W(h)ither mental health services?

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

A view from no-(wo)mans land between 'them' and us'

- Over 30 years working in mental health services ... from clinical psychologist to director
- Over 25 years being on the receiving end of mental health services (inpatient and outpatient)
- At least 25 years of thinking and writing about recovery, mental health, mental health services, and trying to change the world ...

... and I have come to the conclusion that we need to rethink the way in which we support people in their journey of recovery

Today I would like to invite you to rethink with me ...

Ideas about recovery now pervade mental health policy across the UK ...

Progress has been made ... we have got

- recovery strategies,
- recovery training,
- recovery indicators,
- peer support workers,
- recovery colleges,
- WRAP/Personal Recovery Plans

But we are facing tough times (that are unlikely to get much less tough) – there are cuts everywhere

... and in the highly professionalised services that we operate these things are all becoming more difficult to sustain

Tempting to argue ‘no cuts’

Defend the services we have got against the onslaught of the recession

‘Everything would be all right if we only had more of the same’: more doctors, nurses, psychologists, occupational therapists, social workers , inpatient wards, day centres ....

and meanwhile continue to ‘salami slice’ the professionalised model of service we currently operate – cut a nurse here, a psychologist there, decide we can operate with a different ‘grade mix’ or ‘skill mix’

At risk of being lynched:

I will argue that we have got to the point where we can't just keep slicing bits off existing, highly professionalised, models of service

and

question whether we would want to even if we could

Judi Chamberlin (1977) 'On Our Own'

When times are hard it is tempting to call for *'more experts and more of their services, unable to acknowledge that it is the system itself that is the problem."*

Maybe the crisis we are facing offers opportunities for exploring genuine alternatives?

Do services as we know them really provide fertile ground in which people can grow beyond what has happened to them?

Can we find better ways to help people in their journey of recovery:

- different models for understanding the challenge?
- different ways of organising things?
- different ways of evaluating what we do?

The key challenges to be addressed if we are to support recovery

1. Redefining the purpose of services

- From a primary focus on treatment and 'cure' – eliminating problems, deficits and dysfunctions - to a primary focus on rebuilding lives

2. Power and control

- Taking back control is central to recovery: the right to define your own reality and control over your destiny, your life and the support you need to live it as you wish
- The right to define your own experience and determine when you need help and what sort of help you find useful requires **changing the balance of power**

3. Creating inclusive communities that can accommodate people with mental health problems

- The opportunity to do the things you valued – to participate as an equal citizen – is central to recovery and requires **a different relationship between services and the communities we serve**

1. Redefining the purpose of services ...
... or a professionalising of ideas about 'recovery'?

At the same time as ideas about recovery have gained in popularity there are signs that well intentioned (but powerful) professionals and services tend to take over and distort ideas about recovery: **translate 'recovery' into health terms and something that services do:**

- recovery becomes 'getting better'
- 'recovery models'
- 'recovery interventions'
- 'recovery teams'

"Recovery requires reframing the treatment enterprise…the issue is what role treatment **[and support]** ***plays in recovery."*** (Davidson et al, 2006)

Specialist assessment and treatment (pharmacological, psychological, social, occupational) may be 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 ....
- They are only a part of the story (and probably a smaller part than us professionals would care to acknowledge)

Question: Can we really say that our primary focus has changed ... or do we think about inclusion, life chances and citizenship as an add-on to the real business of treating symptoms and reducing problems?

2. Changing the balance of power ... or reasserting professional power?

Really changing the balance of power is not easy ...

the assumption that **professional 'experts' know best** remains widespread (among both people using services and those providing them):

- professionals prescribe whether people need help ('gate-keeping' in services)
- professionals prescribe what is good for people and ensure their compliance – using the force of verbal persuasion and the force of the law if this fails

as a result ....

Compulsory detention under the Mental Health Act increased hugely

- 1997/8: 38,695 detentions;
- 2007/8: 44,093 detentions
- 2011/12: 48,631 detentions PLUS 4220 people on Community Treatment Orders

and at the same time

Many people continue to tell us that they find it hard to get help when they need it

"It feels like I literally have to have one foot off the bridge before I can access services."

