Social inclusion and recovery for young people with first episode psychosis: a London survey of early intervention in psychosis teams and their links with the further education system

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Abstract  
This article is an account of an ambitious change management effort across the inter-organisational divide of health and education. It focused on improving the relationships between staff in health and education sectors, to enable people to work together with a sense of shared purpose and joint vision: to get young people with early psychosis back into education and training, and to keep them there. It involved working on people’s mindsets, and discarding long-held negative expectations of what mental health service users can achieve. The project is based in London.

Key words  
Early intervention in psychosis teams; Mental health care; Young people; Further education; Inter-organisational working

Background  
Early intervention in psychosis (EIP) teams in the UK were set up under the provisions of the National Service Framework for Mental Health (Department of Health, 1999) to create better pathways for mental health care for young people experiencing their first psychotic breakdown. It is known that the period of untreated psychosis could be as long as three years.
Without active treatment, which includes stabilisation on psychotropic medication, and appropriate psychological treatment for the individual and the family, many young people enter a downward spiral of disengagement from society (Reading & Birchwood, 2005). This often happens at a time of their lives when they should be consolidating their progress and achievements in education or training, and moving on to adult vocational roles and active involvement as a citizen in society. The myths of mental illness, resonating over the centuries and leading to patterns of stigma and social exclusion that we are all familiar with, relate to generations of young people who have not been treated or supported effectively; not seen until they enter the end stage of the disease, as it were. By that time it is usually too late to reverse a process of deterioration, with loss of hope and aspirations, both from within themselves, their families, and often from the mental health staff who engage with them.

EIP teams were set up to try and achieve the opposite, a re-entry into meaningful lives of leisure, social networks and vocational activity. This includes reducing the period of untreated active illness, having teams with the capacity to engage the individual and family in psychological issues, and raising expectations to return to education, training and eventually employment. Could we make a difference at the beginning of the care pathway for these young people with a serious mental illness?

Coincidentally, the Learning and Skills Council (2006) was interested in implementing its strategy, *Improving Services for People with Mental Health Difficulties*. Senior colleagues from the Department of Health were also anxious to improve service and treatment outcomes for black and ethnic minority (BME) service users. The *Delivering Race Equality (DRE) in Mental Health Care: An Action Plan* (Department of Health, 2005) was a five-year action plan with the main objectives of improving BME service users’ access to and experience of services, leading to improved outcomes. Outcome indicators should include a recovery and social inclusion focus, with higher numbers of BME service users being able to access education, training and work. This would also be in line with the national social inclusion strategy, and it is known that employment outcomes are influenced by education outcomes (National Social Inclusion Programme/Care Services Improvement Partnership, 2006; Social Exclusion Task Force, 2006).

Therefore, it seemed like a good idea to have a project that focused on improving relationships across the inter-organisational divide between EIP teams and the further education (FE) sector, via a process in which we got people to focus on patient flows across this interface. We would have to improve relationships across the different cultures – health and education – so that young people being treated in EIP teams could be helped to move into education, benefit from their educational experience, and, importantly, be supported in staying there. This means having mechanisms in place to deal with problems when they inevitably arise, and fostering an atmosphere of shared purpose and jointly-held vision. It was not going to be easy.

A consultation event was also held in 2006 with Refugee Action, the Vietnamese Mental Health Association, and the Chinese Mental Health Association to identify different levels of learning need, and perceived barriers to access from the perspectives of the different groups. Poor competence in English language and lack of access to English for speakers of other languages (ESOL) courses were major factors, but also high eligibility criteria thresholds in further education (FE) colleges, which deter people from putting in applications.

In March 2007, The National Institute of Adult Continuing Education (NIACE) reported on a short pilot project that explored the links between adult learning, mental health and race equality. Three FE providers in London were tasked with developing pathways to culturally sensitive learning provision. They were supported to consult with different service user groups to identify existing barriers to learning, to develop inclusive and culturally appropriate learning opportunities, and support pathways that enable BME service users to access learning.

This involved developing new partnerships and capacity building for effective collaboration between education and local community organisations and mental health user groups. The FE providers included the College of North East London (working with Turkish speaking asylum seekers and refugees), Mindlift from Community Education in Lewisham (working with the local settled Turkish community) and Lambeth College (working with black African–Caribbean men).

