr Wolfson, who suggested that I personalize some of the questions. I decided that I would ask the service-users to send me a biography of the most important events in their lives. This really helped me to gain a better understanding of what impact certain events had on their mental health.

September was approaching and I felt confident that I had the right balance of questions for each service user. I was also pleased that I had spent time on finding interesting locations. I felt that I was as prepared as I could be. We had a five-day shoot for the interviews. I was excited and nervous at the same time. I did feel under pressure at times, but I handled it very well. Overall, I am pleased with the content of the film. The interviewees were very responsive to my questions. Listening to their stories made me feel a great sense of HOPE.

I begin post-production in November 2008. I look forward to exhibiting this film next year. I would like to thank all the people who have supported me during the journey of making this documentary.

**Michelle McNary.**

## Paper 3. Auditioning for recovery

It was a stiflingly hot day in late summer. The auditions took place in a mental health centre in Streatham, on the main road, just a stone's throw away from the train station. Hollywood it wasn't. The buzzer on the front door had developed a glitch so that getting into the building was a test of initiative, intuition and advanced social skills. Once inside, the volunteers for the project were offered a chilled soft drink. Then they went into the audition room to meet Michelle McNary, the award winning film director. I was the token psychiatrist.

Michelle spoke to each person about the film. It was going to be about recovery from mental illness. She asked whether the volunteer had a mental illness. Not everyone said yes but most people did. 'Do you take medication?' she asked. Nearly everyone said yes to that.

Michelle said that she was taking Clozapine and Quetiapine. She wanted to know what medication they were taking. They told her and she wrote it down. Then it was time for them to tell their stories. She asked a few questions. The tone was sensitive but straightforward. They had to be able to cope with the situation in front of a camera. She told me later that she did not want to go into too much detail at this stage. She wanted to preserve the freshness of what they would be saying on the day. Finally she asked them about recovering, what it meant to them, what helped, what hindered, how it happened.

Nearly all of them suffered from a major mental illness. Their symptoms ranged from mild to so intrusive that you could not help but admire them for being able to get up in the morning, never mind being prepared to share their insights about recovery.

It was important that they spoke about recovering and that what they said could be shared with others not least because there are still plenty of people, journalists especially, but also mental health professionals and service users who do not believe it is possible for people with a severe mental illness to recover.

How does recovery happen? Patricia Deegan, who spent years in a mental hospital in the US before training as a clinical psychologist described recovery as 'a journey of the heart' (Deegan, 1996) and 'a process, a way of life, an attitude and a way of approaching the day's challenges.' (Deegan, 1988).

The intensely personal nature of that process suggests that watching real people describing it in different ways on a screen might be more effective than reading about it in a book.

When you do read about it you discover that recovery is often described having a defining moment or a turning point, (Allot et al, 2003) sometimes a low point (Rakfeldt & Strauss, 1989). There can be a loss of hope, and grief for the loss of a future becomes compounded by denial of illness. Then, out of the blue or following an interaction with someone else, sometimes a professional but more often another user of services, something happens. It involves a person regaining a sense of self, taking control and responsibility, and combining optimism for the future with acceptance of the past, (Faulkner, 2000; Leibrich, 1999). It depends far more on helping yourself and interacting with others than being treated (Coleman, 1999).

Showing such a personal process in a public forum like a film throws up its own difficulties. The mechanics of film making have their own rules. The art of the documentary maker is to make real things really seem real. It does not matter if a person's story makes an audience uncomfortable, that can actually be a positive thing, but their story must be compelling. They also have to tell their story in a way that engages other people and holds their attention.

What emerged from the auditions, which may also be relevant to understanding recovery, relates to insight. The recovery process involves a person gaining a new insight into their experience of themselves and the world. That insight does not have to include agreeing with their doctors or taking medication. It can withstand the experience of the most intrusive symptoms. But what's important about insight is that it can be understood and shared with others.

### **Dr Paul Wolfson.**

Acknowledgement:

I wish to thank Glen Roberts for teaching me about Recovery and letting me borrow his slides.

