Social Inclusion:
Putting concept and policy into practice, service and service user perspectives.

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Abstract: *In the context of mental health services, social inclusion is being promoted as a top priority, integral to recovery and good practice. What is less clear in the literature is what the process means for clinicians and service users. In this article we make the process more explicit by describing, from both a service user and clinical perspective, what social inclusion means and how it can be facilitated effectively. We go on to explore and describe the process of facilitating and measuring social inclusion as a healthcare intervention, and how the use of person centred practice and evaluation, supports people to achieve personal goals, participate in meaningful community based activity and improve their overall quality of life. We conclude by suggesting that social inclusion interventions should be the core business of mental health services and a top priority.*

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Introduction

> Out of the blue your job has gone, and with it any financial security you may have had. At a stroke, you have no purpose in life, and no contact with other people. You find yourself isolated from the rest of the world. No-one telephones you. Much less writes. No-one seems to care if you are alive or dead. (Bird, 2001)

Social inclusion can be defined as the right of each individual to have the same opportunities as any 'equal citizen' (Disability Rights Commission, 2001). It is about having the opportunity to be involved, to be valued and to be respected alongside other members of a community (Gamble & Brennan, 2006). Social inclusion is an intrinsic part of the recovery process because it can promote hope for people diagnosed with mental illness by nurturing a positive view of the future- particularly when people achieve their potential (Repper & Perkins, 2003). Some authors boil it down to: somewhere to live, someone to love and something to do (Dunn, 1999). However, achieving 'social inclusion' can be an incredibly complex process (Gamble & Brennan, 2006).

Communities play an integral role in involving people in meaningful activity and providing hope for the future (Rankin, 2005). Barriers to achieving Social inclusiveness include: disabilities associated with a diagnosis of mental illness, stigma, poverty and social disadvantage. Of these barriers, poverty and social disadvantage perpetuate exclusion from social activities. This process can then lead people to be viewed as the lowest division of society by their communities, further serving to stigmatise and alienate people diagnosed with mental illness (Leff &Warner, 2006). There has therefore been a huge emphasis on enabling people to be 'socially included' due to the potential benefits to the individual person in terms of finances, wellbeing, and quality of life (Office of the Deputy Prime Minister, 2004). From a political stand point the Government has undertaken many projects to try and tackle social exclusion in many forms (Toynbee & Walker, 2001). Some of the evidence suggests that having good social supports and the provision of community interventions can have a greater impact than traditional medication (White & Angus, 2003).

Making the process of social inclusion more explicit

Although there are many definitions of Social Inclusion in the literature there has been little written about making the process explicit by which people can be supported to feel more 'socially included' (Croucher, 2010). Becker et al, (1997) discuss that through the provision of 'help necessary' the aim is to enable people to continue being socially included or re-engaged in work, friendships and leisure

communities. Health care professionals can have a positive influence on involvement and well-being, however, there is no real indication of what this 'help' looks like or what form it takes when attempting to work with individuals.

In order for this process to begin the service user's goals need to be explored and identified because people have to recover to somewhere on their journey. Research has shown that people diagnosed with mental illness engaged in structured creative activities have fewer hospital re-admissions (Leff &Warner, 2006).

According to Repper and Perkins (2003) health care workers must adopt an individualised approach, enabling people to gain access to the things they want to achieve by tailoring therapy to the person and their goals. They discuss the need to adopt all possible approaches necessary, and the need for creativity in generating a set of solutions. Above all health care workers need to believe in the people they are working with and that everyone has the right to be involved in meaningful activity. Overall, it can be said that the attitude we adopt as individuals is important in order to challenge the mythical perceptions of 'mental illness' and break down the barriers. One of the most valuable forms of evidence to inform the helping process stems from service users.

Social inclusion: A service user perspective

> Social inclusion is not about disability, symptoms or 'treatment management' it is about an individual's activity of daily living and how they relate to the outside world. It is about bringing the world into a life (Bertram, 2008).

