

Recovery, Work and the Opportunity to Contribute

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A view from three perspectives

- Developing evidence based programmes to help people with more serious mental health conditions to gain and sustain employment
- Employing people with more serious mental health conditions within mental health services
- Working with a long term mental health condition

Everyone who experiences mental health problems faces the challenge of rebuilding their life

- Mental health problems: a catastrophic and life-changing experience
- Strange and often frightening symptoms
- Prejudice, discrimination, exclusion - within and outside services: many lose all that they hold dear ...including your job

“Out of the blue your job has gone, 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 totally isolated from the rest of the world. No one telephones you. Much less writes. No-one seems to care if you’re alive or dead .” (Bird, 2001)

- Loss of confidence and self-belief
- Feel very alone and very frightened

Recovery is about getting your life back

Recovery is *“a way of living a **satisfying, hopeful and contributing life** even within the limitations caused by illness. ... a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and roles recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.”*

Anthony 1993

Not the same as cure, not a professional intervention, but an individual journey

- building a new sense of self, meaning and purpose
- growing within and beyond what has happened to you ... and what you have done

Recovery is about ...

- Living **hopefully**
- **Control and self-determination** - taking back control over your life, your problems and the help you receive
- **Opportunity** - gaining/retaining valued roles and relationships - doing the things you value in life and being a part of your communities

Recovery is impossible without opportunity

You cannot rebuild your life if everywhere you turn you are debarred from doing the things you value

The opportunity to

- be a part of our communities – not apart from them
- be a valued member of those communities
- access the opportunities that exist in those communities
- contribute to those communities ... always being on the receiving end of help from others is a devaluing and dispiriting place to be

There are many ways in which people can contribute ...
but whether we like it or not, work has a central role
in our society

Work – the opportunity to contribute

The importance of work in people's lives has long been recognised

“Work is nature's best physician and central to human happiness”

Galen, 172AD

‘the absence of occupation is not rest, a mind quite vacant is a mind distressed’

18th century poet William Cowper, who himself experienced periods of mental illness throughout his life and was confined to an asylum for over a year

People need two things – love and work . Work *“binds the individual to reality”*

Freud, 1961

“Work is the closest thing to a panacea known to medical science.”

Szasz, 1974

“The best thing you can do for someone with schizophrenia is to get them a job.”

Drake, 2006

“Work is just about the only thing you can do for 8 hours a day”

20th century US novelist William Faulkner

Work – the opportunity to contribute

“For some of us, an episode of mental distress will disrupt our lives so we are pushed out of the society in which we were fully participating. For others, the early onset of distress will mean social exclusion throughout our adult lives, with no prospect of training for a job or hope of a futures in meaningful employment. Loneliness and loss of self-worth lead us to believe we are useless, and so we live with this sense of hopelessness, or far too often choose to end our lives.” (SEU,2003))

- It links us to the communities in which we live and enables us to contribute to those communities
- It provides meaning and purpose in life
- It affords status and identity – the 2nd question ‘What is your name?’ ‘What do you do?’
- It provides social contacts
- It is good for our health – mental and physical
- It gives us the resources we need to do the other things we value in life

“My job was my life and my life was destroyed”

(Bodman, 2003)

Work – a right

Article 23 of the United Nations Declaration of Human Rights (1948)

“Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.”

... but a right denied

Most people with a mental health condition want to have a job - people with mental health problems have the highest ‘want to work’ rate of all disabled people
(SEU 2003)

BUT few have the opportunity to do so

- Overall employment rate stands at around 74%,
- The employment rate for disabled people in general is 47%,
- The employment rate for people with a mental health condition is 21%.
- The employment rate for people using secondary mental health services 13.5%
(Work, Recovery and Inclusion 2009)

A combination of ...

- A culture of low expectations

Low expectations on the part of society as a whole, mental health professionals, people with mental health conditions themselves and their potential employers

- Fear

On the part of professionals, individuals, employers - fear that getting a job might worsen mental health, threaten financial security, risk of failure, risk the person may not be able to do the job ...

- Failure to provide the support that we know works

... continue to deny many people the
opportunity to work

... but it doesn't have to be this way ...