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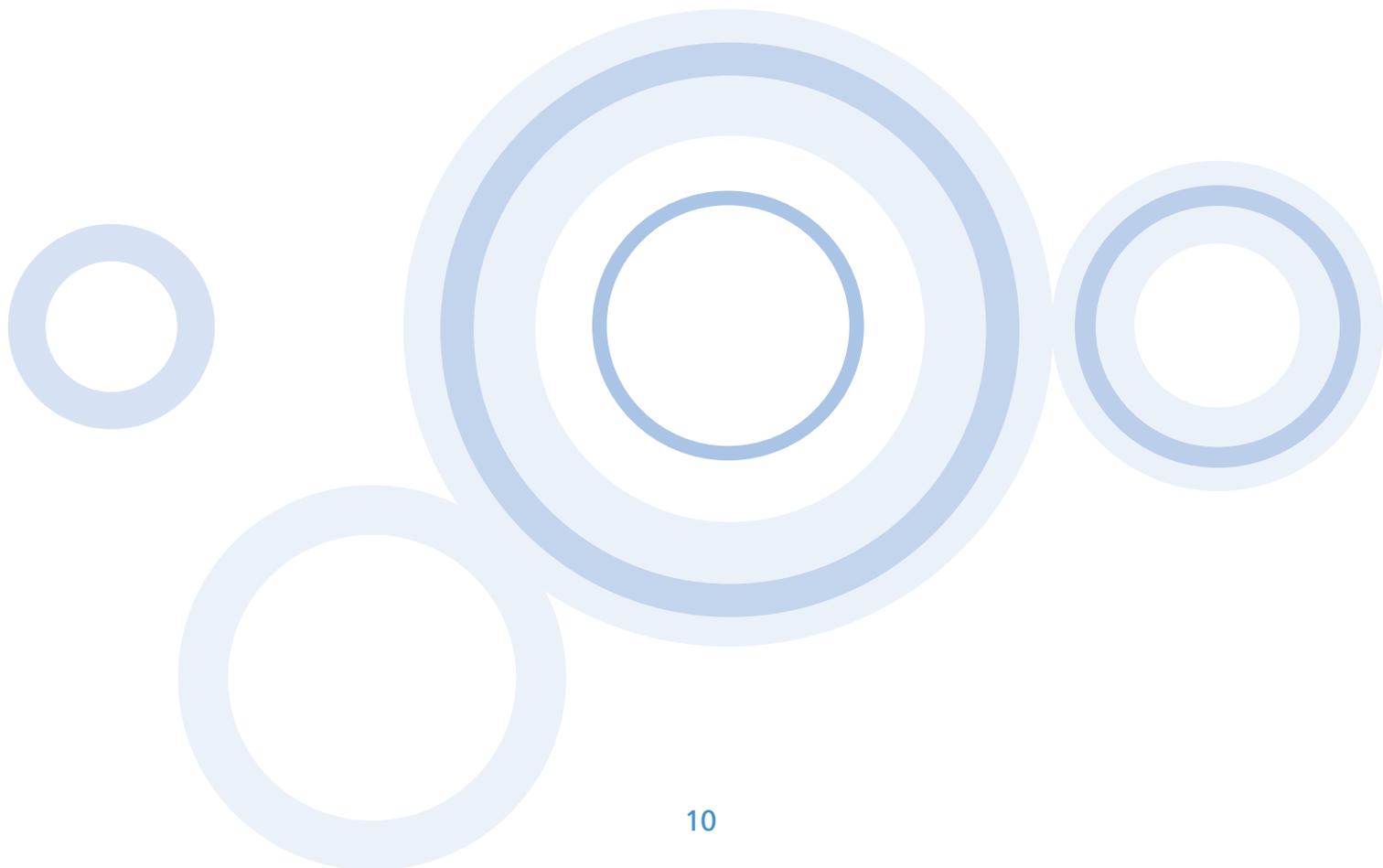
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## Paper 4. Dolly's Story.



Dolly Sen

I was born in London in 1970, and have lived in London all my life. My childhood was not a happy one: Physical, emotional, mental, sexual abuse, racism, poverty, neglect, bullying, and more. Most importantly there wasn't any hope. I think all this contributed to my first experience of psychosis at aged 14. I was not a happy person before I became psychotic but the experience of hearing demonic voices, paranoia, and delusions of being evil sent me to hell, and I stayed in hell, losing skin after skin after skin, and hope after hope after hope, for a decade and a half.

Although I was ill through most of my 20s, I managed to stay out of hospital by not being truthful about my psychosis. But as my abusive dad got worse, so did my paranoia and I was hospitalized for the 1st time in 1999. The incident that put me in hospital was also my turning point. Because I thought my dad was an alien plotting my destruction, I tried to kill him. As I stood over my sleeping dad, ready to kill him, I saw a set of eyes staring at me - from the wall. It was a picture of me as a child, smiling for the camera. I tried three times to stab my father, but a child was watching, and I couldn't do it. "I'm sorry for turning you into a murderer," I said to the photo.

It was the worst point in my life. It had to be if I wanted to kill my father to ease my pain. But strangely enough it was also the beginning of my recovery, because something did click. As I looked at the photo of me as a child, I realised I couldn't let that child live this kind of life. Something had to change. So my recovery began with that decision to change.

“In the fabric of hell that enclosed me like a straitjacket, there was an infinitesimal tear, a hole which unravelled my hell, thread by thread, until the constraints became more hole than limitation...Recovery is a letter of hopes, dreams, songs, peace, hurt, chaos, transcendence, night and light. Recovery is to be able to dream and live those dreams. To shine my brightest, and live my fullest. To seize the day without the weight of the past. To lose any negativity in my life. To find the Dollyness of Dolly.”

But it was not plain-sailing. To find dreams in the midst of the nightmare that is paranoia, depression, delusions of evilness, and horrible, tormenting voices is hard. That is a journey in itself, and I think I spent a decade of my life (my 20s) doing just that. In the fabric of hell that enclosed me like a straitjacket, there was an infinitesimal tear, a hole which unraveled my hell, thread by thread, until the constraints became more hole than limitation.

