



# Hear I Am

Mental health service users, ward life and  
relationships

Project description, findings and recommendations

With a response from East London Foundation Trust

Social Action for Health  
May 2010

ISBN number: 978-1-906770-06-8



## Acknowledgements

### With sincere thanks to:

Service users on Joshua Ward  
Staff on Joshua Ward  
John Ladle, Acting Up  
Sandra Griffiths  
Frances Rifkin, Utopia productions  
Paul Sherman, East London Foundation Trust

## Contents

1. Introductions.....	3
2. Methodology .....	4
2.1. Overall description	
2.2. Project personnel	
2.3. Project structure	
2.4. Project process	
2.5. Community Development	
2.6. Building relationships	
2.7. Care planning and Multi media profiling	
2.8. Reporting into the Trust	
3. Findings and discussion .....	7
3.1. A learning project	
3.2. Care planning	
3.3. CPA and Multi media profiling	
3.4. Forum theatre	
3.5. Shift in focus	
3.6. Being present	
3.7. Ward life	
3.8. Building relationships with patients and staff	
3.9. Concern for the staff on the ward	
3.10. Quality of ward life indicators	
3.11. Quality of ward relationships	
3.12. Motivation	
3.13. Community impact	
4. Summary .....	19
5. Recommendations.....	19
Response from the East London Foundation Trust .....	20
Appendix	

## Social Action for Health

# Hear I Am

*Listen, I am present, I am!*

(Action learning in a complex system)

### 1. Introduction

Who owns the Care Programme Approach (CPA)?

Why are service users not always present at CPA meetings about themselves?

Do service users understand what they are for?

How can we change this?

The Mental Health Guides have been raising these questions on behalf of service users they have listened to, since 2007.

East London Foundation Trust commissioned Social Action for Health to run a pilot project exploring new ways of engaging patients in their own care planning, applying a community development approach. The brief was to share our learning and come up with recommendations.

It was agreed that this project would be emergent, not with a set of targets and milestones pre-set at the beginning but instead, with a set of values and principles to guide us on the journey.

#### SAfH values:

- *We start with the people*
- *We believe that people have the right to take control of their own lives*
- *We believe poor health is allied to social inequity – poverty, racism, unemployment, powerlessness*
- *We believe that healthy communities are good for the whole society*

SAfH developed **4 guiding principles** as a starting point for Hear I Am:

- That service users/patients should be at the centre of their own care planning
- That the experience of shaping your own agenda, planning your own life, is an important one that can be built on
- That relationships are the key to making changes in your life
- That a lay approach to relationship enables greater equality with less unequal power

These principles gave us some **working objectives** that we used to frame the project:

- To explore how African Caribbean men as service users/ patients can become more involved in their own care planning.
- To focus on just one in-patient ward at Homerton, starting with Mental Health Guide sessions. Joshua Ward was picked, seen by participants in health guide sessions in 2006/7 as one of the best wards (then Tuke), seen as a great place for recovery.
- To support and coordinate SAfH lay health guides to build relationships in the ward and facilitate the use multi-media profiling to empower service users in the process of their own care planning.

The focus on African Caribbean men was deliberate. They are the most over-represented user group in the mental health system and for this reason, the initial Mental Health Guide training had been on recruiting and training African Caribbean people - we figured that if African Caribbean people were standing up leading groups, their role modelling impact would be greatest on the people with the least power in the system, that is, African Caribbean men.

## **2. Methodology**

### **2.1. Overall description**

From the beginning, SAfH recognised that this project had two aspects: the social processes involved in engaging service users and staff, and the specific social policy issues involved in the context of mental health. As a community development agency, this is our stock in trade – we function always bifocally, working with personal relationships and with the issues that emerge. In our experience, it helps to be aware of the distinction, even though the processes can often be so embedded that they seem to be invisible to those involved.

The project was not a formal research study, but rather an opportunity for action learning. As such, we expected the project to develop and evolve in light of our learning as we went along. In order to make sure we captured as much of the learning as we could, we put in place a structure for reflection and action, that itself evolved over time.

The action and reflection element of the project took place over an 18 month period, which ended in November 2009. Since then, there have been further opportunities for reflection to support the writing up of the project and the completion of the project DVD. The aim is for the lessons learnt to be disseminated locally in the Spring of 2010.

### **2.2. Project personnel**

5 lay mental health guides, all African Caribbean (this reduced to 3) (Sam Shakes, Neil Thomas, Philip Morgan, Brenda Leacock, Charles Charlesworth,  
2 part time SAfH project coordinators (Mark Whyte and Carly Bond)  
1 part time SAfH project director (Elizabeth Bayliss)  
3 associated “experts” : John Ladle from Acting Up (multi-media profiling);  
Frances Rifkin from Utopia Productions (forum theatre); Sandra Griffiths from Mellow (systems and African Caribbean mental health).

### **2.3. Project structure**

A quarterly reflective group was established that involved all the project personnel and was chaired by Sandra Griffiths. Over time, this meeting took place on a 6 weekly cycle, and lasted 3 hours each. On a couple of occasions we had longer sessions.

A monthly operational group meeting was set up after the project started to deal with practical operational matters as they arose, which involved the SAfH project staff and Acting Up.

The health guides and project coordinators were encouraged to keep a regular daily record of their reflections, describing their experiences and their responses. These were written down, gathered together and circulated to project personnel on a weekly basis for the last 9 or so months of the project.

The health guides and project coordinators also managed to gain access to an art therapist in the Trust who helped them understand the issue of boundaries.

The health guides were encouraged also to have a debriefing session with a project coordinator after each of their ward visits to help them let go of their experiences. Forum theatre sessions also helped the team grasp some of the sense from their experiences.

The reflective meetings were always intense, full on, charged. The personal engagement of all grew as the project developed. All took a full part in the meetings, bringing their own hermeneutic skills to bear, that generated great richness, in which the complexity of the situation emerged. This led to uncertainty and anxiety that created a tension that was on the whole held and indeed utilised. One technique that developed to allow us to hold complex revelations, was the washing line. A telling scenario, a significant phrase, a particularly vivid description, were put on a virtual washing line and kept there. (see the contents in the boxes) A highly complex picture emerged that led to real depth of learning for the project team. We are keen to pass on this learning and have a commitment to finding ways to do so.

#### **2.4. Project process**

We started by running health guide sessions on the ward. These commenced months before the project actually got started and established our willingness to serve, to be of use to both groups: service users and staff. They took place on a regular weekly basis.

