

# *Making Recovery a Reality*

a lived experience perspective of the  
Sainsbury Centre for Mental Health workshops

**Ruth Chandler**  
**Independent Consultant and Trainer**

January 2010

**Abstract**

As part of the project *Making Recovery a Reality*, the Sainsbury Centre for Mental Health ran four workshops in five Mental Health Trusts in the south of England in 2008/09. These workshops were attended by more than 300 health and social care professionals, managers and representatives from local independent organisations, and had extensive input from service users and carers. This paper gives a thematic transcription of these workshops from the perspective of a person with a lived experience. The first workshop looked at changing practice at an individual level; the second focused on recovery-orientated-training, including service user led training for staff and service users; the third looked at organisational change and the fourth brought these themes together, focusing on changing workforce roles. This paper is written from the simultaneous perspectives of being a survivor of services, a person who has given care and a mental health professional, the paper situates emergent themes within an ethical commitment to breaking down unhelpful them/us demarcations in mental health whilst acknowledging their historical necessity. Paying particular attention to those who have lost out the most under poor past practices, the paper concludes with suggestions to broaden recovery-orientated-practice in a multicultural framework.

## Introduction

*Making Recovery a Reality* is not just a project whose time has come. It is a project that that is a long time overdue. For many people who use services, give care and/or are survivors of past poor services, this wait has been hard and enduring. Writing from the perspective of someone who has experienced multiple episodes of psychosis and been a long-term giver of care, anxiety, anger and despair are just a few of the emotions that have been in the pot. Writing from the perspective of a mental health professional, there is also ongoing frustration at the levels of stigma and discrimination that are still rife within mental health services today. Nevertheless, I have witnessed a positive sea change in professional attitudes towards people who experience mental distress that I would not have believed possible even a decade ago. The Sainsbury Centre collaboration is part of that sea change, involving an extended process of consultation across five participating NHS mental health trusts in four workshop days.

The first workshop looked at changing practice at an individual level; the second focused on recovery-orientated-training, including service user led training for staff and service users; the third looked at organizational change and the fourth brought these themes together, focusing on changing workforce roles. This all sounds straightforward but, as the workshops unfolded, it became clear that the perspectives in play were not going to comply with a linear plan! Debates were wide-reaching and intense, bringing together strong positions and a broad spread of lived experience. There was also immense regional diversity around how recovery-orientated-practice evolves in each location, which clarified ideas without reducing them to over-simplified and formulaic conclusions. It has not been possible to convey the subtlety of these processes. While it makes sense to work with a linear plan, the very nature of the topic escaped these confines, bringing new insights and learning from unlooked for areas en route.

### **Starting in the middle: breaking down the them/ us**

My story, within many stories, starts in the middle of overlapping perspectives and workshop roles. Starting in the middle is not starting in the centre. As a survivor of very poor services indeed, this is an ongoing encounter *between* difficult past memories and hope that things could be different for others in the future (Chandler, 2008). While I only had one hospital admission, this was so traumatic that self-managing the subsequent episodes was the best option, despite their horrifying content. Accordingly, I have never experienced a service I could participate in. As a mental health professional, alternatively, there is also tension between contrasting experiences and seemingly contradictory standpoints. Starting from the middle is, therefore, a lived commitment to breaking down unhelpful them/us demarcations between people who are professionals, those who use services and those who give care, whilst strategically acknowledging their actuality for those speaking out from under them. Working towards services I *would have been* able to use and which *would have been* hospitable to me, simultaneously, as a giver of care to a person I love, validates past distress as having constructive rather than negative power in the present ground of action.

Four questions framed my involvement:

1. If I become unwell again, would I be able to participate in the practices developed in the workshops?
2. If I were in the position of giving care again, would I feel valued and supported by these practices?
3. How would recovery-orientated-practice address lived effects of poor service delivery in the past?
4. Would there be room to collaborate now with participating trusts in a non-tokenistic manner?

Clearly, these concerns spring from a subjective place. Nevertheless, I hope that they have some resonance with people who have also felt their personhood to be undermined and/or are seeking meaningful services today.

### **Sussex: a thinking approach**

The aim of the Sussex workshop was to map out what individuals need to change to become recovery-orientated-practitioners. Taking *Making Recovery a Reality* (Shepherd et al, 2008) as a springboard, the task was broken down into four areas. First, to map out key components of recovery-oriented-practice for individuals; second to establish how that differs from current practice, third to establish how to recognize when recovery-oriented-practice was happening and fourth to draw out the pros and cons of change for the range of participants in the room. My brief was to speak from lived experience and give panel commentary on the feedback from the workshop groups.

Up to this point, I had only told my story in a secluded setting. It is one thing to do this and quite another to stand behind a lectern (which looked rather like a pulpit) in a conference room. It is difficult to select out of a life the important things to say in twenty minutes. And very difficult to do this with people who, at first glance, looked like people I would usually avoid! I was especially uncertain whether my expertise would be received as threatening or valued as a practice on its own terms. The latter was the case. The debate focused on recovery journeys as multiple and many staged processes with feelings that would both vary with perspectives and stages. It is not possible to define individual recovery for everybody as it varies from person to person. Core themes would be the best bet.

### *Reflexive Relations*

Taking recovery-oriented practice as a wish-list, there was agreement that this would focus on the service user's subjective experience and personal goals, rather than 'objective' measures of change. The latter may still be important but not as important as two-way dialogue and peer relationships between service users and practitioners. Relationships would be built on a sense of shared humanity and aim to move away from parent/child dynamics towards adult-to-adult relations. This further involves a shift from a clinical to an educational model. Components of this included active listening, affirming strengths and offering real choices. Choices might be limited but honesty is paramount in shared decision-making and at all levels of interaction.

Hope was also central, although there were questions about the cultural appropriateness of hope for everybody. Hope can be for something in particular or for things to be different than they are (Basset and Repper, 2005). Further, lived experience and professional perspectives may interpret outcomes differently so it is vital for practitioners to find out what recovery means for people and to be mindful of the way in which professional language can alienate or impose expectations. Practitioners placed emphasis on including specific goals and aspirations at the start of the relationship, but acknowledged that listening to a person's distress was as important. Rather than turning recovery into something 'done to' people, workers could try positioning themselves as a hopeful resource for the client's pathway and as a source of 'borrowed confidence'.