I didn't know how to change, so I looked – not to psychiatry – but to my interest in Buddhism to show me ways to change. I threw myself into Buddhist practice. Meditation de-stressed me, made me a calmer person. It also helped me challenge low self-esteem's mantra of: 'I cannot do this' or 'I'm not worth it'. I was no longer going to let a sentence that doesn't even last 3 seconds dictate the whole of my life.

To me recovery is a hugely personal journey. No other person can tell me what recovery is and how to do it. Recovery is not a prescription given to a patient by a doctor. Recovery is a letter of hopes, dreams, songs, peace, hurt, chaos, transcendence, night and light. Recovery is to be able to dream and live those dreams. To shine my brightest, and live my fullest. To seize the day without the weight of the past. To lose any negativity in my life. To find the Dollyness of Dolly.

### Paper 4. Dolly's Story.

There were many things that helped propel my life forward, here are some of them:

◆ **Doing voluntary work:** this helped me feel less isolated and that I was contributing to the world and adding light.

◆ **My creativity** is my bedrock, my reason for living, the substance of my ambition and dreams, so being able to be creative has always been good to me. My creativity is my best friend; it is always there to give me strength and meaning and inspiration.

◆ **Having role models** and reading inspirational stories have also been powerful. You realize you don't have to re-invent the wheel. There are people who been there before you who can inspire you with the proof that recovery is very, very possible, and you are not alone. If another human being has done it, than you can do it

◆ **CBT:** A lot of the preceding points helped me move along the road to recovery but it was CBT that zoomed me along that road. Basically, in a nutshell, here I found the tools to control my symptoms, rather than have them control me.

◆ Out of the CBT came my **rejection of self-pity** and the decision to take total responsibility for my condition and recovery, and not to expect other to 'cure' me, or wait for others to change so I could change. I had to do the work.

◆ **Learning to laugh** at myself. Being human is an absurd and ridiculous career.

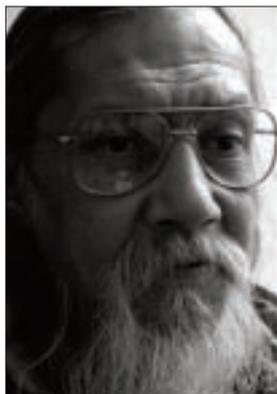
◆ In all the previous points, there were **goals to aim** for. I think this is very important. This helps you being pulled towards the future rather the past dictate your path. And to pace yourself with small steps, but the dreams can be as big as you want!

◆ And **hope**. Always have hope. All the previous points have fed the hope I am feeling in the present to make myself a wonderful future.

There have been many people who have helped me in my journey, but the two who stand out are Jason Pegler and Sarah Taylor. Jason was the first person to truly believe in me. This was so empowering, and one of the major changing points in my life. Also, after the publication of my book 'The World is Full of Laughter', opportunity after opportunity presented themselves which improved quality of life and did my self-esteem so much good. The second person is Sarah Taylor who taught me to climb mountains, both ones in the Lake District and the ones in my mind. She has been a steady source of inspiration and has so changed the shape of my heart it can never shrink again.

**Dolly Sen.**

## Paper 5. Gordon's Story.



Gordon McManus

I was born June 24th 1952 Rangoon, Burma. I came to England, Britain in October 1964. My first English school was Chandos Secondary Modern, in Stanmore Middlesex. I went to Tulse Hill Comprehensive School in September 1965 and left in July 1970 with 3 "O" Levels. In September 1970, I worked for the Crown Estate Office, London for the next year. I then went back to education and enrolled at Kingsway College, NW1. At this College I qualified with 2 "A" levels and 2 "O" levels. I was a founder member of the first Black Student Society at College level in this country. I also sat on the College Board of Governors as the student representative.

In October 1974, I entered the University of Essex, and I read Linguistics with Sociology. I was elected Chair of the Third World First Society. I was a founder member of the Black Student Society at Essex University. My first struggle with paranoia occurred in 1976, when the Authorities tried to turn me into a state agent, by making the Head of the Linguistics Department ask me to research "domino language" in the Black Community and give it to the Police. I refused in a polite way.

In 1980, I became a Communist when I joined the New Communist Party (NCP), which was formed in 1977 after breaking away from the Communist Party of Great Britain. I was expelled from the NCP in 1981 for upholding the Leninist principle of, "paper aimed at the level of the advanced worker". The experience of the NCP was distrust and paranoia due to me being an "intellectual" according to the General Secretary of the NCP. Everyone was watching others, in

**"I** am not free of the symptoms of Schizophrenia but at least I am in the process of Recovery...Recovery for me means, coping with your illness and trying to have a meaningful life."

order to see whether you were a police agent. I joined the newly formed Proletarian in 1982 as one of its leaders. I worked on the Irish National Question for the next four years. In 1986 the Proletarian leadership asked me to work on the Anti-Apartheid issue. I became Chair of Lambeth Anti-Apartheid Group, till I was ousted by the Proletarian due to policy disagreement. I left Communist politics in 1987.