Health guide sessions are transactional, based on giving information and receiving narratives of experience. There were information sessions on the Mental Health Act, on the role of advocates, on healthy living, on mental health services and how to use them, on diabetes, the purpose and function of the Care Programme Approach, talking therapies, men's health.

The choice of issues was a joint one, between health guides and users. The choice of process was that of the health guides who deliberately worked within the framework allowed them by the service users, so that if the TV was on when the session was starting, they abided with that. They did not take the power of staff members. They did not get it turned off. The choice to engage was that of the service users. Slowly, service users who started by turning their back on the sessions to watch TV began to join in.

*Mark went into the ward to run a group health guide session on advocacy. The television was. The nurse said she would switch it off. Mark asked the service users and one man, D, said no, leave it on, I am watching it. Mark set up and began the session. D continued to watch the TV with his back to the group. At the end of the session, Mark asked each person to introduce themselves. When it came to D, Mark expected him to remain silent but with his back to the room, he introduced himself. The next person continued. No comment was made.*

*The next week, it was D. who left a message to say that he would not be able to get to the session.*

40 sessions were delivered on the ward to patients during the course of the project.

Through running regular health guide sessions on the ward, we encouraged the service users to talk, to us and to each other, to enquire, to listen, to engage. We built up trust with service users and with staff, that facilitated our continued presence.

#### **2.5. Community development approach and self management**

Social Action for health is a community development agency. Social relations are at the heart of community development, and in relation to this project the intention was

to use a community development approach to build these up, strengthening them so that they could become more purposeful, with a view to increasing social justice, maximising the participation of people in decisions making about their own lives, promoting equality, facilitating learning and understanding and promoting co-operation.

**Community development**

*Community development is about building active and sustainable communities based on social justice and mutual respect.*

*Community development is about changing power structures to remove the barriers that prevent people from participating in the issues that affect their lives.*

*Community development exchange*

In addition, we know how to teach and encourage people to become more self managing. SAfH is a major provider of self management training for people with long term conditions, with our tutors (all accredited, all living with a chronic condition themselves) having successfully taken thousands of people through the LORIG self management course. We brought this intelligence into this project as Sam Shakes, a Health Guide is a highly experienced and skilful self management tutor.

**2.6. Building relationships**

After our presence was established on the ward, health guides and project coordinators began to visit the ward to chat to service users who were around. This settled into a structured routine of two hour visits on a regular twice weekly basis in pairs. They listened and talked, chatted, laughed, played games, building relationships, particularly but not exclusively with the African Caribbean men living on the ward. They encouraged the men to talk and to reflect on their health and well being.

**2.7. Care planning and Multi Media Profiling (MMP) ©**

Over time, the health guides asked the men about care planning, and whether they had any plans for themselves. They introduced the concept of video profiling as a way for users to present themselves in their own terms in CPA meetings. Although Joshua is an acute ward where the focus of daily life involves medication, with what there is to eat, with which bed you would be sleeping in that night, with boredom and with how to secure some leave from the ward, the health guides did interest some people in making their own profile. Some people wanted to write and record songs, read out their writings. Video was seen as the means to show your creative skills. Some people were interested in telling their story on camera, thus capturing it. Some people were interested in using it to present themselves to clinicians in such a way as to convince the doctors that they could be trusted to go home.

However, there were a few men who became interested in developing their own profiles and work with them took place to develop these. Two profiles were actually used in CPA meetings, both with positive benefit for the men. Two other men gained insight into their mental illness through the process of considering doing a profile. Although only a few people got involved in the actual process of profiling, many of the men in the wards followed their progress with acute interest.

The nature of the project demanded a strong basis in reflection so that at the beginning of the project, the health guides and project team were supported to learn about multi-media profiling, making their own profiles before they started. Acting Up provided the expertise here, training, guiding and supporting the health guides and project workers

We had hoped to be able to film in the activity room of the ward but this was prohibited for understandable reasons of confidentiality. However, it was telling that before the prohibition was laid on us, we took in a camera and when a service user showed interest, he was handed the camera. He immediately began filming the project worker, asking the sort of questions from behind the camera that a doctor would have asked him: have you eaten today?

The videoing went on in Core Arts, whose building is across the road from the hospital wards.

## **2.8. Reporting into the Trust**

The Project Director and Project Coordinators reported progress to the Local Implementation Team, attended 2 Directorate Management Team meetings during the project to report on progress and secure support at which videos of the work at different stages were shown. In addition, the Project Director and a Coordinator attended a couple of Acute Care Forum meetings to explore the practical implications of the project.

In this project report, it is only possible to convey a flavour of the complexity we grappled with in our attempt to understand why African Caribbean men continue to be so over represented in the mental health inpatient wards in Hackney. The DVD offers more flavour. Our priority though is to do more than report on a piece of work but to draw out the implications for service provision from the learning, to turn these into recommendations and to influence policy and practice with them.

## **3. Findings and discussion**

### **3.1. A learning project**

As a pilot project, the focus was on the learning to be had. As an emergent, action-learning project, the focus was on turning the learning into practice as quickly as possible. As a SAfH project, the focus was on the men on the wards, respecting each their unique circumstance. There was a proper tension here between these 3 foci that had to be held:

How to learn without exploiting the men on the wards and  
How to learn without exploiting the lay health guides  
How to ensure the project would lead to practical change and improvements?  
How to ensure the project maintains a community development focus?

A reflective group was set up at the beginning that all who were active in the project attended. Chaired ably by Sandra Griffiths, this group met at least quarterly for 3 or 4 hours to explore the issues arising and draw out their implications. These meetings were complex, dense and emotionally charged.

It became apparent soon after the project started that we needed an operational group in addition, to sort out practical arrangements and work out how to deal with barriers, and ensure that practical support arrangements were in place.

### **3.2. Care planning**

Care planning is at the heart of mental health care. The start of this project had been the fact that in health guide sessions, so few people knew about care planning or the CPA process as it is called (Care Programme Approach). Most people were neither

familiar with the concept nor could they relay any personal experience of involvement in their own care planning in practice.

In the Department of Health 2008 Guidance on the CPA, the CPA is defined as follows:

“ What is the Care Programme Approach (CPA)?