The foundation for our local service developments was grounded in the most valuable form of evidence- insights from the experience of local mental health service users. Extensive consultations, some user-led, identified the range of support that people wanted and the key issues that faced many on their recovery journeys. Some examples include:

• Effective support needs to be person centered and grounded in peoples lived realities: *'Being listened to, feeling understood and encouraged- having a human heart- that's what helps'* and *'replace the fear with real possibilities'.*
• Welfare benefits – advice and guidance is needed: *'The benefits trap is still here'* and *if I show I can do something I get scared about losing my benefits'.*
• Stigma needs addressing: *'The principle causes of low self- esteem are connected to stigma that users suffer from in a direct or indirect way'.*
• Helping people achieve personal goals needs to be the guiding vision for heath and social services: *'Work should be an integral part of any care plan- not just an after thought'.*

- People report increases in confidence, skills and wellbeing through a range of activity- not just employment: *'Education, volunteering and training are valued'*.
- There is no panacea or magic bullet- different people ask for different types of help at different times and locations: *'We should be able to say what we want, not be told what is available and that's it'*
- Access to accurate and local information: *'We need a one stop shop to know where to start our journeys'*.

For some people, the term social inclusion meant absolutely nothing, or it could provoke angry responses and deep skepticism. For example:

It is about the fact that people are discriminated against, marginalised and invalidated by people with power over us. And this especially happens by us being labeled mentally ill.

Social inclusion! That's just a government buzzword that actually means: lets force these malingerers back into work and save the treasury money from the benefit system.

One of the main concerns being expressed by many service users was that they causally linked their difficult experiences in society to the mental distress that brought them into contact with mental health services in the first place. Factors such as poverty, abuse and discrimination featured profoundly when we discussed social inclusion. Understandable feelings of powerlessness, pessimism and anger emerge as the result of their social status and lived realities. As a solution, service users often said they simply wanted a better deal in the world and that building confidence, developing relationships and accessing effective support to achieve personal vocational goals was critically important.

The quality of engagement meant everything and the emphasis they asked for with regard to support was on building trusting relationships and having their experiences validated by others. A human approach consisted of friendliness, warmth and genuine interest. Feelings of safety and autonomy were crucial and some people were also asking for more user run provision. Consequently, over the last six years we have developed a user run vocational project that is integrated into secondary care mental health services.

Vocation Matters:
A practical example of a user run service

User run services are often talked about, but remain rare. Usually, because they help people find their own way forward from a completely different angle to conventional approaches. Given the chance, lived experience becomes an effective qualification

in the helping process. The example described by Shaun Williams (below) is a simple and effective human approach to engagement that produces social inclusion outcome ratios as high as 90%.

When we are assisting users in the Vocation Matters project it feels quite often as if they meet with us and in front of them they are holding up a mirror of their own lives. In this imaginary mirror they are in a very dense wooded area without any light, just themselves looking small and vulnerable. Every tree in this mirror represents a difficulty in their lives. Many of us will have walked though heavily wooded forests and even on the sunniest of days they can be dark, cool unwelcoming places where you could easily get lost. This is more often than not the view of their lives that they bring to the initial meeting. Over a period of time we work together to try and clear the trees a little to get some light shining through. The more problems that are dealt with the happier and more empowered the individual often feels- this is not an exact science and as in everyone's life things do not always run smoothly, but in general individuals do want to do more for themselves.

The Vocation Matters project works in a 'truly' person centered manner and focuses primarily on vocational needs. This also means time unlimited interventions. For example, if you meet with someone for six sessions and they are just getting comfortable with you, and growing in confidence then you stop appointments any progress is lost. We also differ in other ways in that we do not want or need to know a diagnosis, or use any form of assessment tool. In our view the diagnosis has little worth and is overwhelmingly stigmatizing.

By discarding an assessment form we build up a working relationship that empowers individuals to do things for themselves. We therefore do not put people in boxes, we work in a natural way, allowing the conversation to flow freely. Often we do not need to ask the same questions for everyone, and it is often appropriate to allow the service user to be asking most of the questions and taking the lead.

Whilst the main aim is to assist with vocational needs, including welfare issues, we often find that amongst the vocational barriers such as lack of qualifications, experience and confidence there are numerous other needs which might need addressing before they can progress. These are the sort of problem areas often found in a relatively poor inner city area e.g. alcohol and drugs, housing issues, relationship breakdown, family concerns, physical health needs, debt, immigration status, torture and abuse. The list goes on and on. If we can assist individuals with some of these needs by finding help lines, information on the internet- organisations and advice we will do, and depending upon the individual in question we pass the responsibility for dealing with these issues to the service user. If we need to be more proactive we do take a more hands on approach until the individual feels capable of addressing these needs themselves. Both parties are then more able to focus on vocational need, but always with an eye on these other areas of concern.

One thing to note is that of all the obstacles (trees) preventing real change in their lives there are only one, maybe two (if adverse side effects of medication are

counted) directly related to their mental health.