I first became schizophrenic in 1991. I thought it was the Soviets contacting me with a new science of mental telepathy. I lived with this "delusion" for ten years. In 1993, I broke down again with the same symptoms, but my parents looked after me. In 1994, I broke down again and this time I was hospitalised at the South-Western Hospital. In 1995, I stayed "voluntarily" in hospital for a few weeks, because I could not cope with the voices. I managed not to breakdown for the next five years, whilst living with schizophrenia. In 2000, I broke down again and was hospitalised. I came out of hospital in 2001. I broke down again in 2002, and was once more hospitalised. I came out of hospital in 2003, and since then I have not had a breakdown or hospitalisation. The first "therapy" I had was in 2006 at the PICuP Clinic at the Maudsley Hospital. I was referred there by my psychiatrist, Dr. McGowan. In 2007, I entered my second spell of "therapy" with Dr. Jerome Carson. I am not free of the symptoms of schizophrenia but at least I am in the process of "recovery".

The actual process of recovery began in 2001, when I decided to rebuild my life after being diagnosed as having paranoid schizophrenia by

### Paper 5. Gordon's Story.

Dr. Bindman. The catalyst, was a computer given to me by my youngest sister, Moira. I decided to use writing and playing chess against the computer as my means of recovery. During this period a source of comfort was Eric Johnson, son of Linton Kwesi Johnson, the world famous poet and political activist. I did research on Globalisation in order to stop me hearing political voices. It did not prevent me from having another breakdown in September 2002 and I was hospitalised for a few months. From 2003 to 2005, I did research on Globalisation. In 2005 when the voices were getting severe, I decided to write a book on Globalisation so as to prevent hospitalisation (McManus, 2006). From September 2005 to March 2006, I gave all the time I could towards the completion of the book despite hearing "voices".

In 2006 I entered therapy at the PICuP Clinic. This was very helpful because it was the first time that I was able to talk about my condition. In 2005, I started domino sessions at my flat. This contributed towards developing a "normal" life. The other three members of the "domino crew" did not know that I suffered from schizophrenia. They only found out in 2007. I thank Zimmo, Keith and Stanton for contributing towards a more positive approach on my part. My family also played an important role in the rebuilding of my life, and I have to thank my carer, my sister, Laura.

In 2007, I started therapy with Dr. Carson. He introduced me to the works of Patricia Deegan and Rachel Perkins. I began to understand what "Recovery" meant, and in 2008, I now have my own definition of this concept. Recovery for me means, "coping with your illness and trying to have a meaningful life". The therapy with Dr. Carson has helped me to rationalise my condition. He has played a major role in my improvement. We developed a model of Recovery for myself. It helped me rationalise and objectify my illness and the way my life has developed in

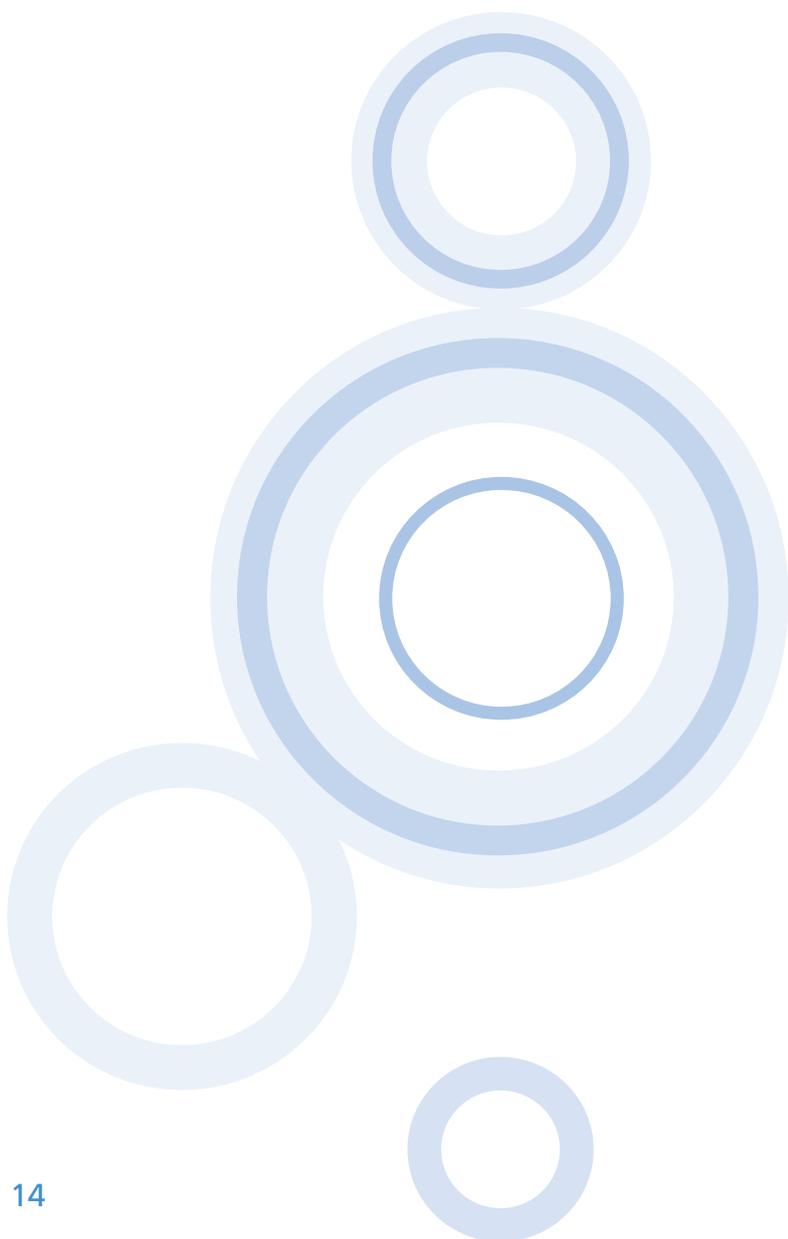
the last twenty years. It provides a goal-orientated approach. The goal of full recovery is essential for me to improve. I am, at present, engaged in writing a book about my "Recovery" (Mc Manus and Carson, 2006), and for this I am grateful to Dr. Carson.