It is **not** about rationing care

It **is** about saying what good practice should be like

It has always been about ensuring your care and support are offered within a set of reasonable principles:

- ▶ assessing your needs *with you*, in relation to any given situation
- ▶ Developing a plan *with you*, in response to the needs identified and agreed
- ▶ Sharing responsibility *with you*, (and others as needed), to put the plan into action
- ▶ Reviewing the plan *with you* periodically, to see that it is meeting your needs and to agree any changes

.....

Help you have as much control of the whole process as possible.”

#### **No care planning**

*Mark talked about one man who had walked out of the ward at the end of his stay to nothing, with no contacts, not introductions. He said he wasn't surprised to hear how the man had got himself back by standing in the middle of the road, directing traffic.*

### **3.3. CPA and Multi Media Profiling ©**

At first, the idea had been for Health Guides to build up relationships with men on the ward with the aim of helping people make their own multi-media video profile. Multi media profiling is a 21<sup>st</sup> century tool, designed and developed by a local Hackney charity, Acting Up. It creates an alternative “language” which enables people, through the use of video and computers, to gather and share information about their lives and the problems they face. In the process, they gain confidence, and take part in their own lives alongside the professionals.

The Health Guides were trained to help people develop their own profiles, trained in listening, in reflecting on their own lives and in handling cameras. Multi Media Profiling (MMP) is a powerful tool that we only glimpsed the value of in this project. Health Guides found MMP useful in developing their own reflective skills and were keen to open up access to this new way of reaching in to self to service users.

However, soon after starting our visits to the wards, we were prohibited from filming on the wards. The expectation had been that we could use the side room for this purpose so that no one who did not want to participate would be caught on camera but this room was put out of bounds. The project had gained initial access to the ward through the Health Guides sessions which were valued by staff as well as patients but the potential of filming was a step too far. On consideration the operational group realised that we could work around the restriction and not divert our energy by negotiating for this. Although we thought it was an opportunity lost for some of the men on the ward it was an issue we could pick up more generally at a later stage. Communication with ward level operational managers was not easy since they were very busy and thus usually inaccessible.

Before we were prohibited from using the cameras in the activity room on the ward, some of the users handled the cameras and in a twinkling of an eye, were using them to comment on their situation. The medium of the camera is a powerful one in our time. It becomes an eye, but one that is detached, creating a space between the

observer and the observed that can permit direct commentary to become safer, less risky, less eyeball to eyeball challenging. We saw the huge potential of this in working with people not ready to handle the intensity one to one therapy.

The Health Guides found that many people were interested in talking but with only a few could they reach a point at which the idea of making a video profile became a reality. We concluded that we needed longer with people than we had; that people needed time to play with the cameras and experiment for themselves without immediate purpose. We concluded too that many people on the ward were wholly engaged with working out their situation, at home and in the ward, and that an acute ward was not the best environment for this longer term, experimental approach.

Nevertheless, all those who did take some sort of interest benefited (6 men ) from thinking about the use of video to communicate and to reflect. One person who saw himself on video remarked that how unwell he was at that point, self reflection that before had entirely escaped him. Another person learnt to smile and another decided to take more care of his own health through changing his eating habits.

The concept of multi media profiling was not an easy one for either the Health Guides or the men on the ward to grasp. Our British culture focuses so much on celebrities that people thought the idea was to make videos as entertainment or as documentaries. In fact, a couple of the men who got involved took to filming ward life on their mobiles as though they were investigative journalists. It was as though meaning came from being watched. The sense that MMP promotes, that sense of agency over your own life, grew slowly, as people circled around their experiences, observing it as journalists do, from the outside, working into their own immediate experience. In one case, a man filmed himself being injected and this went into the profile that resulted in the method of his medication being changed. He had been trying for a long time to persuade the clinicians to stop the injections because he was very bruised and sore. When they saw the bruising in his CPA meeting and heard him ask for an alternative form of medicating to be used, they readily agreed. Video seems to amplify reality, making it visible!

In the end, two profiles were completed and both had a very positive impact indeed for the users who made them. One of these was with a man who was an out patient and that led us to reflect on whether it might be more effective to deploy video in community settings with service users who were not in-patients. We would be keen to explore this medium further.

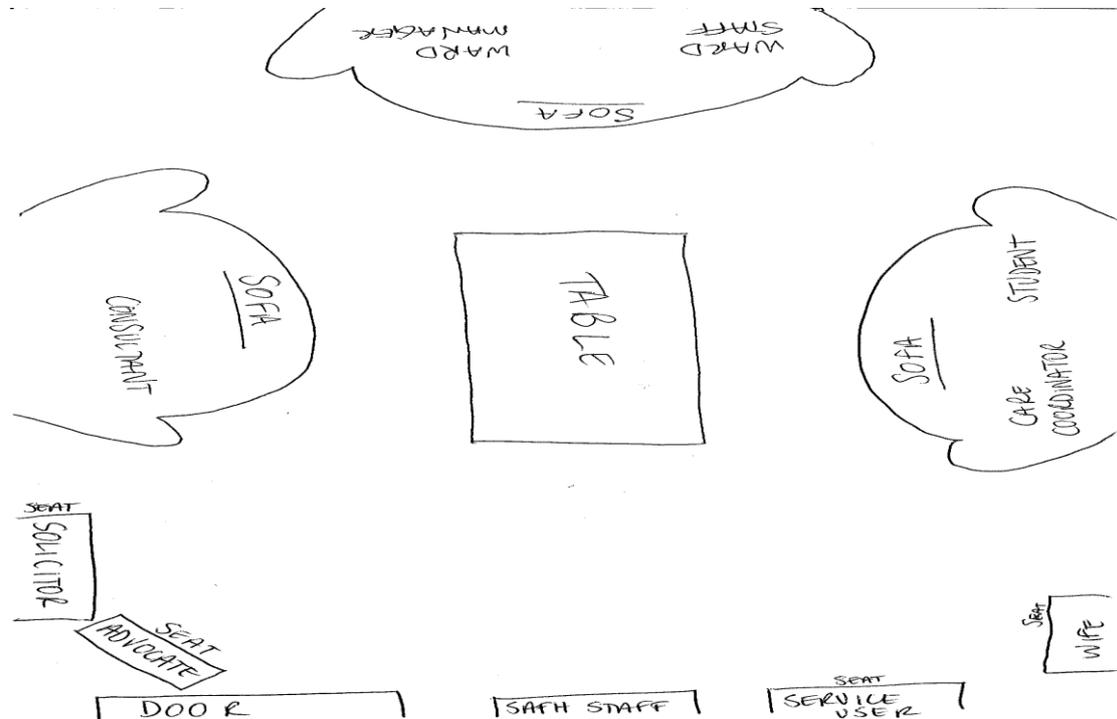
Our original plan in relation to the CPA process and Multi Media Profiling (MMP) was to test how we might enable service users to take control through the process of making and using Profiles in CPA meetings, so that service providers could see the service user as the focal point of the care plan. We thought there may be resistance to the use of video in CPAs but this was not the case. What was more problematic was the timetabling, since it was difficult to find out when the CPA was actually going to take place. Service users are often told at the very last minute, to fit in with when the clinician had time. This difficulty illustrates simply how the process of care planning is not patient-focused but service driven.