There were interesting learning developments around the need to provide culturally sensitive
provision, targeted at the specific needs of different learner groups. For example, Mindlift started a Turkish foil embossing course, which is a familiar cultural learning medium for members of the Turkish community. Lambeth College worked with black African–Caribbean men who were mental health service users attending resource centres, and not engaged in learning. Consultation with the learners in Lambeth led to the formation of a music group that was to be self-directed in order to be sustainable.

Both the Department of Health and the Department for Education and Science have cited the need for more research and development on the barriers that adults from black and minority ethnic groups experience in participating in learning, especially those with mental health difficulties (Cabinet Office, 2005).

In March 2008, Dr Annie Lau, a Consultant Psychiatrist, was given approval to take on the role as Health Lead for this project from Melba Wilson, National Lead for the DRE Action Plan, and the Deputy Director of Mental Health at the Department of Health, Jim Fowles. Dr Alison Black, a Specialist Registrar in Psychiatry, worked with Dr Lau in data collection and analysis of the findings.

Victoria Sturdy had by then started as London Regional Lead, working on behalf of the Learning and Skills Council (LSC) and National Institute of Adult Continuing Education (NIACE). She was one of nine regional project officers working across the regions who were attempting to implement LSC strategy on engaging learners with mental health difficulties. Concurrent with the London study, Victoria Sturdy organised a series of Learning Network events all over London in different venues. Both health and education staff attended these events, which were held along different themes, such as employment. Small groups considered issues, and shared solutions that had been useful and applicable in different settings.

The London survey
Aims and objectives
The aims of the London survey (Lau et al, 2008) were as follows:
- to assess what proportion of people receiving services from EIP teams in London are currently involved in education, training or work
- to assess how clients from ethnic minorities receiving support from EIP teams compare with white British clients, in terms of their presence in education training and work
- to obtain staff views regarding the barriers that their clients face in attending courses or obtaining employment
- to obtain ‘good news stories’ from staff members where clients have successfully attended courses or obtained employment
- to identify successful partnerships that EIP staff have developed with education providers and employers, and how these have been achieved.

Methods
Twenty-five EIP teams based in London were asked to take part in the project, and sent questionnaires to complete by the EIP network co-ordinator at the London Development Centre. Each team was asked to provide basic quantitative data about their team’s active caseload on 21 June 2008. This included the total number of clients on their caseload, the total number of BME clients, the total number of clients within training or education (including school, university and college), and the total number of BME clients within training or education. Each team was also to complete a qualitative comments questionnaire, which had three questions that they were required to respond to.

‘Can you tell us about any issues or barriers your clients have experienced regarding attending courses or obtaining employment?’

‘Can you give us “good news” stories about clients who are successfully attending courses, or who have obtained employment?’

‘Can you explain how you have achieved successful partnerships with work or education providers?’

Interim results received from the first seven EIP teams were presented at the Learning Network event at Barnet College on 7 July 2008. In response to unanimous feedback from participants at this meeting, we sent out a subsequent questionnaire to each EIP team in mid-July 2008, requesting data on the numbers of clients in volunteering and paid employment. Further details regarding BME clients in education and employment were also requested,
which included client ethnicity, gender and age. Unfortunately only eight EIP teams responded to the second round of questions. The returns still provided extremely useful data, which were also for the cohort of patients on the EIP team caseload of 21 June 2008.

Key findings
There was good engagement of EIP teams across London with the survey. Twenty-four out of 25 teams responded to the questionnaires. The majority of EIP teams also supplied narratives around the successful engagement of their clients in education and training, and their views on barriers to effective partnership working. Some shared their solutions. These accounts came across as authentic, and reflected team aspirations to improve services.