We find because individuals are being listened to they feel as if they are working in a partnership rather than being a passive recipient with little or no choice. They are then more likely to go away and do research, visit places that they would not have done before. Some individuals just need in-depth information relating to vocation to move forward with minimal support. Everyone is different and progress towards their goals can be rapid or it can be laborious, but most who receive information and support from the project do make significant gains. By the end of the process we see, and more importantly the service user sees a more confident person in the mirror, with fewer obstacles around them and some direction in their lives. The mental health system as a whole needs to use approaches which are truly collaborative and empowering for service users if they want them to be valued members of society (Williams, 2010).

The Social Inclusion Hope and Recovery Project: Working to achieve social inclusion

Being involved with SHARP has made a difference by me being more confident, going out more and not being afraid… speaking to others rather than being alone.

The Social Inclusion Hope and Recovery Project (SHARP), has worked since 2007 to offer and promote the use of psychosocial interventions as recommended by NICE (2009) guidelines. SHARP differs from regular mental health services in that we are a stand alone service which aims to provide creative client centered interventions tailored to individuals already receiving South London and Maudsley Trust services. Another important aspect of the service itself is the built in structures which promote service user involvement. From providing employment opportunities to involvement of service users in the 'SHARP steering group', service users are involved in the service at every level and what service users say forms the basis of how we operate and what we offer as a whole. According to its ethos, SHARP operates in line with the Recovery Model, in considering recovery as the individuals' ongoing journey in which the aim is to have a valuable and meaningful life where issues may or may not always be resolved (Repper & Perkins, 2003). SHARP works along this model in order to reduce the level of social exclusion experienced by service users. Our aim is to reconnect clients with a sense of hope and meaningful engagement within their communities (SHARP, 2007).

SHARP views social inclusion or exclusion as the level of identification and participation of each individual within their community (Berman & Phillips, 2000). In order to measure the concept of 'social inclusiveness' we have adopted the use of client centered measures. These measures are there to evaluate and monitor

changes that the individual experiences in activity level in the form of the Time use budget (Jolley et al, 2005; 2006) and quality of life according to key domains on the MECCA (Priebe et al, 2002). The two measures together are used to indicate changes in social, physical and psychological aspects occurring within the persons' community setting, thereby used as indicators of 'social inclusiveness' (Prince and Gerber, 2005). When we meet with clients our aim is to get to know their story from their perspective. The measures we use are client led, which open up discussion around how people feel about their situation and what they hope for. Similar to the literature we have found that service users' hopes and goals for involvement are similar to those of the greater community and that recovery in the form of significant improvement in key areas of life is possible (Evans & Huxley, 2000; Thornicroft et al, 2002). Given that Recovery principles aim to empower service users to regain control (Repper & Perkins, 2003) SHARP attempts to deliver its Social Inclusion therapy in line with these principles and using information gained from assessment can adapt and make changes to our interventions in order for them to have the best outcomes for individuals (SHARP, 2010).

Social Inclusion therapy offered at SHARP involves 1:1 therapy aimed at supporting individuals towards achieving social inclusion. As this can often be a complex process, we start by working with people towards their identified goals. Over the course of up to 20 sessions we explore any barriers and look at ways we can work together to overcome obstacles and challenges. Our overall aim when working with people is to increase community engagement and assist service users in developing coping strategies required to successfully achieve their goals and actualize their hopes. For the last 3 years SHARP has been offering Social Inclusion therapy, provided by a skilled team of Occupational Therapists and a Social Worker. Therapists have extensive experience in engaging and working with service users. They often employ a range of techniques to support each individual on their journey to becoming more socially included in the sense that they experience a greater activity level and quality of life (Croucher & Josefsberg, 2010).

One of the important things I learned at SHARP was to open my eyes to problems that on the whole I had created myself, my thought patterns, and how I allowed myself to react to things very simple things that I hadn't realised before, but like a lot of simple things they were the hardest of all to do.

Evaluation of the Social Inclusion therapy intervention offered at SHARP through a recent pilot study showed clients to have statistically and clinically significant improvement in activity levels and quality of life indicators according to outcome measures. These areas are identified as key aspects of social inclusion (Croucher, 2010). As shown in Table I, and in Figures 1 and 2.