*Carly attended a CPA meeting:*

*"When I walked into the ward room with A, his wife, his MIND advocate and his solicitor, I was struck by the fact that the professionals were seated on the sofas in the main part of the room and the rest of us sat on the seats at the edge of the room. It occurred to me that, as it was A's CPA meeting, he should have been at the centre of the meeting and therefore sitting on the Sofa opposite the Consultant, not in the corner! This was also A's discharge meeting, so*

that was an even more important reason for him to be the focal point, especially as the meeting is about and for him and the care and support he needs to be able to recover outside in the community."

### Layout of room during A's CPA



### Video profile in CPA

1<sup>st</sup> April saw the first video profile (MMP) shown in a CPA meeting. Carly accompanied A to the meeting and showed A's profile. Using his profile, A managed to negotiate a change in the way his medication was administered. Instead of fortnightly injections, the medics agreed to tablets, with a 25% reduction in dosage. This was a great success since A has been trying to get this change agreed for over a year!

Just to note here, that we were repeatedly struck by the quality of attention people gave our video progress reports (to the Local Implementation Team and to the Directorate Management Team). The medium of video is powerful indeed in our TV age!

The prohibition from filming on the wards created an obvious block to progressing the profiles with in-patients. We understood the caution of the staff, of course, but it did impede our initial plans. Although we did find alternative venues for the filming (Core Arts) that were close to the wards, if people were not allowed leave from the wards (and on many occasions leave was not permitted, even after being granted because of staff shortages), they could not even make it across the road to Core. However, the reality of our circumstances led us to an adaptation of our approach that was fruitful.

### 3.4. Forum theatre

Frances Rifkin from Utopia was part of the Reflective Group and helped us understand the significance of our work, as symbols of deeper meaning.

Frances worked too with the Health Guides and project team on their observations, using Forum Theatre. By developing scenarios of situations observed, the Health Guides and project team were able to explore what they felt like for patients and staff.

One scenario was the very difficult situation Sam observed when a man on the ward was ignored for hours after asking for leave and then who finally blew up and was eventually led off for medicating. Through Forum, the group looked at the feelings involved from all perspectives and took on the roles, sat in the shoes of staff, patients and visitors. They found it very powerful. Those that took the role of staff in this situation were frightened by their own powerfulness, and those that took the role of patients were distressed; those that took the role of visitors saw that medication was used as a means of punishment and social control. The service users in the group felt especially that this way of working would really help staff members gain a deeper understanding of the social dynamics that emerge.

Another scenario, witnessed by Carly, was the one where one of the men on the ward had his knee on another man's neck. The staff shouted at the man and then explained to Carly the problems they were having with this man. It was a strange dynamic, with the staff trying to get Carly's sympathy. The nurses had little control over this man who was consistently challenging their authority and was described by nurses consistently as being "too loud". Through Forum, it was possible to explore the power relations in an immediate way, turned upside down in this scenario. Because this man was both challenging and determined, the nurses called the police to restrain him.

It made the group wonder about what was really going on, on the wards. We were left with many questions about the function of the wards. It seemed that the prime task of the wards was to contain people, rather than to work developmentally with them.

It was clear from this work that Forum can be a real help in exploring and understanding complex situations that involve emotion, social dynamics, power relations, illness, medication. There was debate about whether, in working with lay people in this mental health context, it would be preferable for them to have some training on key social psychological processes so that they had more understanding. Concepts such as transference and projection were mentioned but there was concern that a little knowledge can be a dangerous thing and that it is important for lay people going on the wards to understand that they do not have such expertise and that their contribution is solely to be ordinary people, bringing expectations of respect and dignity and politeness into the frame of ward life.

### **3.5. Shift in focus**

As an action learning project, we expected the project to change and evolve over time and indeed it did. Starting with a focus on the CPA process and the use of Multi Media Profiling to enable service users to take more control of their own CPA process, it evolved into a witnessing project. The Health Guides took part in ward life, not as experts but as ordinary local people who are skilled at relating to others and who are value-driven, with a commitment to valuing and respecting each and every individual they meet. They built relationships with the men on the ward and they observed ward life.

We had begun by seeing the ward as the context within which the service users functioned, not as a focus in its own right, but ward life took up increasing time in the reflective practice meetings as the Health Guides tried to come to terms with what they were witnessing. They expected to find the sort of attention and respect experienced in general wards so they were surprised when they did not witness this. They were puzzled by the lack of engagement of ward staff with the patients. They saw how bored the men were, and they saw how keen the men were to talk. They saw the men being frustrated and wanting to get out of the ward for a breather and they saw them waiting, hour after hour. They also saw how quickly, the men's expectations rose, by simple actions, like the regular bringing of the fruit. They saw how keen some of the men were learn about how to communicate, how to smile when talking to the staff. They quickly came to feel responsible for the welfare of the men on the wards, since they knew that without their input, the men would be just hanging around, hour after hour.

We therefore organised debriefing sessions after each visit, so they could articulate their feelings from the visit and share their sense of responsibility. The sessions with David Freed on boundary setting helped them a lot.

### **3.6. Being present**

For about 8 months, Health Guides made regular visits to Joshua ward to chat with the men. They might chat to one person for an hour or 6 men over the two hour visit period. They were present and did whatever felt natural, which sometimes included playing table tennis.

#### **A fruitful symbol**

*One of the Health Guides always took in fruit for the men on the ward. Then, after reflecting, he gave the fruit he brought to the staff for them to give to the men as a way of helping their relationship with the men.*

*When another Health Guide began to bring in fruit, she asked to be allowed to wash the fruit and for a bowl to put it in. At first, staff were reluctant at being disturbed since they had to unlock the kitchen door and supervise the washing. Over time, the reluctance by staff mostly disappeared and allowance was given to wash the fruit without supervision.*

*Over the weeks, some of the men on the wards asked a staff member for a bowl when they swathe Health Guide arrive with fruit and helped to arrange it in the bowl. So sometimes now, the Health Guides leave the arrangement of the fruit to the men.  
February 2009*

Trust was a prominent issue. One nurse on the 18<sup>th</sup> March 2009 asked "Are you investigating us?"