The combined total active caseload of the 24 teams on 21 June 2008 was 2,177 clients. Of these, 66.3% were BME clients. Five hundred and thirty-six clients (24.6%) were in education or training. Overall, 22.5% of white British clients were in training or education, as compared to 24.5% of BME clients. Eight of the EIP teams also provided further data regarding their clients in education and work. The total caseload of these eight EIP teams was 650 clients. Sixty-nine of these clients were from BME communities. Within these teams, 25% of all clients were in education or training, and 22.1% in employment, giving 45.1% of total clients engaged in education, training or work activities. When considering BME clients only, the results showed slightly higher percentages; 28.4% of BME clients were in education or training, 25.1% of BME clients were in employment. The mean age of the clients in the eight EIP teams was 24.3. 60.6% were male, 39.4% were female. Of the BME clients, 65.5% were black African, black Caribbean or mixed white and black ethnicity and 21.1% were of South Asian ethnicity.

Barriers to attending courses and achieving employment
Barriers identified included factors relating to the client’s illness. A frequently mentioned factor was lack of motivation. This could result in clients missing appointments with vocational services.

‘Keeping motivation and enthusiasm going is a challenge as clients show fluctuating motivation.’

Poor self-esteem was also cited as a potential barrier, sometimes preventing clients from giving a good impression at job interviews. Mental health instability was also reported, which could be compounded by poor compliance with medication, or side effects of medication such as lethargy. Clients struggled with peer integration. Some had had difficulties accessing courses due to anxieties about travelling alone, and a lack of transport being available. Substance misuse was also identified as hindering engagement.

Social factors were also described as posing barriers, for example, around financial problems.

‘We have a proportion of clients who have come to the UK on a student visa and have consequently become unwell. It is difficult for these individuals as they have often exhausted their financial reserves and can no longer afford the educational fees required for their status.’

The ‘benefits trap’ was mentioned by a number of teams. The client’s work status can have an impact on housing benefit, council tax benefit and their ability to access supported accommodation. There were reports that entry into full-time employment could result in ‘clients moving back to family home or a reliance on family to subsidise their income’.

Childcare was also a potential problem. Clients who are refugees and asylum seekers often did not have the necessary paperwork, eg. certificates from previous studies, or recourse to public funds.

Lack of previous educational qualifications and previous experiences of ‘failure’ were mentioned by a number of teams, as well as language and literacy:

‘Two Bengali clients would have liked to access Asian Women’s Project make-up courses, but English is a requirement and they do not speak English.’

Some BME clients were also reported to experience loneliness and isolation in the dominant white culture.

Of the caseload of the Tower Hamlets EIP team, 85.9% consisted of BME clients, of which 69% were of Bangladeshi origin. The team reported that Bangladeshi women within their sample
– mainly from rural backgrounds and socially deprived circumstances – do not ‘access education, training and work, due to cultural gender-based issues; women attend clinic sessions accompanied by male relatives’. None of the other London EIP teams raised cultural factors as contributing to BME barriers to work or education.

Concerns regarding the stigma of mental illness were raised, and the issue of whether to declare a history of mental illness to potential employers. The experience of one client was reported who accounted for a gap in his CV by telling interviewers he had been in hospital. He subsequently felt that he had not been given a fair chance, due to having disclosed his history of mental health problems.

One team experienced frustration that some college staff had unreasonably high expectations and standards for their clients. The abilities of their clients were measured ‘against the abilities of those not suffering from psychosis/mental illness’. Another team expressed the converse view, that expectations could be too low, and both family and staff were anxious to encourage their clients to engage in work and/or education. They felt that it was important to ‘challenge staff to ask the work question, and to inform clients of all opportunities’.

**Good news stories**

It was encouraging to find that many EIP teams are successfully developing active partnerships with local FE providers and employers. Having a dedicated vocational worker who does not have care co-ordination responsibilities was recurrently reported as a crucial factor in facilitating this.

The Barking and Dagenham Early Intervention in Psychosis Team are working with their local FE provider on an education and career development plan, which will incorporate a wellness recovery action plan (WRAP). They are planning to set up a group initially focusing on helping clients in the group with ‘orientation to, and normalisation of the FE college environment, study skills, anxiety management, as well as supporting the client to access the appropriate learning support’. This is a policy statement, and much will depend on the engagement of staff across the organisational divide.

