A Rights Based Approach to Recovery and Social Inclusion

Julie Repper
Associate Professor – University of Nottingham
Recovery Lead – Nottinghamshire Healthcare Trust
Member of the Implementing Recovery – Organisational Change Project Team
Aims of Today

- To examine the parallel paths of Disability Rights and Recovery Movements and consider what both mean.
- To consider the implications for policy, services, mental health workers, communities and people with mental health problems.
- To describe the role of Recovery Education Centres/Colleges in realising Recovery and Rights.
What is Recovery?

A framework for understanding mental health that emanates from lived experience of distress. As such, it challenges current beliefs about madness within society and has significant implications for service delivery and development.

It is by having the hope that things can get better, and the courage to move on, that we can learn about what works for us and gain control of our difficulties, so that we can pursue opportunities and live a meaningful and fulfilling life.
What is Recovery?

‘...a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and roles...The development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness’ (Anthony 1993)

“...when you are no longer dying..”
“...when you think you will be happier sometime ...”
“...when you have stopped punishing yourself...”
“... when you make a new friend...”
“... when life doesn’t hurt any more...”
“... when something goes right...”
“... when you like going out”
Or is it Discovery...?

- *Discovering* ways of understanding what has happened – and that you are the expert
- *Discovering* that you are more than your illness
- *Discovering* ways of living a satisfying and contributing life
- *Discovering* that you don’t need to rely on services/professionals
- *Discovering* that mental health problems are not totally negative
- *Discovering* that this journey continues even when services deem you to be ‘recovered’
Traditional emphasis on patient in our services

The patient in our services

Primary purpose = treatment and symptom reduction

✓ Symptoms and problems
✓ Diagnosis
✓ Treatment
✓ Prognosis
✓ Services/supports

History, strengths, goals, social circumstances, activities, values, beliefs etc. considered to inform decisions about diagnosis, treatment and support

But symptom removal neither a sufficient nor necessary condition for rebuilding life ....
The role of professional treatment lies in supporting self-management and the pursuit of ambitions rather than ‘fixing people’.

The person in their life:

- Where they have been
- What has happened to them
- Where they are now (home, work, leisure, family, friends, culture, values, interests, likes, dislikes, preferences)
- What they have got going for them (abilities, personal and material resources, family, friends)
- Where they want to be and what they want to do (goals, aspirations, ambitions, dreams)

Diagnosis, treatment and support considered in terms of the extent to which they help the person to do the things they want to do and live the life they wish to lead.

“Recovery requires reframing the treatment enterprise... the issue is what role treatment plays in recovery.” (Davidson et al. 2006)
• A movement of protest against inequalities and discrimination that may hinder civil liberties in everyday life as people with less control have campaigned for equality.

• Recovery first appeared in 1980s as part of a greater movement towards reducing institutional discrimination (sanism ... like racism).

• Challenges psychiatry to remember that everyone has a right to make their own decisions unless they have been determined to be incapacitated or a serious risk.

• Mental illness generally assumed to rob folk of this birthright (“you can only decide if I agree or if and when you prove capable to make ‘good’ decisions... And that depends on ‘insight’...”)

• Recovery transforms thinking – from contingent: when we say you are ready you can go and live life, to facilitative: how can we change the world so you can achieve your goals and ambitions?
Recovery and Civil Rights

- Disability rights (esp mental disabilities) not discussed in global public, political or legal debate until the 1980s: Integration, Mainstreaming; Self-Sufficiency; Disability as a Social Problem - were the principles guiding the disability rights movement.

- Recovery was 'an alien concept' in psychiatry until the 1980s when people with different experiences and ideas raised awareness of the real potential for people with 'mental health problems' to live meaningful and valued lives – and the role that services have within that.

- In these linked movements people with mh problems have become instrumental in identifying violations of their rights and advocating reforms in policies and systems that directly affect their lives.

Purpose
- to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Principles:
- Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- Equality of opportunity, Accessibility; And between men and women;
- Respect for the right of children with disabilities to preserve their identities.
In Summary .... A Rights based approach requires us to

- Recognise the inherent equality of all people regardless of abilities, disabilities or differences

- Group 1 what impact does discrimination have on the lives of people with mental health problems?

- Remove the attitudinal and physical barriers to equality and inclusion of people with disabilities

- Group 2 – what inequalities are experienced by people with mental health problems

- Respect difference and support people to achieve their aspirations (whether we agree with them or not).

- Group 3 – when is it most difficult to support people’s aspirations? How can we overcome these challenges?
Yet... Exclusion of people with mental health conditions is extreme – and breaches human rights:

- 80% are not in paid work yet evidence shows that with the right support most can work (Bond et al, 2001)
- Therefore isolated, inactive and living in poverty (DoH, 1999)
- More likely to get major illnesses and die on average 15 years younger than those without (DRC, 2006)
- More likely to be homeless or suffer acute housing problems
- Denied fair access to justice (seen as unreliable witnesses) Perlin, 2011
- Denied the right to make decisions on their own treatment (Szmuckler, 2009)
- Denied the right to raise families (seen as unfit parents) Mind, 2009)
- Face bullying and harassment to the point of feeling unsafe (EHRC, 2010)
- Face inflammatory media coverage (incitement of hatred) Watson et al, 2011
- Use mental health services which themselves can be unsafe and discriminatory (NPSA, 2006)
Recovery is about replacing ideas about ‘needs’ with ideas about ‘rights’

- Rights to make decisions about our treatment and support
- Rights to live independently – with the supports and assistance required to make this possible
- Rights to participate on equal terms in all facets of life (with the accommodations and adjustments that make this possible)
- Rights to control our own destiny (to identify our own goals and aspirations and receive support to work towards these)
How can mental health workers do this?