To become capable of being this kind of resource, practitioners need to get in touch with their humanity and feel safe to recognize their own vulnerabilities. This, in turn, involves a shift from *caring for* to *caring about*. Meaningful dialogue has its basis in emotional integrity in interactions with people who use services. People are also more able to collaborate and are more hospitable to difference and otherness when they are comfortable with there being more than one expert. All parties need to feel that their messages are being "received" but the onus is on practitioners to ask what they can do to make this happen. Practitioners need to be aware of their behaviour and acknowledge emotional processes, for themselves and clients, as having meaning and value. While the expertise of practitioners remains indispensable, this needs to be held with empathy and humility.

In other words, recovery-oriented-practice asks individual practitioners to take personal responsibility for themselves as emotional as well as behavioral agents of change and to think about how they express this in interpersonal relationships with people who use services and give care. As one commentator put it:

*...in this, thinking about "am I really listening, or am I just being silent while the other person speaks?"; "am I trying to respect this person?"; "am I willing to be aware of and accountable for myself in this interaction – my values, beliefs, prejudices, fears, preferences?"*

This kind of reflexivity (thinking back on one's own fears and vulnerabilities, strengths and weaknesses) is relatively new for mental health practitioners but is not at all new in educational settings. While there may be learned resistance to asking what is it that I am doing when I am doing that, there was consensus that this kind of self exploration would make practitioners much more effective in building relationships and would make work more meaningful, interesting and even enjoyable! Trust employment of more people with lived experience of mental health problems is core to building effective relationships. At the same time, inviting staff without lived experience of mental health problems to share personal stories, e.g. of relationships with people who use services and give care and changes in these, is just as important in supporting practitioners to develop a thinking approach to themselves in peer-relations and to break down barriers. Feeling safe to own mistakes and learn from them is essential to everyone in this process.

### *Work, Risk and Personal Responsibility*

Lived experience participants were quick to point out that this kind of change required time and lots of it! Truly implementing recovery-oriented-practice in mental health is probably at least a ten-year process. The benefits are that more people perceive that meaningful living can include mental health symptoms. Recovery defined more about living well with vulnerabilities and problems than “getting better” challenges the exclusive focus of the illness model of clinical recovery, making space for people to draw on their current strengths to take responsibility for their lives. By focusing on alternative resource networks in the community, recovery oriented practices offer opportunities to increase “personal insurance” or social capital. This could translate into less long-term involvement with services, reducing the trauma incurred by negative experiences. However, some people using services already feel pressured by the ‘drive to recover’ and to enter the community before they are well enough to sustain this.

The above led to extended discussion on work and vocation. Work may be therapeutic but can also be a further source of stigma and discrimination. There was considerable anxiety that commissioners and service providers would focus exclusively on the economic benefits of recovery and not the human agenda. The last is particularly difficult because there is an ethical obligation for services to deliver value for money. Also having a valued work and/or community role is a key recovery outcome for many people. There can be no one size fits all; recovery-oriented-practice is not a quick fix and is wider than the work agenda, e.g. non working-age clients. Long term, it makes economic sense to support recovery as defined by people in recovery, making it more likely that work would become sustainable for those able to do it. Nevertheless, there were real fears that the ‘short-termism’ of service planning could get in the way of sustainable recovery goals. There is still a long way to go in tackling stigma in the workplace and communities to make it possible for service users to build the necessary social capital to make employment viable.

It is also not possible to dig deep into debates around recovery without coming up against the thorny issue of risk. Views ranged from moving from the language of risk to a position of ‘safe uncertainty’ (Mason, 1993) to emphasis on positive risk-taking and shared risk-assessments. The language of risk already invokes a defensive posture and fear of uncertainty that may not be that helpful to facilitating the reflexive skills described above. Safe uncertainty does the same work as positive risk taking but adopts a more welcoming posture to it. (Chandler and Hayward, 2009) At the same time, risk needs sober assessment to keep the safety of all participants central. There were real differences between the concerns of people who use services and people who give care about risk/safe uncertainty. It is all very well encouraging positive risk-taking but what about the impact on family and friends when things go wrong? If more personal responsibility is handed to service users, is that just another way of handing more responsibility to care-givers?

### *Lived Experience and Practitioner Anxieties*

Building in proper support for care-givers was identified as a key indicator for recovery-oriented-practice. Other key indicators were whether service users feel genuinely involved in their care plan and related to: both as a person who can have hopes for the future and as someone free to express their current feelings no matter how negative these are. While everyone agreed that low

expectations for service users is a mistake, there were worries about increasing fear of failure if expectations were too high. For some, personal responsibility is a frightening concept invoking fears of abandonment and stress around not being given time to pause and consolidate. People with lives built around services found the thought of big changes and disruptions potentially destabilizing and threatening. Feeling guided can supply a valuable sense of reassurance, which can be as meaningful as self-management for some. There was also a fear that services would become too urgent about 'getting recovery right'. Would service users feel able to say no in the face of such organisational pressure?

Practitioners' anxieties centered on feelings of professional devaluation and clinical helplessness. The proposed shift is something of threat to hard-earned professional identities and expert roles. Practitioners asked whether they were worth their pay packet if they were doing similar work to others or supporting the self-management of service users. What about their duty of care to people who find self-management very difficult to achieve? There were also concerns about how to measure intangibles like hope, agency and forward thinking. There are tensions between recovery orientated practice, NICE (National Institute for Health and Clinical Excellence) guidelines and statutory governance frameworks which raise questions about how to manage performance and integrate incompatible systems. At the other end of the spectrum, there were concerns that too much measurement would end with managers doling out blunt recovery "targets" to already harassed practitioners. Qualitative targets need to be developed and audited, including lived experience led evaluation. Developing *The Ten Essential Capabilities* (Department of Health, 2004) with each worker into person specific performance targets could start this process.

It was to the credit of this day that the emotional and professional stakes of individual recovery-orientated-practice came to the fore. These were accompanied by a real sense of trepidation (and some scepticism) from people who use services and give care. The workshop closed by raising the question of advocacy, a theme that resurfaced in later workshops over the question of direct payments. Another challenge was the sensitive process of how to contain and process the practitioner's sense of helplessness and personal anxieties about becoming relational and open-hearted. Supporting workers to develop ways of processing negativity is essential if they are to become effective sources of borrowed confidence and mutual support. It is also important to affirm what practitioners *do* know, what they *are* good at. Recovery-oriented-practice should not devalue what already works. Rather, there needs to be a gentle deconstruction of less helpful practices and the creation of sustainable alternatives. A truly recovery-oriented-service would be able to hold disagreement and have supervisory systems in place to support staff to air thoughts and concerns about work. Change produces anxiety and needs careful management to avoid potential pitfalls. Further, identifying the 'tipping point' for organisational change needs more thought. Nevertheless, there was also agreement that this was change worth making. The tricky bit was going to be how...