There were mixed and changing responses by the staff to us over the period. For instance, on the 25<sup>th</sup> February, the Health Guides were told that they had to pursue their "activity " in the activity room. When asked why this was required, they were told that the staff did not know what was going on in the communal area and that it was "too hectic."

However, it did not stop the men approaching the Health Guides to find out what was going on and to go into the activity room where they were located, for a chat. It seemed to the Health Guides that there was great boredom on the ward. Many of the men were keen to chat.

#### **Coming alive**

*"The atmosphere on the ward seems to change upon our arrival, people seem to "come alive"*

*(not easy to describe). Might be the talking aspect. People hover around waiting to talk," 25<sup>th</sup> February 2009*

Again, on the 25<sup>th</sup> February, a staff nurse commented that our visits were "valuable". She felt the fruit and the one to one chats were helpful and that our person centred approach was good. She felt that our presence alleviates pressure on the staff and that sharing fruit normalises and equalises the relationships on the ward to people eating bananas or eating nuts, rather than service user and staff or visitor.

#### **Lets pretend**

*On seeing one of the men pacing, a Health Guide asked him if he would like to play table tennis. "There's no net" – "let's pretend there is one".*

*"He handed me a bat and we played for about 20 minutes. As we played, he visibly relaxed. We talked about pretending there was a net and making the best of situations."*

*"As I was leaving, a nurse commented that she had seen me playing without a net and said "staff would not be able to encourage people to play without a net – it would not have been accepted. Our job is to fix problems and to suggest pretending there is a net would be seen as an excuse for poor facilities."*

*18<sup>th</sup> March 2009*

We were seen as visitors, rather than staff, and as such, received a very different response from the men staying on the ward. We were accepted and trusted as benign and became aware, during our visits, that the relationship between the staff and the men was very complex. More on this point later.

*"I felt slightly perturbed at leaving Neil on the ward alone. It would be better to be witnessing, as a team. Working together opens up the opportunity to share with each other how we practice."*

*Sam May 2009*

The fruit repeatedly opened up a conversation. It was highly appreciated and was the start of many conversations about healthy eating. "One person said that he only ate apples as he didn't want to be called a monkey!".

The forming of ordinary, everyday interactions with the men on the ward was a priority. These played out through issues arising in Health Guide sessions and a key one that was repeated with different people was around healthy eating.

#### **Healthy eating**

*In conversation, a man on the ward told a Health Guide that he had trouble sleeping. She asked him to reflect on why that might be. It emerged that he was called "the lucozade man" because he drank so much lucozade – 3litres a day! He wasn't exercising much either so he wasn't using up much energy. He thought this might be a reason. The Health Guide suggested he might think of reducing his lucozade consumption and replace 1 litre with water. He thought he might not remember so she suggested writing on a piece of paper – 2 bottles of lucozade and 1 of water – and sticking it up in his room. He asked for blue tak and went straight away and stuck it up in his room.*

*A week later, he told the Health Guide that he had reduced his lucozade levels and replaced some with water. He said he felt better and he certainly looked less tired and was no longer taking sleeping tablets. He had had a good week, he said and had saved himself £20.*

*24<sup>th</sup> January – 4<sup>th</sup> February 2009*

### **3.7. Ward life**

Over the period of the visits, it became clear that our initial focus on the CPA process had to be contextualised by life on the ward. Joshua is an acute ward where people

are in crisis or coping with the aftermath of that. This meant the process of planning was more difficult for many of the men to deal with. This was a significant issue with regard to the multi-media profiling that is explored in more detail below.

In any case, our Health Guides and project team focused increasingly on life on the ward. Through their twice weekly visits, they saw the way the dynamics of the social situation for staff and patients was played out. For instance, they saw men come and go through the ward but a core group, African or African Caribbean, stay put. They saw too, that for the most part, ward life was almost arelational, that is, dialogue was not the norm; the men were not asked how they were feeling by the staff. The Health Guides came to have a debriefing session after their ward visits and this issue of ward life became the subject of many of the sessions.

#### **Arelational ward life**

*A new man on the ward greeted the Health Guide and helped arrange the fruit in the bowl. He told the Health Guide that he had only been on the ward for 3 days and needed to get some air for an hour and to sort out a problem with his children's mother.*

*He said he had been told at 9.30 am that he could leave the ward but it was now 2.10pm and he was still waiting. A manager appeared at this point and the man asked him to open the door so he could leave but he was just ignored.*

*He went to his room and when he came back, he had his bags with him. There was a staff member there who asked if he had been discharged. He answered angrily saying it was now 2.25 pm and he needed to leave and that he was discharging himself. The nurse said "Why don't you calm down and talk to this lady (the health guide) nicely, like you were doing earlier?" The man looked at the Health Guide and said "I'm sorry. I'm just angry. They said I could leave".*

*He started shouting and another man advised him to calm down "You know what will happen if you keep going on like this." The man said "I don't care anymore. My patience has gone."*

*A few moments later the Rapid Response team burst in and surrounded him. Two men in the team linked arms with him and began escorting him towards Bevan ward, where medication is administered. He said calmly "Its ok, I know where I've got to go". They released his arms and he led the team towards Bevan.*

*When the man saw the Health Guide 2 weeks later, he apologised twice for his behaviour, saying he was just angry. The Health Guide said that sometimes we need to get angry and express it. He agreed and said "But it cost me a week on Bevan."  
25<sup>th</sup> March 2009*

The men talked about being ignored by the staff. One man said he didn't like being ignored by the staff but had got used to it. He thinks they don't like him because he is too quiet. When asked about another man on the ward, he said they didn't like him because he was too loud. The Health Guide reflected later that the quiet and loud man got on with each other ok but that the staff couldn't.

The impression gained by Health Guides was that ordinary rules of social life do not seem to apply on the ward. Thus, ordinary greetings such as hello, how are you, are not used. Communication is not followed through, so questions are ignored and answers are not followed by action. These ward "mores" make life difficult and stressful for all, disabling mutual engagement.