(Listening to Experience, Mind 2011)

Really changing the balance of power requires professionals and services to be ‘on tap’ not ‘on top’

- **Recognising the expertise of lived experience** and **that each person is an expert in their own experience and reality**: respect each person’s right to define their own experience and reality
- **Use professional expertise differently:** putting our knowledge and expertise at the disposal of those who may wish to make use of it rather than telling people how they should understand their situation and what they should do
- **Enable people to access the expertise of lived experience and peer support**: many people have found that the most useful travelling companions in their journey of recovery are people who have travelled a similar road
- **Support self-management rather than fixing people:** helping people to discover their own resources, resourcefulness and possibilities

3. Creating inclusive communities ...

... or maintaining exclusion?

Highly professionalised services – statutory or voluntary –can (albeit unwittingly) perpetuate exclusion in a kind of vicious cycle:

- People with mental health problems believe that experts hold the key to our difficulties
- Our nearest and dearest believe we are unsafe in their untrained hands.
- And we all become less and less used to finding our own solutions and embracing distress as a part of ordinary life

(Mary O'Hagan, 2007)

The Mental Health National Service Framework may have increased the range of services and helped people to get to them earlier ... but exclusion continued unabated

For example

- People with mental health conditions remain more **socially isolated** than other disabled people (Office for Disability Issues, 2013)
- 87% of people with a diagnosis of mental health problems report **experiencing negative discrimination** (Henderson et al 2012)
- The employment rate **for people with mental illness** has remained stable at **less than 15% for over a decade** (Office for Disability Issues, 2013)
- The proportion of people claiming incapacity benefits because of a mental health condition has risen steadily to 43% (Office for Disability Issues, 2013)

Promoting inclusion and citizenship require a different approach

- Different models for understanding the challenge
- Different ways of organising things
- Different ways of evaluating success

1. A different model for understanding the challenge learning from the broader disability movement

Two ways of thinking about inclusion and citizenship:

- **A clinical approach: c**hanging the person so they fit in (treatment/therapy, skills training etc.)
- **A social approach:** changing the world so it can accommodate everyone

"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)

"Inclusion and citizenship are not about 'becoming normal' but creating inclusive communities that can accommodate all of us. *Not about 'becoming independent' but having the right to support and adjustments (in line with our choices and aspirations) to ensure full and equal participation and citizenship"*

(Perkins and Amering ,2013 in press)

By replacing a ‘clinical approach’ with a

social model based on the right to participate

people with physical impairments have gained a great ... maybe we can learn from this?

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

- UK Equality Act (2010)
- The Disability Strategy – ‘Fulfilling Potential (ODI, 2013)
- United National Declaration on the Rights of Disabled People (to which UK is a signatory) This includes Article 19:

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

This right that is not contingent on ‘getting better’ or living without support.

“...assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”. (UNCRPD Article 19)

A social and human rights model leads to a different approach to facilitating participation and inclusion:

- **Asking not what is 'wrong' with the person, but what are the barriers** (attitudes, actions, assumptions – social, cultural and physical structures) that prevent participation
- **Assessing not what a person can and cannot do, but how can we get around these barriers**: support, adjustments, breaking down prejudice, changing attitudes
- **Helps us to think about creating inclusive communities** recovery is not only about recognising and supporting the resources and resourcefulness of individuals – it is also about recognising and supporting the resources and resourcefulness of friends, relatives, communities

Maybe we should see treatment as essentially part of the assessment process - defining the level of impairment that must be accommodated?

2. Different ways of organising things

Mental health services currently provide

- ***Specialist, technical assessment and treatment*** – definitely require professional expertise ... but who controls?
- ***Day to day support to live your life*** - don't require professional expertise: if professionals provide this it is a waste of money, deskills people and professionals do not know a great deal about living with a mental health problem
- ***Help to navigate services and communities*** ('care-coordination', CPA, case management, support planning, brokerage) - don't require professional expertise - if provided in specialist mental health services they are lost when the person is discharged ... and mental health services have not done it very well

"Not only is the evidence about the fundamental effectiveness of case management equivocal at best, but the CPA is viewed as being excessively bureaucratic and as effectively turning skilled clinicians into administrators. Perhaps the most damming critique is that most patients and their families are not even aware what the CPA is."