Active outreach to education providers, employers, volunteer agencies, and Job Centre Plus was also found to be helpful. Inviting FE providers to team meetings was repeatedly reported to be beneficial in building links. Most teams stated that they found mental health co-ordinators, based at colleges, very willing to be involved. The Lewisham Team reported that South London and Maudsley Mental Health Trust have a contract to deliver supervision to the mental health co-ordinator at Lewisham College.

Camden and Islington Team’s in-house vocational service (Vibe) have developed a successful partnership with The Roundhouse in Camden, which provides a number of short courses in a wide range of creative subjects, including dance, drama and music.

The Kensington, Chelsea and Westminster Team found that a key part of the vocational worker’s role has been challenging employers who present obstacles, ‘particularly around disability legislation’. Providing ongoing support for employers and clients in the workplace to enable clients to sustain jobs has also been important.

Hackney College reported the benefit of having a mental health liaison person – funded through a partnership initiative between the East London NHS Foundation Trust and Hackney Community College but based at Hackney College – very useful for keeping clients on track in the learning environment.

Lambeth College benefited from an 18-month outreach programme of mental health awareness training from 2000 to 2002. As confidence in the partnership arrangements increased, student attendance increased by 400%, and there was a 300% increase in students moving to mainstream courses. Courses on offer increased from four to 22, an increase of 400%. Service users were employed as classroom assistants and tutors. These relationships had to be actively developed, with good leadership across the health/education divide.

**Discussion of findings**

**DRE perspective**

Results from the Count Me In national census findings of 2005, 2006 and 2007 have shown more adverse care pathways and greater entry into inpatient services in secondary care for BME service users (Commission for Healthcare Audit and Inspection, 2005; 2006; 2007). Surveys of patient care pathways, and access to primary care and community mental health teams have not yet taken place.
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The London survey of EIP teams (Lau et al., 2008), using data submitted by the teams on the basis of a one-day audit of active caseload, seems to show that EIP teams across London are reaching BME groups, with 66% of the total caseload comprising BME populations (using the Department of Health definitions). In various forums where this work has been presented, staff expressed surprise at the high numbers of BME uptake in EIP services. This also raises the question of what is happening in other community teams, eg. crisis resolution/home treatment, assertive outreach, generic community mental health teams, and whether similarly high levels of BME engagement are also achieved; and, if not, why not? This would need to happen in order for BME client groups to achieve more equitable access to good patient care pathways, and to achieve the vision set out in Darzi’s (2008) *High Quality Care For All* report.

It would also appear that BME clients in EIP teams have at least equal access to training and education. Where teams achieve high levels of client engagement in education, training and work, BME uptake and engagement levels also appear to be high, reflecting community proportions. So mental health providers in London may be ‘doing some things right’ (personal communication, Professor Chris Hollis) in enabling the ‘DRE dream’ to take shape; in particular, improving service experience and recovery outcomes for BME mental health users in EIP teams.

**Partnership working**

The survey shows the importance of partnership working across both health and education domains, in helping people with mental health difficulties to achieve their potential. This is particularly crucial now as the machinery of government will transfer responsibility for this group of learners to other agencies when the Learning and Skills Council disbands in March 2010.

Links and collaboration between local authority agencies, mental health services and learning providers need to be in place so that good practice is continued, shared and that people at deeper levels of disadvantage are not forgotten. The LSC/NIACE/NIMHE partnership programme showcases examples of partnership working in each region through the annual national conference, network meetings, newsletter and Moodle website (a virtual learning environment that can be found at www.niace.org.uk/moodle). One such example comes from Hackney Community College. Here a dedicated mental health liaison worker is funded by East London NHS Foundation Trust, and works within the College to support learners and staff, while also doing outreach work with inpatients at Homerton Hospital. This has led to more potential learners accessing education.

Many learning providers have well established links with mental health trusts, community mental health teams, and child and adolescent mental health teams. The EIP teams may not have such well-established links in some boroughs, and the London survey (Lau et al, 2008) provides evidence that this is indeed the case.