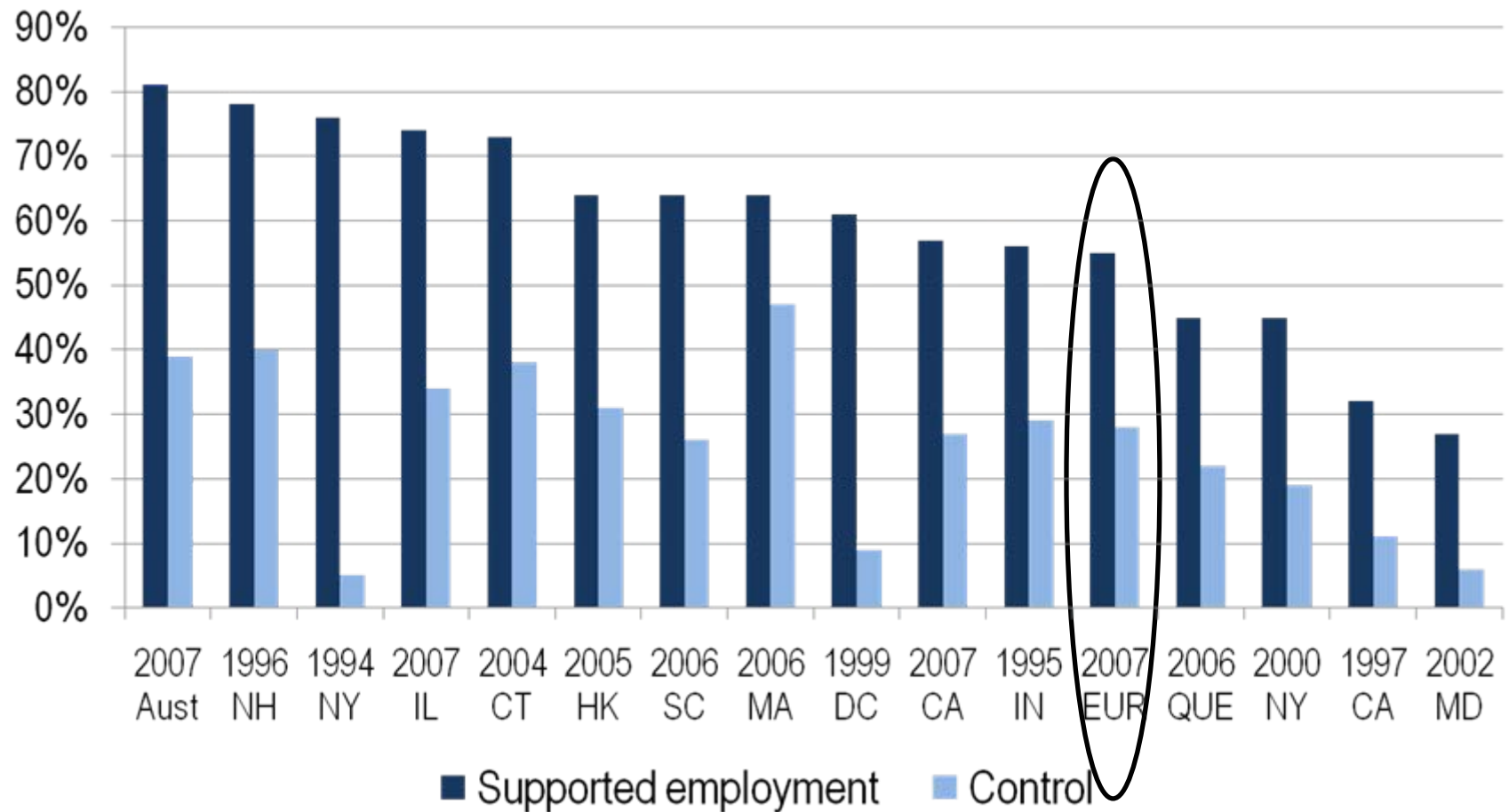
There is strong evidence that with the right kind of help at least 60% of people with serious mental health problems can successfully get and keep work

Individual Placement with Support' evidence based supported employment

- Competitive employment – real jobs
- Eligibility based on client choice – help anyone who wants to give it a try
- Integration of employment support into support and treatment plans – employment specialists in support and treatment teams
- Rapid job search – 'place-train' rather than 'train-place'
- On-going supports
- Job search based on client preferences
- Benefits counselling

(Becker IPS Fidelity Scale, 2008) (Bond, 2004)

Competitive employment rates in 16 randomised controlled trials



European research compared traditional vocational service (non-integrated 'train-place') with IPS for people with schizophrenia (Burns et al, 2007):

- 55% gained in IPS employment vs. 28% in traditional service
 - 13% drop-out in IPS vs. 45% in traditional service
 - 20% readmitted in IPS vs. 31% in traditional service
- Follow-up studies show that work outcomes improve over time
 - Employment associated with improved self-esteem, symptom control, quality of life ... no changes with sustained sheltered employment

And it's not just research trials – it also works in regular day to day practice ...