Through a recent SHARP audit based on a previous audit performed by the team we were able to re-confirm, identify and make explicit the skills and techniques

Table I
Overall change in mean outcomes for Social Inclusion Intervention

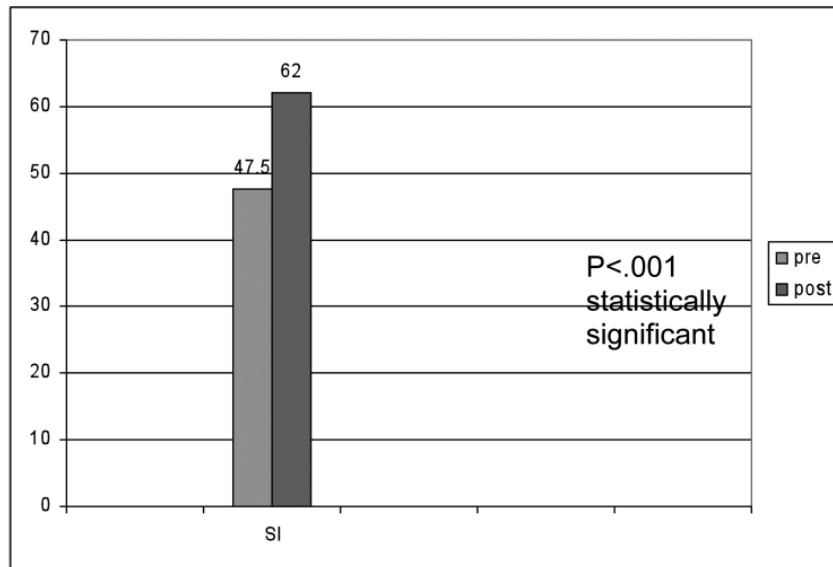| measure	Pre social inclusion	Post social inclusion	P value
Jolley et al Activity Measure	47.6	62.0	p<.001
Priebe et al MECCA Scale	50.9	57.8	p<.001
Health of the Nation Outcome Scales	12.2	9.6	P<.05

Outcomes:
- 84 people have received SI therapy to date
- Up to 20 sessions offered to each person

used at each stage of doing Social Inclusion therapy with clients. The stages were demarcated using Peter Bates, phases and were identified by SHARP as being the *explore* phase, which looks at what is available to the client in their community setting in accordance with their goals (Bates, 2002: 2011; Groake & Flowers, 2008). This process often involves identification of places, support to visit community options and support to start regular routines, reviewing goals and progress with client along the way. The *engage* phase which can be defined as supporting the person whilst they achieve their goals within their chosen community setting and can involve things such as keeping up phone contact, negotiating and offering extra appointments if needed, reviewing goals and activities. Following on from these the *sustain* phase can be defined as maintaining support to the person once they have achieved their goals within their chosen community setting and enabling them to maintain themselves once the intervention is complete. This final process involves offering drop in sessions with community information, having a final discharge meeting, reviewing and providing feedback re: goals achieved through use of outcome measures, and moving on from the service. We were also able to identify the barriers we ran into whilst attempting to do social inclusion work with people. See table 2 overleaf.

Social Inclusion therapy as delivered at SHARP involves a multilayered intervention which is completely client centered. Intervention can involve anything from gaining practical skills to coping strategies and psychosocial approaches. We have identified that there are various levels of social inclusion that range from sign posting to complex psychosocial intervention. Social Inclusion therapy therefore demands a high skill level of therapists and an ability to synthesise learning in order to effectively carry out Social Inclusion therapy. Thus, in order for clinicians to effectively undertake Social Inclusion therapy, this process involves more than just signposting, and is considered by SHARP to be a complex intervention. The recent SHARP Social Inclusion therapy audit (Croucher & Josefsberg, 2010) supports previous audit findings that the process of Social Inclusion therapy consists of a
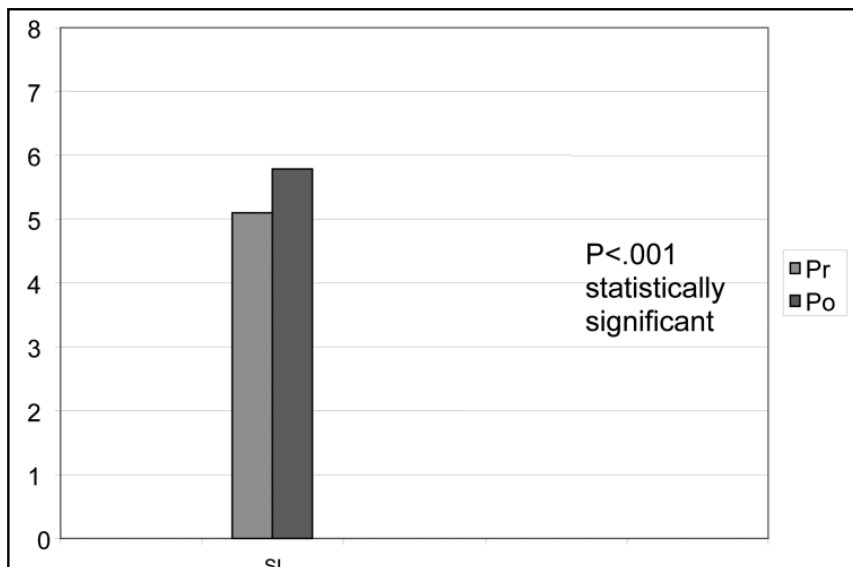
Figure 1
Time budget pre and post Social Inclusion therapy.

