Making a Reality of Employment for People with Mental Health Challenges

Individual Placement and Support Evidence Based Supported Employment



Rachel Perkins BA, MPhil (Clinical Psychology), PhD, OBE

Senior Consultant, Implementing Recovery through Organisational Change Programme

Co-editor of 'Mental Health and Social Inclusion' Journal Acting Chair, Equality and Human Rights Commission Disability Advisory Group

15th December 2017 rachel.e.perkins1@btinternet.com

A view from 4 perspectives

- 37 years working in the UK National Health Service: from clinical psychologist to director ... now consultancy work
- Over 30 years establishing programmes to promote recovery and help people with mental health conditions to gain and sustain employment (18 years developing 'Individual Placement with Support' evidence based supported employment programmes)
- 27 years using mental health services and working with a long-term mental health condition
- Led a review to the UK Government: 'Realising Ambitions: Better employment support for people with a mental health condition' ... and various other advisory roles and continued advisory work

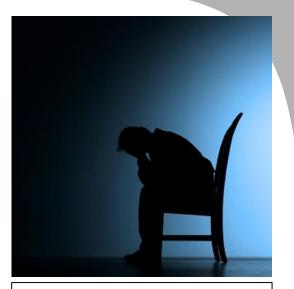
To be diagnosed with a mental health condition is a devastating and life changing event Too many become "I used to be" people

'I used to be a student, a taxi driver, a football player, a bank manager ... but now I am just a mental patient'

loss of a sense of who you are, loss of meaning and purpose in life, loss of position and status, loss of power and control, loss of hopes and dreams

Cut off from friends and family, the communities in which they live, the person they used to be

The identity of 'mental patient' eclipses all other roles and identities



"I felt hopeless, I was lost ...I thought it was the end of my world." (in Allen, 2010)

"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."

(cited in Bird, 2001)

Everyone who is diagnosed with mental health problems faces the challenge of recovery ... rebuilding a satisfying, hopeful and contributing life



Not 'recovering from an illness' but 'recovering a life'

- finding a new sense of self and purpose
- growing within and beyond what has happened to you
- pursuing your dreams and aspirations

Having a job can be central to recovery

but the right to work is a right denied to many people facing mental health challenges

"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 ...a job or hope of a future 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)

There is no formula for recovery - everyone must find their own way - but 3 things appear to be particularly important

Hope

Believing that a decent life is possible Hope-inspiring relationships

Unemployment erodes hope



Control and self-determination

Getting back into the driving seat of your life:
becoming an expert in your own self care,
deciding what is important to you and where you
want to go in life, deciding what help and support
you need to get there

Unemployment robs you of control over your life

Opportunity and citizenship

The opportunity to do the things you value and participate as an equal citizen in all facets of community life and, most importantly, to contribute to those communities

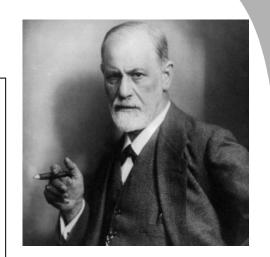
Unemployment cuts people off from their communities

"Love and work are the cornerstones of our humanness." Sigmund Freud

A sense of belonging is central to recovery

Love - having people around you who care about you and who you care about, having people around you who believe in you - is central to building a sense of self and meaning.

Unemployment cuts you off from other people - reduces social networks



Having a purpose in life is central to recovery

Too many people with mental health challenges end up on the receiving end of help from everyone else: a devaluing and dispiriting place to be.

Being able to do things for others, to contribute to your community is what gives us a sense of identity and purpose.

There are many ways of contributing to your community (raising children, supporting relatives and friends, politics and community action ...) BUT

Having a job is probably the most socially valued and validated way in which we contribute to our communities

Work is important for recovery

- Links us to our communities and enables us to contribute to, be part of, those communities
- Affords status and identity
- Provides meaning and purpose in life
- Provides social contacts
- Gives us the resources we need to do other things we value in life

For people who are marginalised and excluded from society by their mental health problems unemployment makes that exclusion worse



"A job defines you ... this is what I am and this is what I do, I am no longer a mental health condition."