### **Devon: putting recovery at the heart of what we do**

The function of the Sussex event was to put some markers down that would distinguish meaningful recovery-oriented-practice from superficial approaches and bring together interested

local people. I was invited to join the Steering Group after Sussex. Rather than tell 'my story', my role was to step back and facilitate the stories of local people interested in recovery in Devon. The focus was on three key 'how' areas: workforce development, training and the contribution of lived experience.

### *Creating a Community Workforce*

First, what would a workforce development programme that produced recovery-oriented-practice and practitioners look like? Answers to this question turned on the core principle that lived experience involvement would not be a special event! The centrality of hope expanded to include control and opportunity in relation to maintaining and/or regaining roles, responsibilities and activities, further integrated into all aspects and steps of staff development.

Within trusts, workforce development would begin with practice evaluation, focusing on 'how things are done' rather than counting 'what has been done and to whom'. Existing practices would be reviewed according to how far they help or hinder recovery-oriented-practices, including detailed examination of the roles of managers, directors and frontline staff. Those recruiting would regard lived experience of mental health difficulties an asset in employment at all levels and increase the number of Peer Support Workers. Recruitment would make sure application processes were accessible and non-discriminatory, providing relevant, knowledgeable support for the employment of people with lived experience.

Additional to valuing lived experience inside the trust, the programme would look outside to specialists and community-based reinforcers of well being. These might come from voluntary and private sectors, church groups and leisure centre employers. This list is by no means exhaustive. The aim is to create a genuine community workforce and not an artificial ghetto or sub-culture. For this to be meaningful at the level of service delivery involves identifying individual recovery needs and people with appropriate qualities in and outside trusts to service them. Extending the Sussex discussion, workforce development would avoid a recovery "model" as this would close down diversity. To be accountable, decisions and behaviour need tangible standards. By taking the Ten Shared Capabilities as recovery 'targets' to be developed with staff *and* as a checklist to be completed by people with lived experience, collective evidence would be generated to feed into the monitoring of staff behaviours and attitudes without setting in stone what recovery was for everybody. Holding practitioners to account by these standards and collective evidence would build on good practices and "untrain", if necessary, by identifying behaviours, types of language and internal structures perceived as obstacles to recovery-oriented-practice. Workers would need to adapt to the different ways in which people understood their recovery and the hindrances to achieving it.

The workshop reinforced supervision as a central conduit for recovery-oriented-practice to take root and grow in routine settings. Witnessing people working well, positively valuing change and providing incentives for this were paramount. By taking a detailed look at power-dynamics at all levels of client-practitioner interaction, this would make space for staff to be open about their own "stuff". Importantly, support for the wellbeing of the workforce (e.g. counselling, peer

support, diet and exercise advice) should be easy and 'ordinary' to access. As well as using WRAP (Wellness, Recovery Action Plan) with clients, staff could use it to support themselves as recovery-oriented practitioners. Everyone, from the Chief Executive to Admin, should see their role as a recovery journey. Asking staff to think about what they need to keep well normalises the difficulties of clients' lives.

Involving Human Resources (HR) in looking at whether recovery is being implemented and in knowing when to take action if not was identified as strategically vital in making sure recovery-oriented workforce development became something more than a good idea. Untrained HR departments can make accessing employment much more difficult for people with lived experience and can be unwittingly discriminatory. To give recovery-oriented practice teeth, organisations as well as individuals and departments need to be accountable for working in recovery-oriented ways and should sign service agreements and staff contracts to do so. By taking a joined up approach at all levels and by developing appropriate quality control, it should be possible to work constructively with recovery-oriented commissioners, also committed to supporting well-being in the community.

### *Reflexive training*

Second, recovery-oriented training would look very different from traditional classroom based learning and one-off training days. Rather than something left at the training site, it should be ongoing development and pre-registration training for all clinical staff. It is particularly important for whole teams to train together. Bluntly put, it is very difficult for junior staff to forward their training if their manager has not been on it! Recovery-oriented training would make room for the kind of reflexivity described in Sussex. It would give space to think about real and perceived constraints to recovery and tap into people's passion to enable healthy conflict. It would be mindful that what it means 'to be a professional' sometimes gets in the way of this. By focusing on human qualities and on how to help clients discover their resourcefulness, practitioners could apply this learning personally. To do this, training needs to be discussion based, promoting shared humanity.

Within trusts, related training strands, e.g. delivering race equality, need to be integrated to bring into the mainstream corporate culture the underpinning themes of recovery-oriented practice. Externally, training would reach out to community providers, formal and informal, e.g. faith communities and communities of practice, facilitated by experts through experience. As with workforce development, recovery-oriented training is necessary at all levels, from frontline workers to top managers. Participants suggested the qualities of an effective recovery trainer were awareness of self and others; being good listeners, empathic and able to tell a good tale. They need to be able to inspire enthusiasm while keeping things real; flexible without losing the plot, making room for group responses and departures from plan. To connect with people, they need to be able share positive and negative experiences constructively. Learning is a shared responsibility so it is important not to rescue and fill the silences. Trainers also learn from teaching so it is important to make this mutual learning explicit by valuing the skills in the room. Recovery is not an agenda to be imposed-it is '*about daring to learn in mutual relationality*' (anon).