(higher scores denote greater involvement in constructive activity).

Figure 2
MECCA Quality of Life scores pre and post Social Inclusion therapy.

(higher scores denote increased life satisfaction ratings)

Table 2
Stages of social inclusion therapy.

Skills/ techniques	Barriers
EXPLORE	
• collaboration and partnership	• external factors
• coping strategies	• skills deficit
• past learning/reflection	• **Mental health problems**
• education	• cognitive deficits
• engagement and rapport building	• DNA
• creating hope & future	
• signposting	
ENGAGE	
• Collaboration and partnership	• external factors
• widening social network	• skills deficit
• coping strategies	• **Mental health problems**
• past learning and reflection	• cognitive deficits
• education/new learning	• DNA
• creating hope and future	• expectations
• signposting	
SUSTAIN	
• Coping skills	• Expects therapist to lead
• Past learning/current reflection/insight	• Requires CBT
• New learning	• Mental health problems
• Creating hope	
• Prioritising skills	

complex series of interventions which encourage clients to develop and enhance skills to support people towards social inclusion.

> *Working in SHARP is different to any other experience I have had working in other mental health settings. I get to hear a different story from my clients, stories filled with hope and dreams of a future, stories of their 'recovery'. I realized as a worker that those stories have always been there; only maybe I just wasn't asking the right questions or focusing on the bigger picture. The work we do is all about the individual person's journey and it feels good to be a part of that.*

Conclusions

People in contact with mental health services are one of the most excluded groups in society and it is critical that exclusion be addressed because the barriers people face can only be described as formidable (Gamble & Brennan, 2006; Repper &Perkins 2003). The key issue is how this is undertaken, in a way that is effective for service users. One way to do this is to ground the content of service provision in what service users say is helpful. It is clear from our evidence that service users want a flexible, human and person centered approach (Bertram, 2008).

Vocation Matters and the SHARP team are two recovery oriented projects which aim to bridge the gap between people and community settings, breaking down barriers, building skills and enabling people to lead valued lives. In order to achieve this we need to work in creative ways, listening to what service users tell us and creating a sense of choice and empowerment around vocation and meaningful activity (Williams, 2010). The primary principle underpinning any helping process must begin with, in an emotional, social and practical sense, where the person is. Once this is identified and a trusting relationship is worked up, then it is possible to address multiple needs through multiple interventions and support people on their journey to achieve their own personal goals (Bertram, 2008; SHARP audit, 2008; 2010).

Social inclusion, as an intervention, is a complex set of interactions between the person, their goals and their community (Croucher, 2010). This throws up questions as to what the core skill set is to facilitate social inclusion effectively- who should be doing it? In our experience, it demands a varied set of skills in order to meet the potential needs of each individual. These skills range from teaching, counseling and reflective practice. Central is the ability to learn from service users and have the belief that with support many service users can be the experts.

The evidence we have gathered reliably measured the impact of the work we do to promote social inclusion. Our results reveal that the health and wellbeing of service users can be improved significantly. Consequently, there is a strong argument that social inclusion interventions should constitute the core business of future healthcare and be spread more widely throughout mental health service provision.

References

Bates, P. (2002) Working for inclusion: Making social inclusion a reality for people with severe mental health problems. *Housing, Care and Support*, 5 (3) 18-22.

Bates, P. (2011) Uncovering emotions at Engagement Sands. *British Journal of Wellbeing.* 2 (2) 15-20.

Becker, T., G. Thornicroft, G. Leese, M. McCrone, P. Johnson, S. Albert, M. & Turner, D. (1997) Social networks and service use among representative cases of psychosis in South London. *British Journal of Psychiatry,* 171: 15-19.