"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 tax-payer again ... realise my aim of contributing to society again."



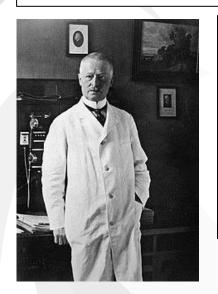
Recognition of the importance of work to promote recovery for people with mental health conditions is not new

18th century pioneers in the treatment of mental health problems, e.g.

- Pinel and Esquirol in Bicetre, Paris
- Tuke and Murray at the Retreat in York







In 1905, when Dr Herman Simon at Gutersloh took over a new asylum in Germany it was in a derelict and unfinished condition ... so he recruited the patients to finish off the works and noted significant improvements in the condition of many of them – most notably the most disturbed - and he became a strong advocate of the therapeutic value of work (Burleigh, 1964)

... but how we are doing it is new ...

Traditional questions:

- What makes people employable?
- How can we tell if someone is 'work ready'?
- How 'far from the labour market' is this person?

Efforts directed towards helping the person to become 'employable' or 'work ready'

These are the wrong questions – research shows:

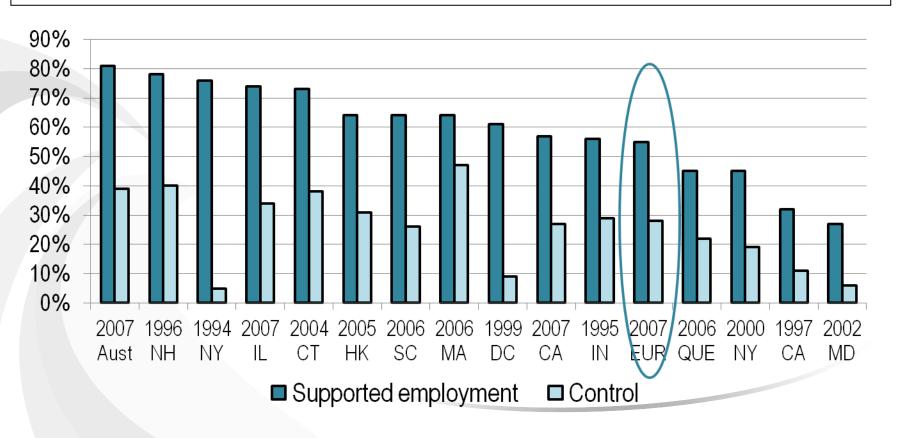
- Diagnosis, duration, severity of problems, not reliably associated with employment outcomes
- The only individual characteristics that influence employment outcomes are 'motivation' and 'self-efficacy' - whether you want to work and whether you think you can (very much affected by expectations of others)
- The most important thing determining whether a person can work is the type of support that they receive

The more important question is 'What is the right kind of support?'

With the right kind of support employment is possible

There is strong evidence from many 'randomised controlled trials' that *Individual Placement and Support evidence based supported employment* many people with more serious mental health problems can successfully gain employment

(see Bond et al, 2008, SCMH, 2009)



... and it doesn't just help people to gain employment, it helps them to keep their jobs too

Switzerland Hoffman et al, 2014	Evidence based supported employment (IPS)	Traditional vocational rehabilitation
Initial competitive employment rate	65%	33%
Employment status at 5 years	43% (28% without support) (15% with support)	17%
Worked continuously throughout 5 years	37%	9%
Hourly competitive wage in last 3 years	10.2 Swiss francs	6.1 Swiss francs