#### **Gordon McManus.**

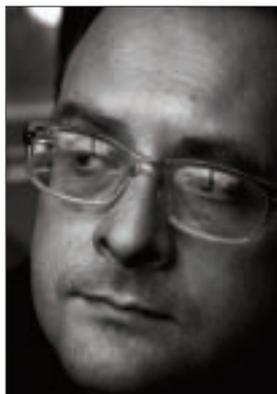
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## Paper 6: James's Story.



James Bellamy

I was born in St. George's Hospital, Tooting and grew up in and around West Norwood. I left school with eleven GCEs. It was only once I turned 20 years of age, that I became mentally ill. This mental illness was diagnosed as schizophrenia and has been treated for thirteen years. Much of this treatment has involved cognitive therapies and a powerful use of mental health medicines, such as haloperidol and clozapine. I have responded well to treatment and have been in a state of Recovery from my illness for some years.

When I look back, it is clear to me that when my illness was untreated, my mind was at an edge of madness because my untreated illness caused delusions and hallucinations of a kind which impelled me to believe that everything human had become "unreal." This meant that I considered television and radio "alien" or else "murderous" and suffered exhausting states of mindless terror about incest and illegal pornography. This meant that untreated madness was indeed my problem and although my Mum and Dad endeavoured to help me, I evaded sectioning in hospital because I was afraid of being imprisoned.

Eventually my parents had no option than to have me forcibly sectioned. I immediately requested an appeal, the result of which proved I definitely needed treatment. I accepted this decision and then co-operated with mental health workers and I have been living in the community since 1995, and this has been a very productive time for both me and my family. (See the account I wrote of the development of my illness, Bellamy, 2000). I am of the opinion that my state of mind is relatively sane and healthy, or what perhaps I mean to say is this: I am a diagnosed schizophrenic with a sense of self-improvement, and that can't be a bad thing?

“I consider recovery as a kind of stepping stone to a better and less insane life... These days I live for sanity. I desire saneness above everything.”

Regarding Recovery, I consider Recovery as a kind of stepping-stone to a better and less insane life. My Recovery from mental illness started as soon as I left hospital. Recovery means peace. I grab a state of Recovery by the hand and insist that it helps me. I have poetry at my side. I have written poetry much of my adult life. Poetry inspires intellect and this means that poetry fights my sickness. I write verse. I love poetry. Poetry has lifted me from insanity. Where poems are written, cleverness kicks in.

I want to live in a world in which schizophrenia is shoved on the "dust-heap." I want my illness crushed and its fragments rubbished. A sane mind for me is a sort of temple in which prayers cleanse one's thoughts of interference. If one stays away from this temple, one must go "mad." I remember long ago, my fascination at school for "altered states", but these altered states proved counterproductive. I imagine that my mind was not in favour of beliefs in alternative therapies or perhaps I liked the idea of altered states once too often?

The man who has assisted me most in my mind-recovery is my father. It is my Dad who helped in having me sectioned. It is my Dad who has helped put my hallucinatory illness in perspective. Without my father, my illness would surely remain "full blown." I have received help from my whole family. This help has helped me lead my life in spite of my mental illness. I have lived with my father since birth. His assistance and advice have aided me for many years. My Dad spends time discussing my illness and this helps me a lot. I have spoken to my father about my mind and the way in which it creates hallucinations and delusions.