Employment Specialists in 11 out of 18 South West London Community Mental Health Teams (2007/8):

1155 people successful in working/studying in mainstream integrated settings:

- 645 people supported to get/keep open employment
- 293 people supported to get/keep mainstream education/training
- 217 people supported in mainstream voluntary work

In a service for people with 1st episode psychosis – 73% were in employment or education after 2 years

"I have re-entered full-time employment. Over a year later I am still working. I now focus more on opportunities in life and less on my condition. I regularly socialise with my colleagues after work and actually feel content to be a taxpayer again ... The support has been immeasurably important ... [it] has enabled me to make the journey towards recovery and realise my aim of contributing to society again through fulfilling employment."

"My passion for my career is immense. A job defines you, provides money, personal fulfilment and a sense of achievement. This is what I am, this is what I do, I am no longer a mental health condition."

"Now I'm a contributing member of society because of my employment. It's worth is altering the life of someone with a mental illness ... helping me to change direction from hopelessness to being worthwhile."

Extra things that can help at the same time as looking for a job

- Learning to manage symptoms and problems in a work context

"Having your own plan about how to cope and what you need is good for employer and employee."

- Time limited 'work experience' or 'internships'

"It's given me my confidence back – now I know I can get a job. It's so good. My husband and daughter go out at 8.30am and I was the one left behind. Now we all go out together."

- Starting work gradually (using 'permitted work' rules) "

"The supported permitted work experience has allowed me to take small steps towards reintegration in the employment market. I am particularly grateful to my Employment Specialist in supporting me and enabling me to take this challenge on."

- Peer support

"People who have been where I have been and made it – they are my source of inspiration."

Not just 'them out there' – employing people with mental health problems in mental health services

Why employ people with mental health problems in mental health services?

- Provides much needed employment opportunities
- Leading by example
- Fostering hope and provides images of possibility for both staff and people using mental health services
- Breaks down destructive 'them and us' divide

Expertise of 'lived experience' is central to recovery ...

- moving beyond 'them' and 'us' – mental health service users as 'other'
- counteracts despair and pessimism: promotes hope and offers images of possibility to both service users and staff
- ways of accommodating, understanding and dealing with problems
- decreasing feelings of isolation
- valuing the experience gained from living with mental health problems – using your experience to help others

... therefore employing people with lived experience in mental health services actively promotes the recovery of those who are employed and those whom they serve

Including the expertise of 'lived experience' in the mental health workforce

1. Employing people with mental health problems in existing positions in the workforce
2. Creating new roles and relationships - employing 'Peer Support Workers' to provide services

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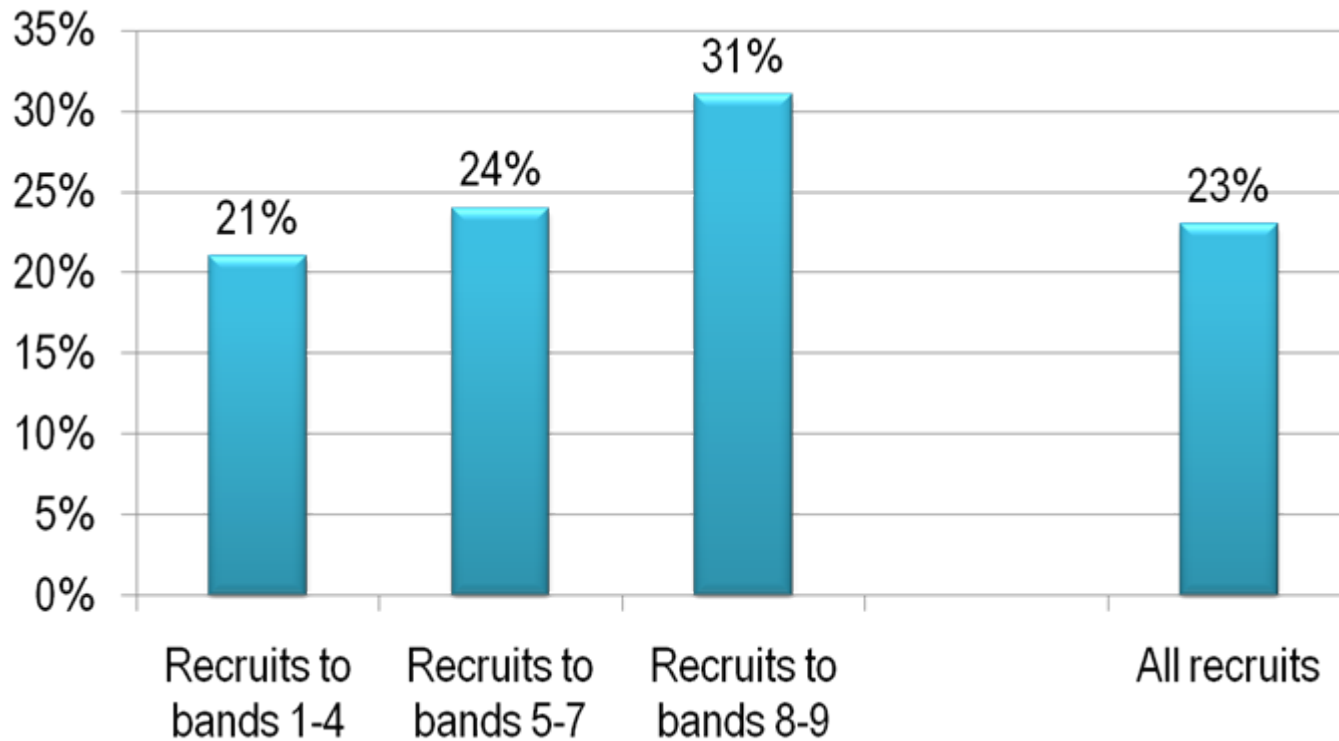
South West London User Employment Programme