### *Lived Experience Training*

Third, it was to the credit of this day that questions of training and workforce development had already integrated dialogue with lived experience at every step of the operation. However, this was also a theme in its own right. Lived experience trainers speak with the authenticity of personal experience, a source of expertise key to staff development. A lot of training is now service user led, acting as a positive role model for people learning to maintain well-being. Training brings together two important sets of expertise – academic/professional expertise of “degrees”, and expertise of personal experience (and sometimes both together). This ‘bringing together’ gives professionals ‘permission’ to be more open about their vulnerabilities and service users also might feel heartened by seeing professionals as human beings. This may be more inspirational and have resonances with both sets of experience. Bringing them together may enable both kinds of expertise to think outside of the box of what they already ‘know’. However, it is unlikely to be an easy or comfortable process. Both parties may be making change from seeing a person as a potential ‘patient’ or as a potential ‘judge’ of mental capacity to seeing them as a work colleague. Moving from adult-child to peer relationships can be a sensitive and emotionally charged experience with lots of room for misunderstanding. Finding ways to process hostility and upset, debriefing for example, is crucial if this is not to be token collaboration. Further, having the confidence and/or resilience to deliver training does not happen by itself: these capacities need nurturing.

As with workforce development, lived experience monitoring of training needs to be in place. Staff training should be renamed person training. While this begs the question of who is this person, the point is to emphasise shared humanity. Practical supports could include budgeting and making training more accessible and/or local. Educational supports may include learning to give and receive constructive criticism and building in time to rehearse and prepare. People can go no faster than they can in this kind of process and many people with lived experience need to be involved. This feeds back to the question of ‘tipping point’. One or two lived experience trainers are easily absorbed in a ‘business as usual’ approach. Rather, there needs to be a critical mass for cultural change e.g. enough people working together for change to become self sustaining and unstoppable.

Service users questioned whether some diagnoses were under-represented in training and workforce development, e.g. fewer people with depression. Further, how would the expertise of lived experience be valued alongside clinical expertise? Would it still be the case that lived experience is valued at the bottom of a hierarchy of knowledge? There were also real worries that NHS culture has too many entrenched obstacles to recovery-oriented practice for it to be viable at all. The NHS, like the armed forces, is deeply rooted in a power-knowledge framework based on command and control. Would organisational resistance to handing over power prove too big? Involvement should never become a new mechanism of control.

These are all valid concerns. As Rachel Perkins pointed out, creating a culture of possibility is scary as it involves giving up deeply entrenched values and behaviours. Some diagnoses do appear to be more ‘beyond recovery’ than others (Chandler and Hayward, 2009). Further, is lived experience

involvement at every level of workforce development and training enough to embed recovery-oriented practice as routine? As people that facilitate patient and public involvement may know from bitter experience, there is an iceberg effect between people whose well-being and communication skills are 'good enough' to be active in consultation and training and those for whom this is not currently achievable, or even desirable. In reaching outside trusts to communities as supporters of well-being, there needs to be recognition that many people would still choose to keep their own counsel. Moreover, the question of how to value lived experience alongside professional experience is still embryonic. Nevertheless, I can think of worse places than training and workforce development to start the task of implementing recovery-oriented practice! The issue was going to be how to manage it...

### **Hertfordshire: on the road to?**

The function of the Devon workshop was to elaborate key 'how' indicators of recovery-oriented workforce development and training. However, it also became clear that recovery-oriented practice is about much more than cultural change. It also involves systemic structural change. The key question begged by this was how would vertical service hierarchies manage change that also asks them to give up (or considerably modify) their way of being? There had also been much debate about how far recovery-oriented practice can be defined in terms of goals and outcomes and/or as an open-ended process. The notion of a 'destination' is deeply embedded in Western thought and still meaningful for lots of people. Hertfordshire picked up the baton of thinking through structural and cultural change against the backdrop of these questions. This was an unenviable task as whichever stance was taken half the room would not like it! Nevertheless, the strong positions on the relative importance of goals or processes fascinated as they pulled out the contemporary edges of debate from seemingly exclusive directions. It is vital to find ways of negotiating these kinds of tensions if recovery-oriented practice is going to get off the ground. For these reasons, I took a day off from 'having a job to do' and joined in as a curious responder to the consultation.

### *An emerging organisational narrative*

The day opened with a paper outlining the way cultural change turned old priorities on their head. If symptom change is secondary to social aims that enhance quality of life, treatment interventions are only useful insofar as they assist these aims. Culture is itself a slippery concept, involving shared assumptions, values, beliefs, norms, stories, actions and rituals which add up to 'the way we do things around here'. These collective beliefs may not always be explicit but they foster a sense of belonging in an organisation and 'control the way they (people) interact with each other and with stakeholders outside the organisation'. Organisational culture defined by traditional stakeholders alone stands in the way of recovery-oriented practice premised on dialogue 'on the nature and course of change' with those who have been historically left out of such discussions.

While recovery-oriented practice is quite clear about what it is not, clarity still needs to be achieved on the 'cultural destinations' sought by strategies aimed at revolutionizing health care and the mechanisms needed to forward them. Continuing the conversations of Sussex and Devon, recovery 'destinations' would overcome traditional divisional boundaries, making room for new

relationships and would cut across sub cultures of different professional groups and teams, integrating health and social care domains. First steps involve achieving common purpose through gathering people and ideas in a creative space and identifying catalysts for change. Second steps include developing momentum to overcome inertia and crystallizing the vision. The organisational vehicle would have outcomes driven by social goals, visions and values driven by user centrality and an organisational 'chassis' fleshed out by workforce development, service planning and communication.(O'Halloran et al, 2008).

The paper invoked a range of responses. Some lived experience participants objected to the use of theoretical language. Others, myself included, wanted to take the analysis further. This highlights a real dilemma in debates around recovery and communication. Should accessibility aim for simplicity or for information giving in a range of languages? While no concept should be harder than it needs to be, does an insistence on simplification risk avoiding difficult thoughts altogether? Professional language can obscure and alienate but is it not just as alienating (and patronising) to dumb down content? Executive planning for recovery was also contentious. While it is possible to plan for a recovery-oriented vehicle, there is no road map for recovery. Yet, with the best will in the world, an organisation that did not set out where it aimed to be in the next five years and how it intended to get there would be unlikely to be trusted with public money! Recovery-oriented practice still needs a business model. Hertfordshire service users echoed this sentiment. It is all very well to think of recovery as open-ended and fluid, but there was also a loud call for SMART recovery deliverables in the near rather than distant future!

### *Changing organisational structures*

Other questions turned on whether the drivers of change are top-down, bottom-up or somewhere in the middle. What would be the role and structure of the NHS in supporting recovery-oriented practice? Is there a need for more horizontally organised systems or, more radically, will the role of trusts shift from service provider to service broker? This has particular significance in relation to social care mechanisms for change, e.g. direct payments and individual budgets. If the perimeters of responsibility for recovery-oriented practice extend beyond NHS trusts, their role may need to shift towards community engagement to develop more inclusive/welcoming opportunities, e.g. encouraging local charities to fund recovery-oriented innovations.