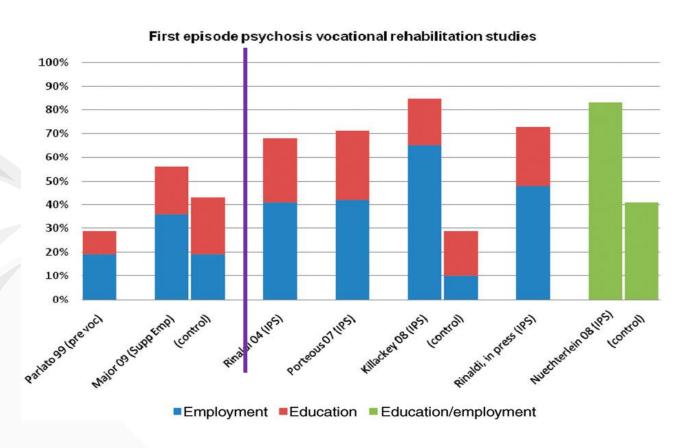
... and people's use of mental health services decreases

Fewer hospital admissions (mean 0.4 vs 1.1; 21% vs 47% had no hospital admissions) and fewer days in hospital (mean 38.6 days vs 96.8 days) (Hoffman et al, 2014)

...and fewer people drop out than with traditional vocational rehabilitation

People receiving IPS 13% dropped out, 45% dropped out in traditional vocational rehabilitation (Burns et al, 2007)

... and it is particularly effective with younger people in their first episode psychosis



From Rinaldi et al (2010) First episode psychosis and employment: A review. *International Review of Psychiatry,* April 2010; 22(2): 148–162

... and they are not all stacking shelves (doing basic entry level jobs)! (Perkins et al, 2006)

Wholesale manager Accountant IT assistant Mental health development worker Ward assistant Bookmaker Call centre handler Retail assistant Receptionist Hairdresser MH advocate Occupational therapy assistant Accountants officer Care assistant Catering assistant Chambermaid

Cleaner

Baker x2 Carpenter Caretaker Hairdresser Sales Assistant x8 IT Support desk Administrator Decorator Street cleaner Warehouse worker Market research administrator Plumber's assistant Post assistant Recycling assistant **English Teacher** Actor **Journalist** Leaflet dropper IT Helpdesk

Civil Servant (administrator) Production assistant Assistant special needs teacher Administrative assistant x5 Regeneration project worker Glazier Plumber Catering manager IT trainer Nurse Health records officer Financial controller Admin worker Credit controller Project worker Cleaner

Hairdresser assistant Indian Restaurant waiter Leisure assistant Driver Bar work Barista Sales Advisor Boatyard worker Café Assistant Catering assistant Teaching assistant Hotel Porter Labourer Admin Assistant Civil servant executive officer Social worker Youth Worker

What makes IPS different?

Based on 8 core principles

1. Do not select people on the basis of whether you think they can work ('employability' or 'work readiness') – help everyone who wants to have a go



- 2. **Focus on ordinary jobs** and a **'can do'** attitude: recognise challenges but believe in people's possibilities raise expectations
- 3. Rapid job search help people to start looking for jobs as quickly as possible 'place-train' rather than 'train-place'. Training and support are better done 'on the job' if some training/experience is needed, do this in parallel with job search.
- 4. **Base job search on client preferences** a person is more likely to get and keep a job that is in line with their interests/preferences

- 5. Integrate employment support with treatment (employment specialists in clinical teams) and provide treatment and employment support in parallel. (Integrate all the support a person is receiving e.g. mental health treatment, social care, housing services and employment)
- 6. Approach employers with the needs of individuals in mind not just passive applications for jobs, but pro-active job finding an emphasis on **building** relationships with employers to access the 'hidden labour market'
- 7. **Time-unlimited**, **personalised support to both employee and employer** employment involves a relationship between employee and employer and both parties may need support ... but does not have to be continuous (see Burns et al 2015 IPS-LITE)
- 8. Assistance with financial planning and welfare benefits

Need to adhere to all 8 principles the higher the fidelity the better the outcomes ... and the higher the fidelity the greater the cost effectiveness (NDTi, 2014) (average cost per job outcome: evidence based sites = £2,818 - traditional vocational rehabilitation = £8,217)

But implementing IPS is not without challenges ...