I have suffered in my mind for fifteen years now. I recall awaking in the spring of 1993. My mind was mad and I simply did not know what to do. When Recovery from a mind illness occurs, I can think alone without interference. I love being alone. What I mean by this is that when I am freed from hallucinations, aloneness feels lovely and loveliness means that I might lay in bed without hearing things which simply are not there. I like being alone, I realise the true necessity for peace and quiet. These days I live for sanity. I desire saneness above everything. When ever I feel sane, then I feel ecstatic, and the buzz I get from challenging my illness with sane thoughts and sane feelings makes me happy.

**James Bellamy.**

#### **Anniversary.**

Were we really rain that night  
Or did we  
Simply trade our words for clouds?  
We were not seen  
To dream of common storms  
And, calmly,  
As if it were wrong to scream,  
Gaped notes of passion,  
With skin set to war-scrapes  
And eyes  
Robed in chapel-lashes...

I believe our thunder was a lie  
Clapped  
In certainties,  
Wailing over shadows of growth  
But tending a jungle of drought...

We were never rain...  
We could never have been...  
But the madness of time burns deep in us  
As this widow  
Hammers our veins...

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#### **Reference:**

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Psychiatric Rehabilitation Journal, 24, 1, 73-75.

#### **Poems by James.**

#### **Do Not Go Mental.**

(After Dylan Thomas' poem, "Do not go gentle into that good night.")

Do not go mental into that mad night,  
Nor rave where thought deludes the words  
Of men who cry for midwinter birds.

Do not dictate a state of sallow rape  
Nor shallow the cheeks of a child at womb;  
Neither let the sun nor the summer boom.

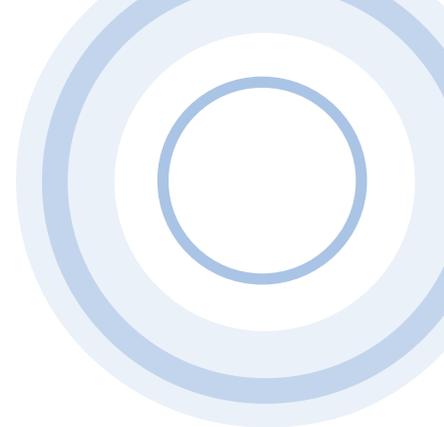
Do not go mental into that mad night  
Nor rave where thought denudes the words  
Of men who cry for midwinter birds.

This earth is changing; see this madness  
Warp the coasts of the mad at heart  
And break their stars in their deadly art.

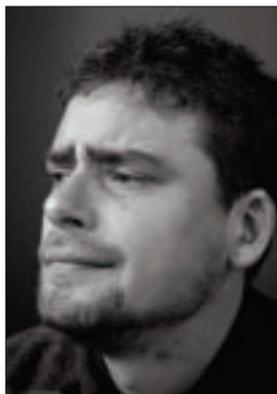
Do not dictate a state of mindless rape  
Nor shallow the cheeks of a child at womb;  
Do not go mental into that vast moon.

Do not go mental into that mad night,  
Nor shade a way for woman's love  
Nor rend the dreams inside mad light.  
Do not go mental to the cars above.

Copyright © James Bellamy 2008.



## Paper 7: Ben's Story.



Ben Haydon

I first became ill when I was travelling in Indonesia after dropping out of art college. I was twenty one. Looking back, things had begun to go wrong before this. I had abandoned courses in two colleges to start an ill thought out business scheme, which was in turn abandoned so that I could experience the world and grow as an artist, leaving all my debts behind. Convinced that I was being constantly watched and followed, I returned to London, six months later, in February 1991, arriving unexpectedly on my parents' doorstep early in the morning. They realized immediately that something was seriously wrong. I was admitted to hospital for what was hoped would be a one off psychotic experience. Unfortunately it wasn't and so began many years of struggling with medication, that left me unable to cope with life, and a growing drink problem that destroyed relationships.

There were periods of relative stability when I felt my head clear, when I could talk to people, and do things. But these periods were linked to me stopping my medication. I didn't believe I was ill, it was everyone around me lying, conspiring against me, so why should I take these pills that made me feel dead when I could be alive again? Of course, I always sank down, after a short time, as the voices took over, always with me, always telling me how useless I was, how I would be better off dead.

Quite early on in my illness, after a long stay in hospital, I made the decision to live independently, first in a privately rented flat and then in supported housing. This was to allow myself the space to paint but also for my self-

“Recovery to me means being able to live with my voices, they are still there but they are not constantly in control...It means experiencing happiness after years of often feeling nothing, or of not knowing how to laugh or even smile properly...My recovery is not complete, I still find myself slipping sometimes but the difference now is I can recognise it and ask for help...”

esteem. I didn't want to be seen as someone who still had to live with his parents.

My journey towards recovery, a journey I am still making, has been dependent on my having this freedom and on my art. I use it as a constructive and creative coping strategy, to become stronger and more confident, to feel valued. Recovery to me means being able to live with my voices, they are still there but they are not constantly in control. It means that I am more able to concentrate, ideas can be thought through and are more likely to become a reality, not just something I am going to do tomorrow, later, never. It means experiencing happiness after years of often feeling nothing, of not knowing how to laugh or even smile properly. It also means being able to accept that my voices are coming from me, not outside. Perhaps they can be a positive part of me, even a strange sort of comfort.