Participants suggested that GPs, as first point of contact with the NHS, were strategically vital in community engagement, especially in terms of referral choices. GPs usually refer on because they do not feel sufficiently trained (or do not have the allotted time) to deal with the clinical side of mental health. Yet recovery understood socially and as an individual meaning making process may simply require a good listener or, perhaps, referral to a community activity. While it is important not to throw the clinical baby out with the bathwater, recovery-oriented training might give GPs the tools they need to support well-being in the community and avoid unnecessary contact with services. Similarly, supported access to GPs and financed self-help initiatives might enable people to ask for help that actually does help at the first port of call.

Leading multi-directional change is the responsibility of all stakeholders. As with the first two workshops, the emphasis was on working collaboratively and, most saliently, working with commissioners. Much can be achieved when this relationship is constructive. When it is not, local politics and conflicting service agendas can get in the way of services organised around what people who use them and those who give care really need and focus instead on what services think that services need to survive! Lack of collaboration is unethical, wastes a lot of time and money, and leaves people who use services and give care frustratingly marginalized under the next wave of 'corporate squabbling'. Further, change driven from the bottom up and/or the top down can result in real tensions at middle management for trusts and commissioners alike. It is strategically important to support the creativity of these groups, especially around the question of recovery-oriented practice and performance management. There is already a statutory obligation for both trusts and commissioners to consult with people who use services and give care. Learning the lessons of Devon, this consultation does not have to be a 'special event' but, instead, could become a platform to facilitate genuine recovery-oriented practice at all levels, opening up a 'third space' of innovation between different political agendas.

### *Overcoming obstacles*

In the afternoon, practical problems and solutions were identified with lack of a joined up corporate recovery approach, e.g. training peer support specialists who are then not supported into the workforce. Service users asked why is it that if lived experience is so valued in the workforce, so few staff are willing to 'come out' about it? That there is an invisible cohort of mental health professionals with lived experience is a statistical certainty. The short answer is that lived experience is not yet routinely valued as part of day-to-day operations. This problem is not specific to Hertfordshire. It has been a regular feature of my existence to be the only person in a team who talks about mental distress as an ordinary and acceptable part of their life. Pockets of recovery need connecting through strategic vision and leadership. All job descriptions need to state that lived experience is desirable. This needs HR backing, highlighting again the strategic need for this department to be facilitative rather than bureaucratic and obstructive. For example, HR could record lived experience employment for a baseline and then be actively involved in workforce planning and procedures to change the mix. In particular, evaluation of the inconsistencies between lived experiences of services and what trusts think is experienced is necessary for corporate 'cultural destinations' to build in the flexibility to change. By generating process goals at strategic points in a 'cultural destination', it is possible to structure planning and performance measurement without setting outcomes in stone before the process gains momentum.

It was to the real credit of this day, that some of the awkward corporate questions about power and control came to the fore. As the opening paper stated:

*The more powerful domains of expertise and knowledge such as among professionals are often the only narratives that surface and are recognized as a legitimate description of the organization and its direction...that is the organizational narrative is often uni-dimensional constructed by limited numbers of professionals ("experts") and not given depth by the narrative of those with the expertise of lived experience of recovery. (Davies et al, 2000, as cited by O'Halloran et al, 2008).*

It was somewhat ironic then, that lived experience perspectives were notable by their absence. Nevertheless, there was no complacency about this at the workshop and those who were there punched well above their weight. Most notably, I was both honoured and moved to hear the story of bereaved parents, whose son had committed suicide. For these people, personal recovery was about making sense of the death of a loved one as having posthumous meaning in the treatment of others. As we detail below, making recovery-oriented practice a reality can *and should* start nowhere else than where it is. Anything else is just an insult to people still grieving for the ones who have been lost. The special contribution of Hertfordshire was to unpack some of the systemic tensions of implementing recovery corporately in relation to hard to hear stories from people who use services and people who give care. This seemed a particularly authentic way to set off in a direction of travel, while remaining attentive to the kinds of vehicles (and drivers) needed to take you anywhere at all...

### **London: Bringing it all together**

The function of the Hertfordshire meeting had been to foreground the challenges involved in thinking about recovery-oriented practice organisationally. Given the wide-ranging nature of all three workshops, the Steering Group identified a need to pull these threads together. The joint workshop hosted by SLAM (South London and Maudsley) and SWAG (South West London and St George's) took on this task. The morning opened with papers exploring recovery-oriented practice, extending the implications of the workshops throughout.

#### *Peer Support Workers (PSWs)*

The workshops honed in on peer support specialists and changing professional roles. Confining our narrative to these themes, participants developed the role of PSWs as a key catalyst for change. What would a job description look like? How can peer support be facilitated as *an evolving-process-in-relation* to the people they are working with? Core themes were a willingness to offer learning and insight from their story to prompt exploration of new possibilities. PSWs need to be familiar with the day-to-day routines that matter to a person and to be able to connect at this level. They need to acknowledge their role as offering support in a person's individual recovery while remaining willing for clients to lead the direction of conversation. This involves listening to clients and disconnecting appropriately to look after themselves. Appropriate support needs to be offered for PSWs to look after their wellbeing, for example, time out or talking through.

There was considerable discussion about where PSWs should sit in relation to trusts. PSWs are in a position to directly affect change. However, the peer support service to SWAG is currently a separate organisation. The rationale is that PSWs function better (and perhaps only) if they are independent and non-hierarchical. They still have to be accountable, considering issues of risk, information-sharing and reporting but do so autonomously to the agencies involved in a person's care. PSWs have explicit permission to be overt about their experience. Ideally, however, this permission should spread out to other members of staff. It is thus difficult to imagine how this could happen if PSWs and staff belong to separate organisations. Yet sending PSWs into service

hierarchies that are not ready for them takes a big risk with their safety. How is possible to extend this sense of permission to trust staff and at the same time keep PSWs safe?