#### **Planet Joshua**

*Neil (Health Guide) had been talking to M who was a resident on the ward. Neil had*

suggested in communicating with ward staff that it might be an idea to smile sometimes. They were human, he explained, and responded better to a smiling face than a scowling one.

We, (Neil and Mark W. Project Coordinator) had made it routine to exit the ward after a health guide session through the ward office so we could say goodbye to the staff and log our next visit in the ward diary. On this particular day, as we entered the office, M (a man staying on the ward) followed behind us. The ward manager, a nurse and a ward doctor were in the office. Ward residents were not allowed in the office.

M asked the doctor why his leave had been taken away. He smiled as he asked. The doctor replied, "M. I'm a bit busy at the moment, I will talk to you when I finish talking to E, (ward manager)." M stepped back but not completely out of the office.

The doctor turned back to talk to the ward manager. "Is that ok?" he asked the ward manager. "Yes" replied the ward manager conclusively.

"Right M, shall we..."

"Why has my leave been taken away?" M asked calmly, with a pleasant smile. Tension filled the room. Patients are not usually allowed in the office. We were just about to leave but we paused to see how this would roll out.

"Ermmm...." the doctor glanced at the ward manager but he was busying himself in paper work. He looked at the nurse from Barbados. She seemed to see it as her job to protect the doctor from her fellow African Caribbeans and turned to us.

"Are you finished?" she asked, edging us out of the office.

"Yes, we are just leaving" I said, but didn't move.

The doctor turned to one of us, "Who are you, are you a friend?"

Taking the hint, Neil apologised to M, "sorry to be bailing out on you but I have to leave."

Mark said, "you cant bail out on him now."

"Why has my leave been taken away?" M asked again. We all wondered why too.

"Well, M, you need to socialise more and speak" said the doctor.

"This is what I was saying to you, M, said Neil. "Even if I hate everyone in this room, I still have to be pleasant and say hello and goodbye and smile at people."

The doctor then began to discuss with the nurse how M could get his leave back. Progress!

The meeting ended with M promising to get involved with activities on the ward and to communicate more. The doctor and nurse said M would have escorted leave over the weekend if they could muster the staff. Neil promised M he would sit with him next week to review what had been discussed.

Mark Whyte May 09

### **3.8. Building relationships with patients and staff**

The Health Guides remarked in Reflective Group meetings how the ward "came alive" during their visits. One to one meetings and group meetings on an informal basis took place. Sometimes there was a party atmosphere!

Sam Shakes, one of the Health Guides is an experienced self management tutor who engaged the men in meaningful conversation on a regular basis. She takes a positive attitude to problem solving. For instance, on the 29<sup>th</sup> April, she noted in her

reflective diary “Crisis teaches us something about our relationship with life” in the context of a conversation about how people ended up in hospital.

*After 12 weeks of Sam making eye contact with a man on the ward, smiling, offering fruit, with no response at all, he asked her with a nervous smile, for some fruit. She was pleased as it demonstrated that consistency is important in building trust. Sam Shakes 15<sup>th</sup> April 09*

Neil Thomas, one of the Health Guides realised how concerned many of the men were about getting back into the community. They talked about being isolated and having to cope with boredom. As a result of his conversations with some of the men, he initiated a series of sessions on the ward for the men on healthy living and on cleanliness which proved popular.

There was concern expressed in Reflective Group meetings about developing relationships and then leaving people high and dry. It was important that we sustained relationships once built since the men got so much out of them. It was on this basis that regular weekly visits were organised. When it came towards the end of our time on the wards, we talked to the men and encouraged them to attend Core Arts and build up contacts there.

The Health Guides, as lay people, were helped by the sessions with David Freed to understand boundaries. This became important as they got drawn in to help the men in all sorts of ways. They worked alongside the men, with no power but with energy to help. This led them into going errands to the shop, to go Hackney Adult Services to chase up applications for Freedom Bus passes, to letting men make calls on their mobiles, to escorting men to their CPA meetings, to responding to requests and bringing in healthy food, like nuts and fruit.

*“Did you bring those juices? Why they all the way down there.” Neil placed his hand gently on his shoulder. “Don’t be shy, help yourself, brother.” His manner completely changed. He smiled, got up and helped himself.” Sam Shakes 20<sup>th</sup> May 09*

*There is a change in the interaction. People were joining us in a group and chatting rather than wanting one to one sessions or sitting alone.*

The relationship with staff changed over the time we were visiting the ward as well. There was an incident with two of the men wrestling, playfully. Carly, one of the Coordinators was there and saw it. The nurse came and told the men to stop, explaining to Carly that they may have an aneurism. It was as though they were seeking Carly’s approval and needed to justify themselves.

The Health Guides found that their relationship with staff did change. They became concerned about the staff and their welfare.

### **3.9. Concern for the staff on the ward**

It became a matter of great concern within the project to make sure that our project was not used to blame front line staff for the state of affairs on the ward. The SAfH team felt that the staff would not take it upon themselves to behave relationally; they must have been encouraged by their managers not to engage with patients. We felt that the staff would not take the authority on themselves. We reflected that the concern about boundaries had resulted in staff not sharing their own local knowledge about local resources. We were worried too that the staff would burn out unless they

were encouraged to debrief, especially in the context where staff are continually worried about their paperwork. The staff will be taking their day to day interactions home with them and if these are unsatisfactory, they are likely to be replayed at home.

We are aware how easy it is for us to come in from the outside and comment on services when we do not have to cope with the day to day pressures which we know are great. Staff feel under pressure and this we became very aware of. When we discussed our concern about the staff at a Directorate Management Team meeting, concern that they would end up being blamed, we emphasised how positively Joshua had been described. Indeed, it was because service users spoke positively about it that we chose to work on that ward. We know that staff work hard and try to provide quality care. At the same time, we have to honour the process we are in, for the sake of current and future service users.

### **3.10. Quality of ward life indicators**

After much discussion, and a good deal of debriefing, a set of quality of life indicators for ward life were devised. These were developed over time and checked with service users.

They are rather shocking because they are aspirational, not reality.

1. Have a bed and know where you are going to sleep
2. Be asked how you are each day
3. Be recognised and acknowledged by name
4. Be able to take part in organised group work through which we can be introduced to and get to know each other
5. Be given information on healthy living whilst on the ward, and help with understanding what it means for each person individually
6. Be able to get privacy when visitors come
7. Be given individual help to explore what you aspire to in your, what you would like to do, what skills you would like to develop, starting with where you are at, at the moment
8. Be part of a conversation with clinicians about the inevitable tension between risks and recovery
9. Be part of a discussion about your own medication, how it feels, what impact it is having, how it can be adjusted
10. Have a person to accompany you when you leave hospital so you are not entirely alone.

