Personalisation and Recovery: the need for a fundamental change in culture and approach

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The need for a change in approach

Traditionally mental health conditions = a **clinical challenge**:
- diagnosis, treatment
- cure, care and containment

Recovery approaches and personalisation: mental health conditions = a **social and personal challenge**
- To be diagnosed with ‘mental illness’ is a devastating and life changing event
- The biggest barriers people face are what it means to have a diagnosis of mental health problems in our society
The challenge of rebuilding your life: ideas about recovery

Born with lived experience of rebuilding their lives

Recovery is about rebuilding a life:

■ finding meaning in what has happened
■ finding a new sense of self and purpose
■ discovering and using your own resources and resourcefulness
■ growing within and beyond what has happened to you
■ rebuilding a satisfying, hopeful and contributing life

“Recovery is ... a personal journey of discovery: making sense of, and finding meaning in, what has happened; discovering your own resources, resourcefulness and possibilities; building a new sense of self, meaning and purpose in life; growing within and beyond what has happened to you; and pursuing your dreams and ambitions.”
‘Recovering a life’ NOT ‘recovery from an illness’

- Not the same as ‘cure’
  
  “Recovery is not about waiting for the storm to be over. It is about learning to dance in the rain.” Peer Recovery Trainer, CNWL London Recovery College

  “Recovery is not fixing what’s broken. It’s finding wholeness, meaning, and purpose” Duane Sherry

- Not a theory about the cause of mental health conditions

- Not a professional intervention: mental health services cannot ‘recover people’: the challenge is how to support people in their recovery journey – provide fertile soil in which people can grow.
No formula for recovery ... but 3 things seem to be important: hope, control and opportunity

**Hope** – believing that a decent life is possible, hope-inspiring relationships

**Control** – over your life and destiny, the challenges you face (becoming an expert in your own self-care) and the help you receive

**Opportunity** - the opportunity to do the things you value, pursue your ambitions and participate in your community as an equal citizen.

Obvious fit with personalisation … less obvious fit with traditional approaches with mental health services
Recovery and Personalisation: a shared vision

- Rooted in lived experience
- Goal of equal citizenship for people with mental health conditions
- Beyond care and cure to focus on rebuilding lives
- Challenge mental health system to see ‘patients’ as people
- Rebalance the importance of clinical treatment:
  “Recovery requires reframing the treatment enterprise…the issue is what role treatment [and support] plays in recovery.” (Davidson et al, 2006)

Treatment (pharmacological, psychological, social, occupational) remains important BUT we need to evaluate them differently: not ‘do they decrease deficits and dysfunctions’ but ‘do they enable people to do the things they want to do and live the life they want to lead - access jobs, homes, friends, social, educational, spiritual opportunities...
A fundamental change in culture and approach

1. A redefinition of the purpose of mental health services - from eliminating problems, deficits and dysfunctions to rebuilding lives

2. A change in the balance of power between professionals/services and those whom they serve – mental health professionals/services ‘on tap’ not ‘on top’, supporting self management and self-determination rather than fixing people, a different approach to ‘risk’

3. The creation of inclusive communities that can accommodate all of us – equal citizenship and the right to participate in all facets of community life
Is this change in culture and approach happening?

**Progress has been made:** recovery indicators, recovery strategies, recovery training, peer support workers, recovery colleges ...

**BUT** there are signs that powerful professionals and services are ‘taking over and distorting ideas about recovery:

- translate recovery into health terms and something that services do
- recovery becomes ‘getting better’
- recovery models, recovery interventions, recovery teams
  ... and social exclusion continues unabated
The balance of power has not changed

- The assumption that, because of our special training and understanding, professional ‘experts’ know best remains widespread (among both people using services and those providing them)

- Use of ultimate power – detention and compulsion via use of the mental health acts - has increased
Number of people compulsorily detained in hospital or subject to Supervised Community Treatment Orders at March 31st

Source: NHS Information Centre for Health and Social Care (2012) Inpatients formally detained in hospitals under the mental Health Act 1983, and patients subject to supervised community treatment, Annual figures, England, 2011/12, Health and Social Care Information Centre

Number of Community Treatment Orders Issued

Number of detentions in hospital under the Mental Health Act 2007 - 2012
Both recovery and personalisation require a different model for understanding the challenge...

Two ways of promoting inclusion and citizenship:

- Changing the person so they fit in (treatment/therapy, skills training etc.)
- Changing the world so it can accommodate everyone

Learning from the broader disability movement:

**Replacing a clinical framework with a model predicated on human rights and a social model**
“It is society that disables people. It is attitudes, actions, assumptions – social, cultural and physical structures which disable by erecting barriers and imposing restrictions and options ... **The social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment.**” (Oliver, 2004)

“... having a psychiatric disability is, for many of us, simply a given. **The real problems exist in the form of barriers in the environment that prevent us from living, working and learning in environments of our choice** ...[the task is] to confront, challenge and change those.”

Deegan (1992)
A human rights approach based on a social model

A social model of disability underpins equality and human rights legislation (which explicitly includes people with mental health conditions)

- UK Equality Act (2010)
- The previous ‘Independent Living Strategy’ and the forthcoming Disability Strategy ‘Fulfilling Potential’
- United National Declaration on the Rights of Disabled People (to which UK is a signatory)
UN Convention on the Rights of disabled people

Article 19: “right to live independently and to be included in the community”

In mental health services independent living’ too often means ‘being discharged’, ‘living without support’

but this right is not contingent on ‘getting better’ or living without support

It include the right to “...assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”.
A social model of disability makes us think differently about the way we understand the challenges people face and the way we organise services.

Not what is ‘wrong with the person’ but:

- **What are the barriers** that prevent participation
- **How can the person get around these barriers** to do the things they want to do and live the life they want to lead
- **Provides a different way of thinking about ‘living independently’**:
“All disabled people having the same choice, control and freedom as any other citizen – at home, at work and as members of the community. This does not necessarily mean disabled people ‘doing everything for themselves’ but it does mean that any practical assistance people need should be based on their own choices and aspirations.”
(Office for Disability Issues, HM Government, 2009)

... and at the bottom line this is what recovery and personalisation are all about