- IPS first piloted in the UK in South West London in 1999
- A recent benchmarking shows that there are around 90 supported employment services for people with mental health conditions in England, although some are very small and their fidelity to the IPS approach is not clear

It remains the case that

- A great deal of money is still invested in non-evidence based vocational services: sheltered work, pre-vocational training
- Most people with serious mental health problems using mental health services do not have access to IPS (or indeed any other sort of employment support) ...

English national community mental health survey of people using mental health services (2016) - 28% said they had definitely received help

- 29% said they had received help 'to some extent
- 43% said they would have liked help but did not get it

Some of the challenges ...



- Lack of joined up working between agencies at national and local level (health, employment, social care, welfare benefits, housing, addictions...) leading to confused and contradictory policies and confused and contradictory messages to people using services
- Failure to prioritise employment for people with mental health conditions:
 - People with mental health conditions not really seen as a priority for disability employment programmes often seen as 'too difficult'
 - Employment not really seen as a priority for mental health services - not part of their 'core business' ... therefore largely ignored in treatment and support plans
- Training and developing a workforce and availability of IPS expertise in operation and commissioning of services

Failure to implement it properly

There are 8 principles of IPS and the higher the fidelity the better the outcomes

Many existing UK services say 'we are already doing **MOST** of those things' ... but you've got to do them all!



Often problems arise in integrating employment support with treatment (employment specialists as equal members of clinical teams) and providing treatment and employment support in parallel.

Without full integration:

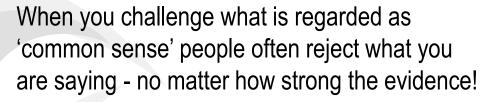
- Employment not seen as a routine part of treatment/support ... and many people fail to get any appropriate employment support
- Failure to join up treatment, social support and employment support around individuals leading to and contradictory messages to people with mental health conditions - mental health professionals saying one thing, employment services saying another
- Mental health professionals fail to raise issues of employment and refer people to appropriate services in parallel with treatment
- 'Selection' in who is referred to employment support service - those mental health professionals deem 'suitable'
- Employment advisors do not understand the person's mental health challenge

Some UK initiatives to address these issues:

- Increasing access to IPS is now a key target of the Government
 'Five Year Forward View for Mental Health' (2016)
- Employment outcomes for people with mental health conditions are one of the 'performance indicators' for mental health and social services
- A Government Work and Health Unit has been established to bring together health and employment services at a national level ... and a main plank of their work is increasing access to employment for people with mental health conditions
- This Unit is exploring the development of a national infrastructure to support the development of high quality IPS services ('IPS Grow')

However, possibly the biggest challenges in implementing IPS are more fundamental:

It challenges traditional assumptions and ways of doing things



We should never underestimate the strength of people's investment in the status quo.





It challenges prevailing low expectations about what people with mental health conditions can achieve

Traditional assumption: 'You have to get better before you can work'

Traditionally in we adopt an 'illness' or 'clinical' model when thinking about mental health problems and work and assume you have to get well in order to work



- 'what is wrong with the person?' (symptoms, skills deficits etc.)
- 'how can we put it right?' 'how can we make the person work ready?' (therapy, medication, training)



'change the person so they fit in'

Therefore we traditionally assume that

- a) We must treat people before we think about employment support a treatment first/work second approach
- b) Until a person is better they cannot work

IPS challenges this:

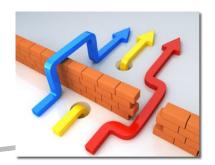
- You don't have to be 'well' to work don't select people on the basis of their 'work readiness' - help everyone who wants to have a go and provide the support and adjustments they need
- Treatment and employment support are provided in parallel

Not 'how do we change people to fit in, but how can we 'change the world so that it can accommodate the person'

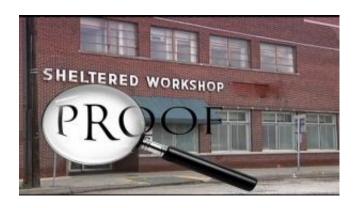
This is the sort of approach adopted in the broader disability world - a 'social model' of inclusion - that focuses not on 'treatment' and 'cure' but on asking

- 'what are the barriers to working?' (including attitudes, assumptions expectations)
- 'how can we get around these barriers?'