### **3.11. Quality of ward relationships**

We returned time and time again to the issue of the quality of the relationships between staff and service users. There was a good deal of concern expressed for the ward staff. The sense was that this lack of relationship was not all the fault of the front line staff, that it must be a systemic issue since staff do not have the autonomy to decide on how they behave. The system of management seems very much about command and control, top down, with front line staff not at all empowered. The Health Guide Team did not want to blame the front line staff but did want to convey to managers an accurate picture of what life on the wards actually feels so they could take responsibility for sorting it out. The purpose of the ward staff did not seem to be to care, but to control.

Some front line staff expressed the view several times that the atmosphere on the ward improved when the Health Guides were around, breaking the sheer boredom of inaction for some, giving the chance of purposeful action or the chance to talk and be

listened to, to others. Some front line staff remained suspicious of us. The Health Guides felt that some were jealous of them because the Health Guides were “the good guys”, like the therapists, who came and went, whilst the ward staff were constant, having to be “the bad guys”, having to say no, having to control and limit. We felt that there was some substance to this, and that certainly the staff and the patients were in this together, both adversely affected, albeit in different ways, by the poor social dynamics of ward life.

We came to the conclusion that the closed, impermeable nature of the ward was leading to these dynamics, in which such splitting was taking place. We think it unhealthy for service users to be in such a segregated environment where ordinary life seems to be suspended and that even in acute wards, the sense of ordinary life was damaging by its very absence. We saw how important it became for some of the men to help with arranging the fruit in the bowl. Keeping people on the wards in a state of suspension, by virtue of the way ward life is conducted, aggravates and enervates both patients and staff, rather than creating the sort of stabilising and empowering situation that promotes care and recovery.

The sense was that medication was all and that the social and emotional dimensions of the men’s lives did not seem to be valued, not recognised, not respected. We were concerned that the longer people stay in that environment, the worse it is for them – the impact is corrosive on personality and identity. This is of particular concern when it comes to black men who are staying longer on the wards than their white counterparts. The over-representation of black men admitted to the wards in Hackney remains problematic, and then the fact that they are staying longer aggravated the problem. This was certainly the case with Joshua as we saw the black men staying longer and being readmitted more frequently than others.

### **3.12. Motivation**

Many of the men we engaged with through health guide sessions or through ward visits were very dispirited. Although there was some equipment on the ward, we did not see it often used. Our impression was that staff were frustrated that the men on the wards did not mobilise themselves to take up interests and use the resources available. It seemed that they themselves despaired at the lack of motivation in the men.

We saw how men on the wards rallied when we got into conversation (sometimes slowly, sometimes very quickly) and listened to their concerns: coping with day to life on the ward, diet, health, medication, leave, getting through the tribunal hearing, getting out. Applying a community development approach, we started from there, where they were at. We found that they embraced the opportunity to talk with us and with each other. We found that they had not been formally introduced to each other!

Motivation emerges from self worth, it comes from the inside, it can not be imposed. The motivation to change comes out of a recognition that on the one hand, you do not like the way things are and on the other, that there are steps you can actually take on towards that change.

In our experience, the self worth emerges from being listened to, being recognised in your immediate environment. Self management is a structured, evidence-based means of beginning the journey. What change do I want to make? What can I realistically do this week towards that? For example, the man who was not sleeping because he was drinking too much Lucozade: how about drinking one less bottle this week? It needs to be broken down, step by small step, so that you can begin without too much fear. This needs to come first. Motivation will develop.

### **3.13. Community impact**

We know from our Mental Health Guide project, from our Mental Health and Faith project and from our broader community work in SAfH what a significant concern mental health is to local African Caribbean people. It is striking not only how many African Caribbean mothers are worried that their sons will end up in the mental health system, but how many local people are frightened of mental health services. Local people do not know how the services work but they do see the people emerging from the wards, lost, with no confidence, having lost their social contacts, physically frail. These men who have been through the system are its ambassadors, the more significant because local people who work in the system keep their work life and their home and social life so separated.

## **4. Summary**

In this project, we have aimed to remain within our frame of reference, that of community development. This is the basis of our lay approach: we have not brought clinical expertise to this project but an understanding of social relations, both in terms of values and the processes involved.

In terms of our objectives, we found that the introduction of MMP into the CPA process has great potential but that this would be potential but that the potential value for users might better be released with people who are outpatients, rather than acute in-patients.

Our involvement in ward life raised many issues that can be summarised in terms of the social dynamics of ward life and the within that, the quality of the relationships between staff and patients. In order to convey the reality of ward life, we have described the subjective experience of our Health Guides who visited the ward on a regular basis over a period of around 12 months, interrogated by the broader project team leading to the reflections incorporated here.

The recommendations we make here emerge from our orientation and on our findings. We understand therefore that we approach the CPA process and ward life from a different starting point from that of clinical staff and NHS managers and from patients themselves.

We consider that this is a positive in the situation which seems so stuck and remorseless. The findings reveal dynamics that seem to be long term, systemic, endemic. In recognition of this fact, the recommendations are as clear and direct as we can make them, and focus on action that we believe realistically can be taken. The changes are prosaic, even easy, we hope. There are no quick fixes, of course. The changes recommended will lead in time, *over time*, to a shift of orientation that we judge will lead to improvements for both patients and staff.

## **5. Recommendations**

Below are some recommendations that we would ask the Trust to consider implementing:

- a. The separation of life on the wards and ordinary life in the community is hurtful on many different levels for all involved. It is proposed that ways are found to make the wards more open to ordinary life. We consider that the only way this could be done authentically would be by facilitating the participation of local people in the life of the wards on a routine and regular basis. A framework could be established and volunteers recruited who would

- be briefed and supported to carry out specific tasks, like bringing in some fruit and chatting with the people on the wards.
- b. The men we engaged were very keen to learn about healthy eating and healthy living, cleanliness. It is proposed that a programme of sessions are run on the acute and rehabilitation wards on a regular basis, run by health Guides or others from the local area who are not clinicians but ordinary people who can model the impact.
  - c. The men are crying out for a handle on managing their own lives and health and so it is proposed that self management courses are run on a routine basis in the wards, by tutors who are accredited and who have a chronic condition themselves.
  - d. The issue of leave from the ward is key. The men on Joshua were often hanging around, waiting for leave. The dispiriting nature of waiting coloured daily life. It really should be possible for the Trust to organise a system of checked out volunteers, in twos, to escort people to take some leave from the wards. These people could be encouraged to use their own local knowledge so that people on the wards could be given a physical introduction to fresh networks in the community.
  - e. Training for staff in more depth, on relational skills, perhaps using Forum Theatre covering group dynamics, the balance between professional boundaries and being local people, able to be hospitable, using the SAfH quality of ward life indicators.
  - f. Encourage and establish a reflective process for front line staff, not on a one to one counselling basis, but as a group process, that is part of their working day.
  - g. Set up a Multi Media Profiling project for outpatients, so that outpatients can be assisted to make their own profiles for use in their CPA meetings.