One suggestion was to create coalitions between PSWs and trust workers. There are already similarities with third-sector experience of providing information to acute inpatient wards. However, there was also concern about what increased peer-support would release nurses to do? PSWs should not plug gaps and let staff off their responsibilities (withdrawing into the office for example) and most definitely are not an extra bank of care assistants! This raised important questions about whether qualifications are necessary to create relationships with people. On the one hand, does too much focus on skills lose the humanity? On the other, the absence of a career structure for PSWs could mean that they only occupy relatively low paid roles, reintroducing them/us divisions within workforce roles.

One of the special skills of peer support can be the ability to hear some of the trauma of acute care and use this to generate a more useful response from nurses. This is just as important in the community, especially with CRHT (crisis resolution home treatment) teams and post-discharge. While it remains vital not to set these roles in stone, there may be some overlap with advocacy roles. Most importantly, PSWs cut across service functions and boundaries. They are in a good position to take on care-coordinating roles within trusts that are ready for this kind of initiative, ensuring that recovery-oriented practice also cuts across different functions and boundaries.

#### *Changes in traditional roles*

Suggested changes to traditional roles included coaching for self-risk and support for negotiation and constructive challenging of unhelpful stock responses. Rather than be on top, practitioners *should be on tap* and assist in dismantling barriers, acting as brokers and/or guides to exploring new options. The role would no longer be about *doing it to* but *doing it with*, assuming shared decision making, especially in assessing risk and care planning. Professionals need to actively challenge barriers to meeting need and, if necessary, use repeat conversations to make sure they have understood this need. Ideally, there would be less form-filling, releasing time for the dialogue necessary to recovery-oriented practice. Systems need to be simplified and easy to share and remove some of the environmental barriers, e.g. a no closed doors policy. Crucially, the employment of people with lived experience should extend to top management levels, ensuring that shared decision-making, respect and communications are corporately rooted in an empathic base.

There was also concern about the increasing dominance of the medical view of mental (ill) health and the filter-down-effect operationally through governance. The evidence base for recovery-oriented practice needs to be strengthened to influence NICE guidelines and other core influential bodies to sit alongside clinical evidence. Organisations also love changing structures, creating new roles and new jobs while nothing really changes. Re-organisation for its own sake is unethical, wasting time and money while producing the happy illusion of doing something different. It is not enough to move the furniture around when the shape of the room needs to change. In particular, workforce development needs thinking through alongside the personalisation agenda. In future,

people will be able to define what they need and how to get it. The personalisation agenda hands over the ability to commission services to the people who use them, putting people in charge of their own destiny. This vision does not necessarily involve trusts although it can if people choose to use them (or there are no other choices available).

### *Working with and working for*

It is to the credit of this workshop that PSWs were valued as independent practitioners cutting across traditional boundaries. Perhaps the most important insight, however, was that there was not that much perceived difference between PSWs and remodeled traditional roles. How far would it be possible for practitioners without lived experience of mental distress to unlearn past practices and work in peer collaborative ways? This and the question of employing experts of lived experience in (or outside) corporate structures goes to the heart of the question of implementing recovery-oriented practice.

Speaking from personal experience, the nub of the problem is, arguably, the respective interpretation of the relations of *working with* and *working for* by agencies run on *authoritative* and *authoritarian* lines. As an Independent Recovery trainer, I have many good experiences of *working with* authoritative mental health professionals without firsthand experience of mental distress. For example, *Psychosis Revisited*, (Bassett et al, 2007) is a small horizontally organised collaboration between people who use services and/or have survived them and people who work in mental health. Arbitrary divisions between service user, survivor and professional have little meaning as we all have different sets of strengths and vulnerabilities. By writing and training together, we demonstrate that people can live with difficult symptoms and live meaningful lives. We make decisions together, give each other support when times are tough and have written a book together.

By contrast, *working for* authoritarian mental health organisations has been rather like asking a vegetarian to eat ham. Managerial responses have ranged from patronizing and belittling to out and out bullying in the workplace. The 'p word' (psychosis) can invoke tremendous anxiety in service managers. Although I have not had an episode for over ten years, the distinction between managing my actions at work and managing my mental health has not always been understood! At the risk of understatement, mental health organisations have not always been the safest places to disclose in, bringing to the fore stigma (and often repressed hostility towards clients) that can lurk disconcertingly close to the surface in the most well-intentioned of teams.

How can *working with* and *working for* be reconciled? Why should it be safe to speak from lived experience as an external trainer and unsafe as an internal worker? The core factor that has made the difference here is professional identities organised on adult/child relations. Drawing on the tools of transactional analysis, genuine collaborative working involves people relating at adult, child, and peer levels in different degrees and stages of the development of expertise. There is nothing wrong with adult/child relationships if these are authoritative and trustworthy. Authoritative adult/child relations support the growth of the (relational) child to a relational peer and/or adult. Introducing peer relations *inside* authoritarian management systems threatens

adult/child relations based on control, in which professionals arrest the growth of the 'child' to stay on top. Sadly, this toxic illusion of 'authority' still takes up far too much room in mental health today. As a lived experience colleague put it recently, those that desire power over others really should not have any!

In sum, trusts that are serious about employing PSWs need to think carefully about the interpersonal dynamics and priorities organising management hierarchies before testing out the role as a catalyst for change. Trusts need to be clear whether they are employing people with lived experience on equal opportunity grounds or because they value lived experience in the workplace. In either case, there needs to be support for disclosure. It is just not feasible to 'add service user and stir'.

### **Making sense of it all**

As with all perspectives, my pathway through the Sainsbury Centre collaboration has been one amongst many, situated, partial and incomplete. It has only been possible to reconstruct the workshop transcripts from memory and this is selective, forgetting most of a process for a narrative to take shape at all! In this sense, the above is a 'snapshot of transition' (Bergson, 1988). Like a photograph, the viewpoint frames the content and freezes its mobility into a story form that says little of its creative dynamism. I have not presumed to speak for everyone yet transcribing multiple notes is more than my participation. I also have not included repeated themes in later workshops unless they added something discernibly new or consolidated a point. This (necessary) editing introduces the false appearance that earlier contributions had more to say. Notwithstanding these limits, I hope this 'snapshot' has offered a respectful treatment of the unique contribution of each workshop as well as sensitivity to issues that may not have stood out for people with little or no experience of mental distress or of giving care.

### *Looking back*

It is fair to state that I went into the collaboration with mixed feelings towards participating trusts, looking at what needs to be done, organisationally, to make recovery real at the level of service delivery. For a start, this can do no other than begin as an *aspiration* which can irk those (myself included) who wonder what services were doing before they considered the recovery of people to be at the heart of everything they do!