Berman, Y. & Phillips, D. (2000) Indicators of social quality and social exclusion at national and community level. *Social Indicators Research*, *50*, 329-350.

Bertram, M. (2008) What does social inclusion mean? *A Life in the Day* 12:2, 24-27.

Bird L (2001) Poverty, social exclusion and mental health: a survey of people's personal experiences. *A Life in the Day,* 5: 3, 4-8.

Croucher, A. (2010) A qualitative study of the lived experience of moving on from a residential rehabilitation service and the journey to social inclusion using interpretive phenomenological analysis.(Unpublished paper available from the first author).

Croucher, A. & Josefsberg S. (2010) *Social Inclusion Service Evaluation*. (Unpublished paper available from the first author).

Dunn, S. (1999) *Creating Accepting Communities: Report of the Mind Enquiry into Social Exclusion.* London: Mind.

Disability Rights Commission (2001) *Who We Are and What We Do.* London: Disability Rights Commission.

Evans, S. & Huxley, P. I. (2000) Quality of life measurement in mental health: some recent findings. In *Proceedings of the Third Conference of the International Society for Quality of Life Studies* (eds F. Casas & C. Saurina), pp. 271-282. Girona, Spain: Institut de Recerca sobre Qualitat de Vida, University of Girona.

Gamble C. & Brennan G. (Eds) (2006) *Working with Serious Mental Illness: A Manual for Clinical Practice.* Edinburgh: Elsevier.

Groarke C. & Flowers C. (2008) *SHARP Social Inclusion Service Evaluation*. (Unpublished paper, available from the first author).

Jolley, S., Garety, P., Dunn, G., White, J., Aitken, M., Challacombe, F., Griggs, M., Wallace, M., and Craig, T. (2005) A pilot validation study of a new measure of activity in psychosis. *Journal of Social Psychiatry and Psychiatric Epidemiology*, 40: 905–911.

Jolley, S. & Garety, P., Ellett, L., Kuipers, E., Freeman, D., Bebbington, P.E, Fowler, D.G., Dunn, G., (2006) A validation of a new measure of activity in psychosis. *Schizophrenia Research,* 85: 288– 295.

Leff, J. & Warner, R (2006). *Social Inclusion of People with Mental Illness.* Cambridge: University of Cambridge Press.

National Institute for Clinical Excellence (2009) *NICE Guideline on Core Interventions in the Treatment and Management of Schizophrenia in Primary and Secondary Care (Update).* London: NICE

Office of the Deputy Prime Minister (2004) *Mental Health and Social Inclusion: Social Exclusion Unit Report.* London: Office of the Deputy Prime Minister.

Priebe, S., McCabe, R., Bullenkamp, J., Hansson L, Rössler W, Torres-Gonzales F, Wiersma D. (2002) The impact of routine outcome measurement on treatment processes in community mental health care: approach and methods of the MECCA study. *Epidemiologia e Psichiatria Sociale,* 11, 198 –205.

Prince PN, & Gerber GJ (2005) Subjective well being and community integration among clients of assertive community treatment. *Quality of Life Research*, 14,1, 161-69.

Rankin, J. (2005) *Mental Health in the Mainstream: Mental Health and Social Inclusion.* London: Institute for Public Policy Research. http://www.mentalhealthshop.org/document. rm?id=847

Repper, J. & Perkins, R. (2003) *Social Inclusion and Recovery: A Model for Mental Health Practice.* London: Balliere Tindall.

Social Inclusion Hope and Recovery Project (2007) *Policy on Service Delivery.* (Unpublished paper available from the first author).

Social Inclusion Hope and Recovery Project (2010) *Away Day Prospectus.* (Unpublished paper available from the first author).

Thornicroft, G., Rose, D., Huxley, P., Dale, G., and Wykes, T., (2002) What are the research priorities of mental health service users? *Journal of Mental Health*, 11, 1-5.

Toynbee P, & Walker D (2001).*Did Things Get Better?* London: Penguin.

White M, Angus J (2003) *Arts and Mental Health Literature Review.* Centre for Arts and Humanities in Health and Medicine. Durham: University of Durham.

Williams, S. (2010) *Can't see the wood for the trees (A non-clinical approach to Vocation & Inclusion within Mental Health Services –Lambeth)*. Best practice guide: Lambeth Living Well Collaborative. (unpublished paper, copy available from the second author).