I have had contact with groups offering supported activities for mental health service users for many years. Gardening, walking, life drawing, drop in centres, photography, picture framing – all have helped at one time or another, together they have given me some sort of contact with people and stopped me from becoming completely socially isolated.

Some years ago I lived in a supported housing flat where I suffered abuse and theft of my belongings by people who took advantage of my vulnerability. This left me at a low point in my life. I had to return to live with my parents until alternative accommodation could be found. After a year I was offered the flat that I live in

### Paper 7: Ben's Story.

now, a home that gives me security and the space to paint. This roughly coincided with one of my spells of coming off medication because I felt so disabled by it and then increasingly felt that I wasn't ill anyway. For the first time in my life I was in danger of being sectioned rather than going into hospital voluntarily. It was my fear of this that made me agree to try yet another new medication. This one proved to be the most successful by far.

The past two years have been the longest stable period I have had since I first became ill and also the most positive and constructive time. My recovery is not complete, I still find myself slipping sometimes but the difference now is that I can recognize it and ask for help. I am starting to take responsibility for myself and also realise that I need to go slowly, at my own pace so that I don't feel stressed.

I'm lucky enough to have supportive parents, I know not everyone has this. They are there to back me up while still recognizing that I need my independence. They have also always kept in touch with my CPNs. My last one, Linda, helped me exhibit at the Novus Gallery. Being at the opening, inviting my guests, seeing how seriously it was taken by the media and also selling some of my work, was one of the proudest moments of my life. Before Linda, Theresa found me my home. Sandy now helps me organize the practical bits of my life and introduced me to this project. A picture framing course that I completed last year gave me the skills to frame my own and other peoples' work. I can still book sessions there when I need to and it helps to keep in touch.

Although many friends have disappeared over the years, there have been a few who have kept in contact, accepting me without being judgemental. It has often been difficult for me to socialise, even with people I know well. Seven years ago, on the understanding that I played a part in her care, my parents got a dog from Battersea. Mimi has been my friend, my comfort and the companion who accompanies me to places that I might not have been confident enough to go alone. She gives me the

opportunity to be responsible for someone else other than myself. Earlier this year I flew, with my parents, to Australia for my sister's wedding. Managing to socialise with so many new people was not something I could have dealt with a short while ago but I felt good about it this time.

I know that I still often struggle to cope but I also feel that I'm getting stronger. There will still be bad times but everyone has to go through these at different levels of intensity. I am currently working on my first solo exhibition, very slowly doing up my flat and thinking that I might even be able to visit my sister on my own.

**Ben Haydon.**

## Paper 8: "Recovery: where now?"



Jerome Carson

To my mind Recovery is one of the most exciting developments in contemporary mental health services. Uniquely, it is an approach that is being embraced all around the world. It is also gaining increasing acceptance amongst both mental health professionals and service users. The key focus of the Recovery Movement is the service user, for as the Social Perspectives Network reminds us, "Whose Recovery is it Anyway?" (Social Perspectives Network, 2007). It is of course the service users' Recovery.

One of the most influential proponents of the Recovery Approach is the American clinical psychologist, Dr Patricia Deegan, herself a long term service user. I heard her speak on the topic at the World Psychosocial Rehabilitation Congress in Rotterdam in 1996. I was so impressed by her talk, that I bought the videotape of her presentation. I shared this video with hundreds of mental health professionals and have also shown it to many service users. She talks of Recovery as a journey of the heart (Deegan, 1996). However I never really embraced the Recovery Approach until I moved from Norwood to Streatham as part of a major service reorganisation within Lambeth in 2006. The new service I moved to comprised an Assessment and Brief Treatment Team as well as a Recovery and Support Team (previously referred to as Case Management). One of the advantages of a job move is that there is a certain amount of time to settle in. I decided that I would offer the Recovery and Support Team some regular teaching input on Recovery related matters. This enabled me to research a range of topics, then to present these to staff. I was educating myself as well as the staff. One of my first presentations was "Who put the Recovery into Recovery and Support?"

“What is so exciting about Recovery is that we are still elaborating what the core constructs are and how we can best help individuals with their own Recovery Journeys.”

Another great advantage was having access to the Internet and a wide range of electronic journals, via both SLAM and the wider NHS network. This means that I can e-mail world experts on Recovery and often receive resources within 48 hours. Years ago, such exchanges would have taken weeks if not months.