Further, the word 'recovery' has become very fashionable. There is great (and well-founded) suspicion from people with first-hand experience that professionals have hijacked 'recovery' with no attending (or even intended!) practice change on the ground. With notable exceptions, 'recovery' has become the 'new black' for service re-branding, which is broadly interpreted as 'we-need-to-look-like-we-are-recovery-oriented-to-get-funding-for-our-service'. Another common (and equally irritating) response is 'DATA' (doing all that already). Services that really are not 'doing it already' seem to feel compelled, for reasons of their own, to say everything in the garden is rosy when confronted with the thought of changing the way they work. People with lived experience of hollow recovery services have been swift to speak out about such shortcomings.

Wallcraft (2009) points to the anti-recovery movement on Facebook, highlighting the very real limits of 'recovery' as the latest thing that services do to people.

Despite these very real difficulties, taking a step back from (reasonably held) distrust of the current recovery hijack is, I believe, vital if people who use services and people who give care are to successfully work with current service providers to make recovery *a genuine reality* for all. Arguably, the sheer volume of superficial approaches to recovery is precisely the reason for a carefully thought through corrective and was one of the chief motivators behind the Sainsbury Centre collaboration.

To give credit where it is due, some services really are doing all that already. For example, House 48 (in Bognor Regis) has never promoted itself as recovery-oriented but, I would suggest, has simply been doing the work for years. It is a very gentle service, working with people, some of whom have forgotten how to choose, to take tiny steps towards decision-making. For people who have never experienced how hard it can be to get out of bed after a prolonged period of mental ill health, the importance of this kind of service in supporting social recovery may not be that obvious. Most of the clients who use this service are not ready for WRAP and other recovery tools. But the practitioners work alongside them in the hope that they will become so.

Yet while the workshops brought together many such pockets of recovery-oriented practice, everything in the garden is decidedly not rosy. There would be no need to think about making recovery a reality if people who use services and people who give care were expressing their overwhelming satisfaction for services, as they currently exist.

The workshops required a bighearted admission from participating organisations willing to say that service delivery could be much better and historically has never been good enough. The ethical demand of this admission is a rigorous thinking through of a fundamental change in what service delivery is and the kind of workforce needed to deliver it. These moves may be long overdue but they are no less welcome. Out of the two, starting from an honest aspiration to practices that are not yet in place is infinitely preferable to DATA mentalities. Although there were inevitably going to be DATA moments in such a big consultation these were decidedly outweighed by the collaborative ethos. Thinking in terms of dialogue between lots of points of view rather than opposition requires openness to criticism, (positive risk taking par excellence) and willingness to learn from the practices of others. Thinking about recovery carefully and critically is and should be uncomfortable. As a learning process for everyone, moments of defensive practice simply go with the territory. The trick is to be able to process these as and when they come up.

### *Looking forward*

I am satisfied that I have been related to as a different and equal partner in the workshops. There has been room for dialogue that has been constructive, critical and peer based. If I were to become unwell again or in the position of giving care, I am equally satisfied that practices based on the ideas above would treat me with respect and look for ways to support my wellbeing in either capacity. However, these practices are not the majority case now and, if they were, I am confident

enough to make myself heard should the need present itself again. This kind of confidence is still not the majority case for people struggling now.

What else is necessary to make recovery-oriented practice a more socially inclusive reality? Six areas stand out. First, I remain horrified at the levels of dehumanizing practice that are still normative in socially deprived areas. What about recovery-oriented practice for people living with the effects of past practices and/or have had their capacity to make a decision snuffed out? Much as it is vital to re-orientate services to support the social recovery of people who live with clinical symptoms, I would suggest that there is an under acknowledged work of reparation for trusts to do with those most disabled by past poor practices. Conflict resolution and diplomacy may offer tools to start this work. Second, and not unrelated, palliative care, forensics and rehabilitation are the hard ends of recovery-oriented practice. Services for Older People, in particular, have barely appeared on the radar. Questions still need to be asked about recovery-oriented practice for these groups as well as which diagnoses appear to be more 'beyond recovery' than others.

Third, there needs to be socio-economic and political analysis of 'recovery values' and the ideas of personhood that support them. The personal is political insofar as individual recovery pathways create new ways of living within socially constructed discourses about personhood, e.g. gender and ethnicity. While it may be possible to discern key features of recovery-oriented practice, recovery-oriented values are unlikely to be universal or generalisable. Without further analysis of the questions of value and personhood, recovery-oriented practice risks becoming a new ideology that does not know its name.

Fourth, and related, recovery-oriented practice needs to start thinking 'beyond hope' as the only source of cultural optimism. While hope is central for many, so is meditation based on being in the doing of the now, devoid of any sense of past and future. Recovery journeys are vehicles for different understandings of temporality that carry meanings that are hard to place, or are ambiguous within, Western understandings (Briginshaw and Chandler, 2009). To avoid cultural imperialism, recovery-oriented practice may involve considering optimism and pessimism that start from Non-Christian traditions and their secular derivatives.

Fifth, recovery-oriented practice needs more detailed research on the range of ideas about what reality is (or is becoming) in individual recovery pathways. These may be philosophical, spiritual, religious, scientific, aesthetic etc. Some understandings of reality are mutually exclusive (e.g. dualism and monism), which 'really' is a problem. Multi-cultural populations will inevitably contain more understandings of reality than those of mental health services, which could work against non-mainstream understandings. Appreciation of a wider range of functional realities for individuals may militate against the negative stereotyping of those that are not mainstream.

Sixth, taking their cue from the workshops, Shepherd and Boardman suggest that one of the by-products of implementing recovery-oriented practice is a shift from a clinical to an educational model (Sainsbury Centre for Mental Health, 2009). It is vital that people who use services and give care have a say about the terms of this model. There are many educational models, some person

centred and some less so and learning styles vary. Developing resources and practices that work with the full range of learning styles would seem essential to optimising recovery-oriented practice for all.

The points above are an invitation to open dialogue rather than a closed list. Part of my learning in the workshops is that mental health organisations and individual workers also bring recovery narratives with them. Part of these stories is the emergence of NHS organisations *as organisations* in unequal power relations and in a position of co-dependence on the people who use them (Chandler and Hayward, 2009).