 (adjustments and support the person needs in order to work)



Traditional assumption: 'Stepping stones'



Traditional assumption in the mental health arena: people need to build up their skills and confidence in a safe, sheltered setting (including voluntary work or work experience) before they can move into open employment

The reality:

- few people move from sheltered work and settings and 'pre-vocational' training into open employment
- people learn that they can only work in a safe, sheltered setting



IPS challenges this:

- Focus on ordinary jobs
- Rapid job search help people to get a job as quickly as possible
- Provide individually tailored support to both the individual and their employer (for as long as they need it) to help make a success of employment
- Treatment and employment support are provided in parallel



People need 'water wings' – support to keep them afloat in employment - rather than 'stepping stones' so they never get their feet wet!



But often the biggest challenges are low expectations ...

Low expectations erode the hope, a person's belief that they can work (self-efficacy) and their desire to get a job (motivation) that are so important if someone with mental health problems is gain and prosper in employment

Nicola Oliver (2011) a woman with bipolar disorder

- "My first obstacle was my employer. Ten days after I disclosed my disability I was sacked.
- "My second obstacle was my community psychiatric nurse. He was lovely but recommended I consider only low stress jobs and part time hours; maybe I could stack shelves in a supermarket! I hadn't studied for three degrees to stack shelves.
- "My third obstacle was my psychiatrist. She told me that it was unlikely that I would ever work again."
- "My fourth obstacle became my-self. I became 'Nicola the bipolar person': incompetent, inadequate and worthless."

"I was offered ... therapy to overcome my low self-esteem, but **the psychologist became my fifth obstacle**. She was adamant that I should stop yearning to return to work."

Many would have given up at this point ... but Nicola was determined despite all the negative messages she continued to try to get work

"I contacted a **recruitment agent** who told me I had a great CV ... but she quickly **became my sixth obstacle.** When I explained the gap on my CV was due to bipolar disorder I never heard from her again."

"My final obstacle was a Disability Employment Advisor [Government Job Centre] who was supposed to help me find work. She wanted to send me on a confidence building course! I didn't want training, I wanted a job."

"If only ...

- someone had helped me reassure my employer I was still worth employing.
- they had shown conviction that I could still achieve.
- I had met other employees with bipolar disorder to inspire me to believe that one day I too could return to work"

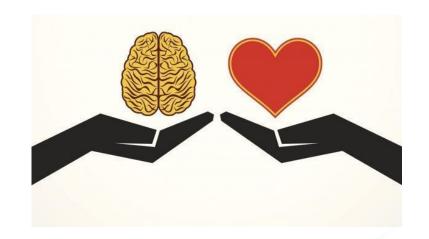
Despite the evidence, many people – mental health workers, employment workers people with mental health conditions – simply do not consider employment a realistic goal for people with serious mental health conditions

"When I said I wanted to work I was told this was an unrealistic goal, that I was too sick and the stress would be too much."

Low expectations erode hope and limit possibilities ...

Recovery is about growing beyond what has happened - pursuing your dreams and aspirations

IPS helps people to do this ... but, as well as the practicalities, we have hearts and minds to win if we are to deliver it



Enabling more people with mental health conditions to gain and prosper in employment is not going to be easy ...



It will require us

- Think about our priorities: really start seeing employment as a priority for people with mental health conditions and a priority for our society - stop wasting skills and talents!
- Provide the support that we know works and stop doing things that are not effective ... this can be hard!
- **Be creative** in thinking about what work a person can do and how we can support them
- Share skills across networks: health
 professionals can't become employment experts –
 employment advisors can't become mental health experts
 ... but we can work together and use each other's
 expertise
- Achieve better joined up working around individuals: ensure that health treatment/social care plans and employment action plans offer consistent messages and complement each other

It may not be easy, but it's worth it!

The cost of unemployment is immense - both for individuals and communities - and the benefits of employment are equally large ...

"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."

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

"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."