- Recognise two sets of expertise working in partnership – a fundamental shift in balance of power at all levels - professionals ‘on tap not on top’.
- Shared decision making “an open experiment for two co-experimenters – the client and the practitioner’ (Deegan and Drake, 2006)
- Personal Health Budgets – people choose their own supports
- Coaching skills rather than therapy skills
- An educational approach rather than a treatment approach
- Personal Recovery plans and Joint Crisis Plans
- A different workforce to break down ‘Them’ and ‘Us’ – peer support workers.
Changing the Individual or Changing the World?

The UNDRDP rests on the premise that the real barriers to equal participation lie not with the individual but with society. As Deegan (1992) states:

“...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 barriers and to make environments accessible”

We must therefore work towards creating communities that can accommodate all of us,

But mental health services and professionals can perpetuate marginalisation and exclusion by claiming expertise and specialisation. ... So we all become less able to find out own solutions and embrace distress as a part of ordinary life.
How can we create more accommodating Communities?

- **Group 1** – How can we tackle negative attitudes and beliefs – in services, in education/employment, in communities?

- **Group 2** – Making adjustments so that opportunities are accessible – what are the emotional equivalents of a wheelchair, ramp and hearing loop?

- **Group 3** – Increasing the competence of communities to accommodate people with mental health problems – how can we raise awareness of mental well being, mental capital, achieving work-life balance etc.
Recovery Education Centre/College: one way forwards ....

“We decided to use education as the model for promoting Recovery, rather than develop more traditional treatment alternatives. We did this because we wanted our center to be about reinforcing and developing people’s strengths rather than adding to the attention on what is wrong with them. The guiding vision we had for the Recovery Education Centre is reflected in the mission statement: People will discover who they are, learn skills and tools to promote recovery, find out what they can be, and realise the unique contribution they have to offer” (Ashcroft, 2000)
Aims and Objectives of our Recovery College

- To enable people to recognise, develop and make the most of their talents and resources in order to do the things they want to do in life.
- To enable people to assert their wishes - and when necessary rights - in decisions about their treatment.
- To promote an educational/coaching model to guide work across the organisation.
- To complement and enhance the effectiveness of specialist therapies, individual social support or home treatment and inpatient services.
- To break down barriers between ‘us’ and ‘them’ by offering training sessions run for and by both service users and staff.
- To improve access to information for the local population as well as staff, service users and their family members.
- To reduce discrimination and self stigmatisation.
Therapy vs Education

**Therapeutic model:**
- Focuses on problems, deficits, symptoms
- Strays beyond the therapy sessions and becomes over-arching paradigm
- Transforms all activities into therapies
- Nature of therapy is chosen and offered by the (expert) therapist
- Involves an expert (therapist) & non-expert (patient)
- Maintains power imbalance and reinforces the notion that expertise lies with professionals

**Educational approach:**
- Helps people recognise and make use of their talents and resources
- Helps people explore their possibilities and develop their skills
- Helps people achieve their goals and ambitions
- Staff become coaches who help people find their own solutions
- Training and courses replace therapies
- Students choose their own courses, become experts in their own self care
Structure and Operation

- Run in partnership with those using it (peer trainers, peer course leaders, peers on REC Advisory Group)

- Employs specialist trainers where appropriate (local police, gyms staff, fire brigade, college staff)

- Central building with training rooms, recovery library, staff office and refreshment area.

- Satellite courses offered in different parts of locality so that everyone can access the courses they would like.

- Courses 12 weeks, 3 weeks, 1 day or 1 hour long.

- Introductory peer-led programmes offered in involvement centres .... Further development courses offered in local colleges
Prospectus of Five Strands

| Staying well eg | • Understanding/living with different Mental health conditions,  
| | •Mental health treatment/ managing my meds/coming off my medication  
| | •Introduction to Recovery  
| | •Planning your own Recovery  
| | •Coming off medication safely  
| | •Making the most of your outpatient appointment  
| | •Physical health – eating well, getting fit |

| Rebuilding your life eg | •Telling your story  
| | •Issues of disclosure  
| | •Life coaching for Recovery  
| | •Problem Solving Skills  
| | •Time management  
| | Personal safety  
| | Fire safety  
| | Safe Dating |

| Developing Skills eg | •Word power (literacy)  
| | •Money matters (budgeting)  
| | •Home sweet home (tenancy skills)  
| | •Return to education and study  
| | •Return to work |

| Family, Friends and Carers | •Living with someone who has substance misuse problems  
| | •Carers Education and Training Programme |

| Getting Involved eg | •Peer support worker training  
| | •Peer researcher training  
| | •Peer Governance training (including chairing committees, being a ‘user rep’  
| | •Peer interviewing and recruitment skills |
A rights based approach towards recovery and social inclusion changes the focus of services:

- from ‘treatment of problems’ to ‘achievement of aspirations’
- from a protective culture to a permissive culture
- from ‘managing risk’ to ‘creating opportunity’
- from ‘perpetuating discrimination’ to ‘raising expectations’
- from involvement to partnership
- from ‘on top’ to ‘on tap’
- from centre stage to the margins ....