Designed to increase access to employment in mental health services for people who have themselves experienced mental health problems – employment in ordinary existing positions on the same terms and conditions as everyone else

- Support for people with mental health problems to get/keep jobs if they need it – 208 people supported to work in existing positions on the same terms and conditions as anyone else
- A 'Charter for the Employment of People with Mental Health Problems' – actively trying to recruit people with mental health problems
 - Personal experience of mental health problems 'desirable' on person specifications for all posts
 - Advertisements encourage people with mental health problems to apply
 - Confidential equal opportunities monitoring includes mental health problems

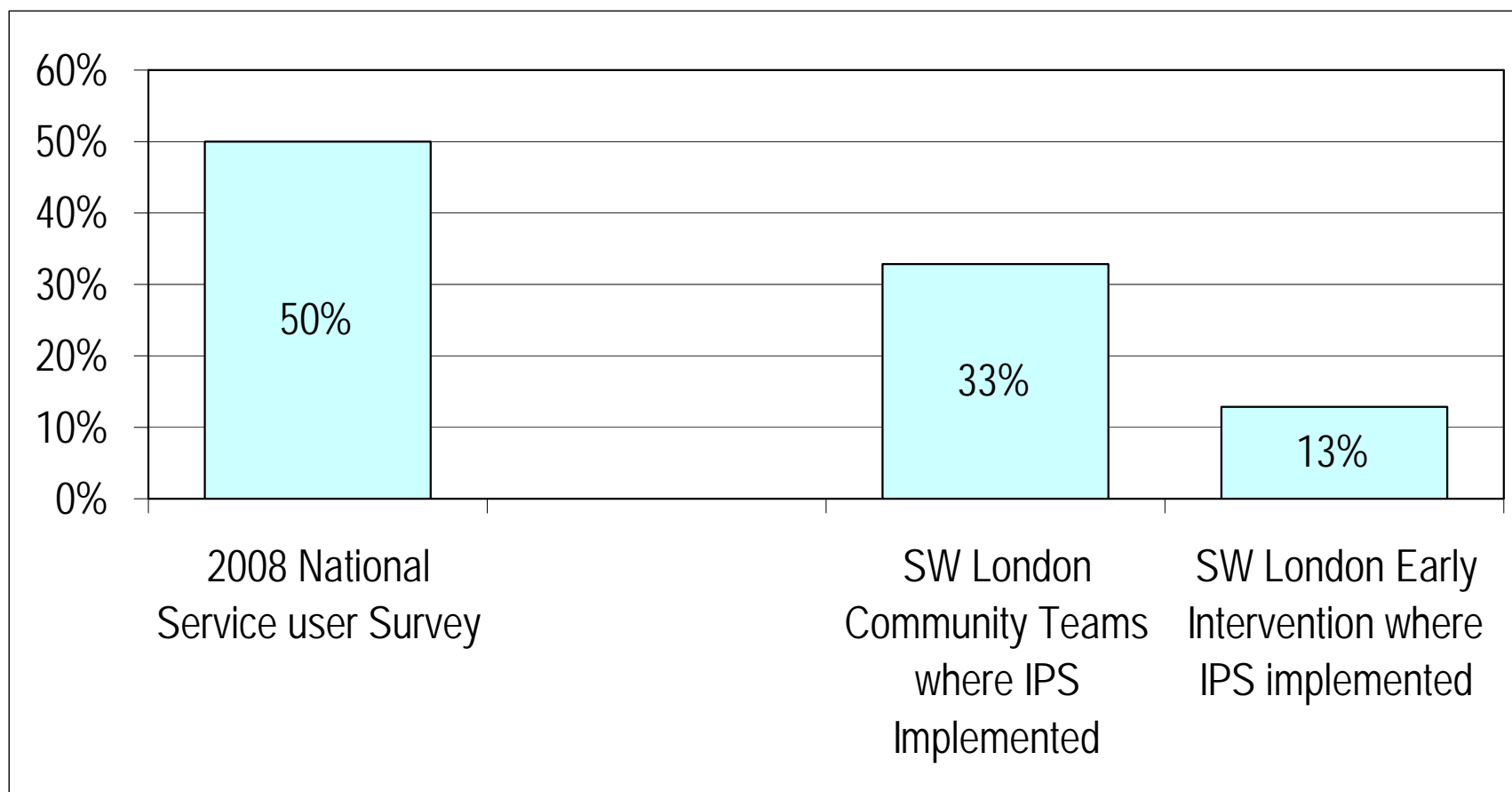
Beware - if you come to work in South West London you don't know whether your colleague (or your boss) is one of 'them' or one of 'us'