(Centre for Social Justice Report on Mental Health, 2011)

How about ...

Stripping mental health services back to providing the specialist, technical assessment and treatment ...

Easily accessible when needed ... In the background when they are not

And individuals having **personal health budgets** so they can **control** what treatment and support they receive and when they receive it ... either from NHS treatment and therapy services or elsewhere should they so desire

(See English Department of Health Personal Health Budgets Pilot , 2012)

Taking care planning and care co-ordination out of statutory services ...

Maybe into peer led services

Personal navigators or recovery coaches to assist with support planning - getting the help you need to navigate day to day life and manage personal budgets – and brokerage

(See Office for Disability Issues Support Planning and Brokerage Pilot, 2011;Centre for Social Justice Mental Health Report , 2011)

How about ...

Recovery Colleges

Professionals ‘on tap’ not ‘on top’

Recognising the expertise of lived experience alongside professional expertise in co-produced, co-delivered workshops, seminars and courses to help us think about how we can best make sense of/manage our loves and explore our possibilities

And why should these only be available to people with mental health challenges and their relatives/friends **...**

They could be a resources to increase the capacity of our communities to understand and accommodate mental distress

- open to everyone who wants to better understand mental health and emotional challenges
- open to anyone who needs to rebuild their life following devastating and life changing events (physical illness/injury, bereavement, relationship breakdown unemployment, addiction problems ...)

See ImROC Recovery Colleges Briefing Paper (2012)

How about ...

Taking day to day support to live your life out of statutory services ...

maybe using peer support and support available within communities to provide this

fostering peer networks and community networks

And individuals having **personal budgets** so they can **control** what the support they receive and from whom they receive it in line with their priorities and preferences

(see Repper and Carter (2010) ; Recovery Rocks, 2013)

And why should support planning and support to live your day to day life be restricted to people with mental health conditions?

There are many other people who need help to navigate their lives and support to participate his sort of help, like people with physical illnesses, learning disabilities, literacy challenges, homeless people, ex-offenders, care leavers ...

JR7

So what about research and evaluation?

- Recovery is about **rebuilding your life not symptom reduction** therefore we need different outcome indicators
- The recovery journey is individual and deeply personal therefore we need **different outcome indicators for each person** ... and people's goals and aspirations change as their journey progresses therefore **outcomes change over time**
- Control and self-determination are central to recovery - we know that individuals put together their own **'personal medicine'** which is invariably multi-faceted

"Personal medicine was found to be those activities that gave life meaning and purpose, and that served to raise self-esteem, decrease symptoms, and avoid unwanted outcomes such as hospitalization. When psychiatric medications interfered with non-pharmaceutical personal medicine, non-adherence often occurred. " (Deegan, 2005)

"Over the years I have learned different ways of helping myself. Sometimes I use medications, therapy, self-help and mutual support groups, friends, my relationship with God, work, exercise, spending time in nature – all of these measures help me remain whole and healthy." (Deegan, 1993)

JR7 keep the same structure, this is 3. Different ways of evaluating services.
Julie Repper, 07/08/2013

Just as clinicians tend to distort ideas about 'recovery' into' into health terms and something that services do so **researchers tend to try to fit 'recovery research' into their existing paradigms**

'Does recovery 'work'? Is recovery 'effective'?

'Does X work to promote recovery?

Research relating to recovery does not fit neatly into existing evaluation and research paradigms:

- are largely based on population averages
- require a single dependent and independent variable that is held constant

We need a different approach to accommodate multiple individually tailored supports/assistance and multi-faceted outcome variables both of which are under the control of the person and are likely to change over time!

But I am not trying to offer a blueprint ...

We must embark on a journey of discovery together and we must use all the resources available to us:

- The expertise and ingenuity of lived experience
- The expertise and ingenuity of communities, friends and families
- The expertise and ingenuity of mental health practitioners and researchers