In the first six months of this new role, I developed a slightly cynical perspective on Recovery. I was very impressed by Whitwell's critical account of Recovery, describing it as "a mirage" (Whitwell, 1999). I began to feel that while as Roberts and Wolfson have said, Recovery is open to all, (Roberts and Wolfson, 2004), it is not possible for all. Within our own team we had an interesting debate with one of our social workers, who had published in this area (Kruger, 2000), arguing in favour of the Recovery Approach, with me arguing the case against. Somewhere along the line, my own views changed to become more Pro-Recovery. Apart from Patricia Deegan, I was also impressed by other workers such as Retta Andresen and Julie Leibrich. Retta Andresen and her colleagues have developed a very helpful stage model of Recovery (Andresen et al, 2003). They argue that there are five stages to the Recovery process. These are Moratorium, Awareness, Preparation, Rebuilding and Growth. Few of our service users could be said to be at Stage 5, Growth, though there are some. Of course by definition, people who have Recovered, will have left the mental health system. Retta and her colleagues have developed a very complex 50 item self-report questionnaire for determining an individual's stage of Recovery (Andresen et al, 2006). I prefer the much simpler, single item Self-Identified Stage of Recovery measure, where the individual chooses the stage of Recovery they feel they are at.

### Paper 8: "Recovery: where now?"

Julie Leibrich edited the book that I feel is one of the most influential in the field of Recovery, "A Gift of Stories," (Leibrich, 1999). This comprises 21 service user accounts of what it is like to live with a wide range of mental health problems, from anxiety and depression to psychoses. The individuals come from a wide range of social backgrounds. The book is beautifully produced and illustrated, which makes it more appealing than some other books, equally well-written, of this genre (Barker et al, 1999).

#### Where now?

What is so exciting about Recovery is that we are still elaborating what the core constructs are and how we can best help individuals with their own Recovery Journeys. No doubt we will see more developments of individual measures of Recovery, such as the Mental Health Recovery Star (McKeith and Burns 2008, a, b), and of services such as the DREEM (Dinniss et al, 2007). These will assist clinicians work out how best to help service users. We also need to develop our understanding of concepts that are likely to be central to the Recovery process. These are concepts such as Hope, Meaning, Identity, Self-Determination, Spirituality, Support and Social Inclusion, to mention only a few. The new field of Positive Psychology (Seligman, 2002), is likely to have an important role and some workers are beginning to apply these concepts to Recovery (Resnick and Rosenheck, 2006). Clinicians will need to work more collaboratively with service users. Geoff Shepherd once expressed the hope that "Professionals should be on tap, not on top." Quite how we might achieve this is another matter.

The Recovery Film that inspired this short book, was a unique collaboration between a service user (Michelle), service managers (Jill Lockett, Dan Charlton, Zoe Reed, Godfried Attafua, and Patrick Gillespie), and clinicians (Frank Holloway, Paul Wolfson and myself). There are other similar projects in SLAM, such as the Involvement Register, which offers service users payment for participating in activities on behalf of the Trust, eg. through staff teaching or in staff selection, as well as time banks and other co-production approaches (Reed and Harries, 2008). Greater partnership working is to the benefit of us all.

The Retrain Project within SLAM, which teaches staff the principles of Recovery over a four and a half day period, is something that needs to be made available to service users. Some might argue

that it is the staff who need re-training most. On the first day of this training, we were presented with four Recovery Heroes. These were Mary Ellen Copeland and Patricia Deegan from America and Peter Chadwick and Rachel Perkins from Britain. In my opinion, this book suggests that we now have local heroes within the SLAM service, in Michelle McNary, Dolly Sen, Gordon McManus, James Bellamy and Ben Haydon. Such heroes are to be found not just in our own service, but in all services. Their stories can serve an inspiration not just to other service users, but also to families, staff and the wider community. It is now time for their stories to be told.

#### Dr Jerome Carson.

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### ...All About

#### ....Recovery websites

The Scottish Recovery Network  
[www.scottishrecovery.net](http://www.scottishrecovery.net)

Recovery Devon [www.recoverydevon.co.uk](http://www.recoverydevon.co.uk)

Yale Programme for Recovery [www.yale.edu/prch](http://www.yale.edu/prch)

Ohio Department of Mental Health  
[www.mhrecovery.com](http://www.mhrecovery.com)

Mary Ellen Copeland (WRAP)  
[www.mentalhealthrecovery.com](http://www.mentalhealthrecovery.com)

US National Empowerment Centre  
[www.power2u.org](http://www.power2u.org)

Rethink Organisation [www.rethink.org](http://www.rethink.org)

National Voices Forum [www.voicesforum.org.uk](http://www.voicesforum.org.uk)

Boston University  
[www.bu.edu/cpr/repository/articles/process.html](http://www.bu.edu/cpr/repository/articles/process.html)

Community Recovery Service East Dorset  
[www.recovery-dorset.org.uk](http://www.recovery-dorset.org.uk)

Care Services Improvement Partnership  
[www.csip.org.uk](http://www.csip.org.uk)

Patricia Deegan [www.patdeegan.com](http://www.patdeegan.com)

South London and Mudsley NHS Foundation Trust  
[www.slam.nhs.uk](http://www.slam.nhs.uk)

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#### ....SRA

SRA is a registered charity which provides intermediate employment opportunities for people with mental health problems. Established in 1991, it has bases in Camberwell and West Norwood. For further details please visit [www.sra-ltd.co.uk](http://www.sra-ltd.co.uk)

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