23% of recruits have mental health problems ... and the higher up you go the more of them you find



Lowest grade → Highest grade

Supported employment in community teams PLUS User Employment Programme has **raised expectations** as well as raised employment rates – because support is there - and because they can see others working - more people believe they can work think they can work



2. Creating new roles and relationships Employing 'Peer Support Workers'

Peer support means moving beyond traditional expert/patient roles.

Creating relationships where people can learn and grow as equals drawing on each other's expertise and experience

Founded on mutuality: shared responsibility, shared journey

- A way of sharing our personal story
- A way of offering help and support as an equal
- A way of being in a relationship that empowers people to recover
- A way of teaching, learning and growing together
- An attitude that values each person's experience

Peer support workers on an acute admission ward

Just two workers two days per week employed trained and supervised by local voluntary sector user organisation

People who spent time with a peer support worker were significantly more likely to

- feel they had someone they could talk to about their worries and concerns,
- say they had received support in their recovery
- report increased hopefulness about being able to do the things they want to in life.

What did you find useful about spending time with a peer support worker?

"The peer support worker understands what it is like."

"She listened and was sympathetic because she had been through things herself."

"You cannot always rely on the doctors for help as they do not understand how it feels - the peer support worker does. "

"It helped me to feel more hopeful and believe I could still do things because I could see they had."

"Chatting about our problems - being with someone who has been through it themselves."

"Being able to discuss my personal issues and also doing a comparison with her own."

Realising that there is life after mental illness."

We have barely scratched the surface ...

META - 'Recovery Innovations' - Phoenix, Arizona:

Over 50% staff are 'Peer Support Specialists' trained, employed as equals alongside other professionals

"As services become more truly focused on service users' needs and accept the value of 'lived experience', so there are obvious implications for the composition of the workforce ... we expect to see a greatly expanded role for 'peer professionals' in the mental health service workforce of the future. We recommend that organisations should consider a radical transformation of the workforce, aiming for perhaps 50% of care delivery by appropriately trained and supported 'peer professionals ..."

(Sainsbury Centre for Mental Health, *Implementing Recovery. A framework for organisational change*, 2010)

Reinventing a very old wheel?



In late 1700's at France at Bicêtre Hospital, the superintendent Jean-Baptiste Pussin, instituted a policy of seeking staff from among 'recovered and convalescing' patients

The physician, Philippe Pinel said that because of their own experiences such people are better placed to understand and respond sensitively to the problems of patients

"They are the ones who are most likely to refrain from all inhumane treatment ..."

Most of all keep daring to dream

One of the biggest barriers to recovery and to getting a job is
low expectations

“The greater danger for most of us lies not in setting our aim too high and falling short, but in setting our aim too low and achieving our mark.” Michelangelo

- If those of us with mental health conditions are to rebuild our lives they must believe in the possibility of a decent future ourselves
- If health workers are to help us in our journey they must believe in our possibilities

A few words of advice from the experts ...
people with lived experience of getting back to work
with mental health problems

"Stay positive – have hopes and dreams and aspirations and move towards them. Anything is possible ... there are real opportunities out there."

"I have a friend who is chronically schizophrenic and has just passed a six year law course, another who has their own business, so if they can do it so can I. Stories like that need to be publicised to show us that we can still do things. "

"Never lose sight of the light at the end of the tunnel, if it's not there, look for it because it may not find you."

"Shoot for the moon. Even if you miss, you'll land among the stars."