A second part is organisations thinking critically about their effectiveness in these kinds of power relationships. It cannot be assumed that the story of inequity is dead (or if it is it is a surprisingly lively corpse). Further, for those emerging from under it, reversing the speaking position of 'us' and 'them' under the signs of lived experience has been a way of establishing a space to be heard that is still necessary from time to time. However, it is not helpful to stay there too long. Opposition on its own is like playing ping-pong. The ball goes back and forth across a divided court. Winning points may feel quite good but the table does not change and there is always a loser – it is only the height of the net that alters....

Throughout the workshops, there have been stories of workers who have gone the extra mile with clients, often in the face of tremendous resistance. People who use services and people who give care have shared their stories, some encouraging and some emotionally bleak. This collective act of story-telling places a question mark over the credibility of the them/us dualism, eroding its divisive power. Making recovery a reality is also part of a bigger evolving narrative that is both international and culturally specific (Slade, 2009). Core to this creative evolution is an open-ended dialogue around what it means to be a human being (Larsen, 2009).

Recovery-oriented practice is an emergent narrative of social justice in relation to the specific values and goals of different people (and peoples) whose potentials are always more than you can make of them. The ethical demand of this emergent narrative is practitioners willing to adopt a service orientation towards people who need their support and organisations willing to make room to care for the wellbeing of all parties in a new *other-regarding-relationality*. All we can really know of this transformation is that it is unlikely to look like ping/pong further down the line. *Making Recovery a Reality*, then, is just as much a narrative about organisational recovery, of people also willing to take a step back and think about what needs to be done to deliver more humane services and, in so doing, become more human ourselves.

### **Postscript: a life lived in sepia**

There has been another story in this story. During the last year, I have been visiting a friend's sister. Anne-Marie (name changed) is slightly older than myself, terminally ill and bed bound in a psycho-geriatric unit as the local hospice does not feel able to provide care for her. She has a diagnosis of schizophrenia and been institutionalised most of her life. Anne-Marie's history

includes a brief period of using knives and matches dangerously in the 1980's. She has been treated as high risk ever since, despite her current physical limits.

It is possible to think in recovery-oriented ways in palliative care and I would argue that it is imperative that this happens. Now that workers have overcome their initial fear, they make every effort to optimise the quality of the short time left to Anne-Marie. There have been obstacles in so far as the pain management team did not always speak the same language as the mental health team and there has been lack of understanding sometimes that bed ridden clients might need some stimulation. However, there is a general agreement that the end of life should respect Anne-Marie's dignity, support her choices and her capacity to make them. While this capacity fluctuates, I am given hope by the quality of this care.

Recovery-oriented practice has come too late for Anne-Marie. What stopped services from offering the same amount of dignity and choice when living her life was still an option? What potentials remain unexplored? How much life 'unlived' under hopeless expectations for her? Anne-Marie does not regard her life as unfulfilled yet, for her sister, it has been '*a life lived in sepia when it should have been full colour*' (anon).

The social debt falls due. If recovery is to become a reality for all, services must be able to work optimistically *and remedially* with the wounded parties of past practice as well as people encountering services for the first time. As well as being carriers of hope, they need to be able to recognise (and perhaps even apologise for) bad treatments in the past and, in these acts of reparation, take the first steps towards developing real recovery pathways with those who have paid the highest price.

## References

Basset, T. & Repper, J. (2005), Travelling Hopefully. *Mental Health Today* November, 16-18.

Basset T., Hayward M., Chandler R., Blank A., Cooke A., Read J. (2007) *Psychosis Revisited: A Recovery Based Workshop for Mental Health Workers, Service Users and Carers*. Second Edition. Brighton: Pavilion.

Bergson, H. (1988) *Matter and Memory* (Translated by Nancy Margaret Paul and W. Scott Palmer). New York: Zone Books.

Briginshaw, V.A. & Chandler, R. (2009) Rethinking Temporality: intertextual plays within and between discourses of space, time and performing bodies (Chapter 3 in: Briginshaw, V.A. & Burt, R, *Writing Dancing Together*. Basingstoke: Palgrave).

Chandler, R. (2008) Recovering Recovery: Getting Better the Long Way (In: Hayward, M. & Slade, M. *Getting Better... who Decides? The Psychologist*, 21, 198-200).

Chandler, R. & Hayward, M. (2009) *Voicing Psychotic Experiences: a reconsideration of recovery and diversity*. Brighton: OHM-Pavilion

Davies, H.T.O., Nutley, S.M., Mannion, K. (2009) Organisational culture and quality of healthcare. *Quality in Healthcare* 9, 111-119.

Department of Health (2004). *The Ten Essential Shared Capabilities: A Framework for the Whole of the Mental Health Workforce*. London: Department of Health

Larsen, J. (2009) Recovery and being: the service user experience in practice. Paper presented at the Sainsbury Centre Recovery Workshop 'Implementing Recovery-Focused Practice: The Implications', 27 January 2009, Springfield Hospital, London

Mason, B. (1993) Towards Positions of Safe Uncertainty, *Human Systems: The Journal Of Systems Consultation and Management*. 4,198-200.,

O'Halloran, P., Munt, C., Marwick, A. (2008) Developing Recovery-Orientated Services and Culture: an emerging organisational narrative-the HPFT story. Paper presented at the Sainsbury Centre Recovery Workshop November 11<sup>th</sup> 2008, Hertfordshire Foundation Trust.

Sainsbury Centre for Mental Health (2009) *Implementing Recovery – A new framework for organisational change*. Position paper. Sainsbury Centre: London.

Shepherd, G., Boardman, J. & Slade, M. (2008) *Making Recovery a Reality*. Sainsbury Centre: London.

Slade, M. (2009) *Personal Recovery and Mental Illness: A Guide for Mental Health Professionals*. Cambridge: Cambridge University Press.

Wallcraft, J. (2009) *Recovery - a double edged sword*, June 22<sup>nd</sup> Dunston Hall Norwich

### **Acknowledgements**

This paper would not have been possible without the collective effort of the hosting Trusts, individual speakers and delegates and the facilitation and commentary from Steering Group members. Special thanks to Lisa Bruton and Karen Thompson who meticulously recorded each of the workshop sessions.

The real person behind Anne Marie passed away before publication. We wish to acknowledge her contribution to the shaping of this report posthumously as well as the contribution of her sister in our many discussions around recovery in palliative care.