We found that good provision that is flexible and meets the needs of learners makes a big difference. This often depends on dedicated staff with motivation and good local contacts. Some learning providers have a dedicated mental health liaison officer who is able to co-ordinate and smooth the transition from mental health services to college for learners. The London survey (Lau et al, 2008) showed that not all learning providers respond well to enquiries about support for learners with mental health difficulties, and some are concerned about risks posed by the presence of service users with serious mental illness. The example from Hackney College may be a way forward. They piloted sharing the service user’s advance directives with the college, with support from the mental health team, and with clearly agreed steps around mitigating and managing risk.

There are also gaps in awareness of the current offer by LSC, for example, to Modern Apprenticeships – whereas there is now an LSC Apprenticeship scheme that is more inclusive. Language difficulties, isolation and loneliness reflect social exclusion and access to learning and skills provision. BME learners are also experiencing increasing difficulties in finding ESOL classes, due to changes in funding. In Tower Hamlets, NIACE has just engaged a project co-ordinator who will lead a team focusing on engaging Bangladeshi women. Strategies to be used will include community-based, culturally appropriate, gender-based activities, similar to the successful Lewisham exercise.
Importance of dedicated education and employment liaison staff

Comments from EIP teams who reported good liaison relationships with learning providers or employment providers, repeatedly stress that having liaison staff on their teams to actively facilitate good relationships across organisational interfaces was essential to sustain the client’s initial engagement with learning or work. It was also important that these staff should not be burdened with care co-ordination responsibilities, as this would be too distracting and divert energy from liaison tasks.

Implications of the survey

The survey has shown quite convincingly that engagement is possible across the organisational interfaces of health and education. Where there are dedicated staff willing to take risks and develop supportive relationships across organisational boundaries, young people can be supported to at least engage in the recovery process. The survey showed that half of the cohort could be helped to return to employment, education, and training.

Sustainability of this project is, however, a different matter, and there is a clear risk to achieving this with the growing economic pressures on health and social care systems. It will require prioritisation by commissioners and providers, and concerted, keen leadership. The Learning and Skills Council, which has been key to this development, ends at the end of March 2010. The cultural changes need to be embedded into the system so that service users use their ‘entitlement rights’ to demand a continuation of this activity.

Next steps

It is planned to re-audit along the same lines in 18 months time to assess the effectiveness of developing partnerships in London, and measure movement from current baseline levels of engagement. It is envisaged that mental health trusts and learning providers in London should continue to invest in joint work, and expand areas of co-operation. The Royal College of Psychiatry is also supporting publicity for scaling up the project out of London to cover key urban areas, and this will link to the existing LSC regional leads and networks. This is the Back on Track 2 programme, led by LSC/NIACE, and is currently in progress.

Annie Lau and Alison Black are supporting data collection and analysis. Annie Lau is working with medical directors of the trusts linked to the pilot sites to encourage the spread of the initiatives to other mental health teams.

Current initiatives include:

- a briefing sheet outlining all the LSC and Department for Work and Pensions (DWP) pathways available for learners with mental health difficulties will be made available for practitioners working in EIP teams

- possible reciprocal training sessions between EIP teams and their local FE providers focusing on awareness of early detection of problems in learners, and how to help vulnerable clients to maintain their educational commitment at times of difficulty

- NIACE is leading an ESOL-based project targeted at women in London entitled A Woman’s Place, which considers mental health support needs of a group of learners from traditional Muslim societies, many of whom do not speak English

- guidelines for FE providers on mental health/learning/race equalities competencies are being developed and critically appraised by local groups, as part of the wider research into learning styles.

It is recommended that PCT commissioners should invest in dedicated learning and employment liaison posts in all EIP teams, so that the recovery needs of all mental health service users can be further progressed. The evidence shows that where these posts exist, engagement in education and training leading to employment is higher than baseline levels of around 25% (Rinaldi et al, 2006; Rinaldi & Perkins 2007a; 2007b).

Communications strategy

Every opportunity is being used to communicate and share the learning from this survey with all relevant stakeholders, in order to achieve comprehensive coverage. Initial results from the survey of seven EIP teams were presented at the NIACE London network meeting at Barnet College in July 2008. There was a focus on workable strategies that had been identified, and the experiences of Lambeth EIP team and Lambeth College in active partnership development. This meeting was well attended, by further education
work into the regions, and also engage other community mental health teams in exploring similar partnerships with FE providers in their regions.

References


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