Elizabeth Bayliss

On behalf of the Hear I Am project team:

Mark Whyte

Carly Bond

Sam Shakes

Neil Thomas

Stephen Laudat

Philip Morgan

Brenda Leacock

Charles Charlesworth

Sandra Griffiths

Frances Rifkin

John Ladle

Social Action for Health

12<sup>th</sup> May 2010

## **Response from East London Foundation Trust**

We welcome this thought-provoking report by Social Action for Health and commend the project team who carried out the work on Joshua Ward. The report brings a fresh perspective to how life on an acute psychiatric admission ward is viewed by service users.

Our challenge therefore is to ensure that we have assimilated as much of the report as possible into the day to day running of our wards.

At our Acute Care Forum, we have been working on a comprehensive plan to improve the quality of our wards and many of the Quality of Life Indicators for Ward Life in section 3.10 are included. However, we will be ensuring that the Quality of Life Indicators merit a separate section of its own within the action plan to reflect its importance.

With regard to the recommendations in section 5, we feel that the rightful place for this to be looked at is at the Acute Care Forum, and therefore we would like to ask a representative from the SAfH Project Team to attend the Acute Care Forum on a regular basis to facilitate a dialogue aimed at achieving the aspirations outlined in the recommendations.

We hope that through continued dialogue, reflection and action we can work towards improving the quality of life on our wards for all who use these services.

## **Appendix 1**

### **Original proposal and the starting point for this action learning project**

#### ***Facilitating mental health service users ownership of the CPA process***

##### **Aim**

To shift the focus of the care planning process onto service users so that they can own it, articulate their interests and negotiate these with service providers.

##### **Objectives**

- To train and support a group of service users, carers and health guides in negotiation skills.
- To train a group of front line mental health practitioners in negotiation skills.
- To train Health Guides to help service users create their own personal profiles using multi-media techniques that validate and support their priorities in the care planning process.
- To test out a different way of care planning that is based not on paper but on live, direct, verbal communication, using multi-media techniques that enables the service user to be pivotal to the process.

##### **Process**

The basic concept is that the care planning process is just that – it is a system involving sets of people with different interests. At present, there is little negotiation involved between the participants and often, the subject of the process is not even present at the meetings set up to decide on their future.

What we want to explore in this project is how we might do 2 things:

- help service users understand that they are the subjects of the process not the object of it, that their agency in it is the only way to validate the process
- help service users and providers (clinicians and managers) understand that negotiation is elemental in the process and that it is a process of accommodation between different interests.

This issue is a complex one with many providers in the system understanding how unsatisfactory the process currently is; a great deal of dissatisfaction all round and a sense amongst the providers that this is a mechanistic requirement of top down management. The sense is that if they were left to do it in their own way, the process would be more realistic and perhaps even more humane. From the point of view of service users, the CPA feels often like something the providers do to comply with their managers, and that it has little to do with themselves. Service users often leave hospital mystified, with no sense that anyone has helped them plan their own future.

##### **Methodology**

Therefore, the task is to examine the process itself and to explore how we change the dynamics of it.

In order to do this, we are introducing two related techniques:

- multi-media profiling
- Forum theatre

We will be training Health Guides, carers, and service users in multi-media profiling and we will be training Health Guides, service users and clinicians in negotiation skills using Forum theatre. Service users will be supported to develop their own video profiles, describing, depicting their own priorities which will then be shown to clinicians to inform the CPA process. Through Forum theatre training, participants will learn how to see how the CPA process

works dynamically, opening up options in the way forward for service users and providers as altered relationships are acted out in different scenarios.

This training will create a changed environment in the hospital, the details of which we do not yet know.

At the same time, Mental Health Guides are already running sessions within community meetings in Joshua ward so they are beginning to get a sense of which patients might be interested in participating in this project. The idea is that 3 or 4 patients will become engaged in the project and develop their profiles, over time, supported by Health Guides. They will be working with self chosen patients to construct their own profiles which will become part of the CPA process, informing clinicians' decision making.

The process will take place over a period of time. The different stages will be documented on video so that maximum learning by all involved can be achieved. We expect the process to be iterative, so that we can learn at each step we take. Learning will be at different levels and of different sorts. This is a pilot project so that learning how things might be different is the purpose of it. However, we are intending that all involved will gain learning for themselves out of it, thus influencing the environment.

We expect:

- some service users to learn how to use a video camera and how to develop their own profile
- some front line providers to gain an understanding of the way the system is dynamic, fluid, dependent upon the nature of the expectations of the participants in the process, the hierarchical lines of authority, the confidence of the service user in being heard
- some Health Guides, carers, users and

### **Accountability**

The project team will report into the Mental Health Guide steering group, in September, December and February, informing the group, acting as the accountable body, of progress, barriers and learning emerging.

### **Reflection on learning**

A Reflection Group is being set up to reflect on the issues arising, drawing out the lessons being learnt, identifying the impacts, both intended and unintended and the outcomes. This group will comprise the project team, the HGs, carers, any involved NHS staff and any patients interested in the process as it evolves. The group will identify the universal implications of their learning from the particular with a view to throwing these up to the London Development Centre Network on advocacy for their further reflection and feedback. Sandra Griffiths will be chairing the Reflection Group and will be the link into the LDC Advocacy Network. These will take place in October, January and March/April.

### **Intended Outcomes**

- Staff, carers, health guides and users trained and experienced in multi-media profiling, in the use of Forum theatre
- A series of profiles designed and owned by service users
- Cross sector group of participants can see alternative scenarios opening up
- More service users will have with a greater sense of owning their own CPAs and will be engaged in planning their own care, experiencing the process of negotiation with health professionals implicit in the system.