A radical change: Personal budgets coming soon to a service near you
Two strands of thinking currently shaping mental health policy and practice internationally – *Recovery* and *Personalisation*.

Will explore what recovery and personalisation mean and look at the relationship between them.

What are Personal Budgets and how and where do they fit in?

Benefits and challenges.
"Instead of relatively short and sharp encounters with the health service, more people are embarking upon journeys of years or decades, requiring assistance and support ... .

[The question is] what kind of services and care best fit the needs of people who are on a patient journey?

It is better to spend time working out what provisions the patient needs for their journey than rushing to complete and document the plan and plug every hole ...... nothing beats actually hearing what the patient has to say and finding out what they think they want and need.”


National Health Reform Summit. Canberra.
A Few Questions to Start ……

People with mental illness are far less dangerous than most people suppose? 38% disagreed

Less emphasis should be placed on protecting the public from people with mental illness? 64% disagreed

Residents have nothing to fear from people coming into their neighbourhood to obtain mental health services? 36% disagreed

Most women who were once patients in a mental hospital can be trusted as babysitters? 75% disagreed

People with mental health problems have the same right to a job as everyone else? 36% disagreed

Attitudes to mental illness 2011: research report. London. Department of Health
“For some of us, an episode of mental distress will disrupt our lives so that 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 future in meaningful employment. Loneliness and loss of self-worth lead us to believe we are useless.

…… Repeatedly when we become ill we lose our homes, we lose our jobs and we lose our sense of identity ..... we lose the ability to contribute .....”
“To have a mental illness in Western Society is to be treated as an outcast …. Often people talk around me and not to me. They do not look me in the eye. I want to tell them I am a human being, too.”

Consumer

Murphy, M.A. [1998]. Rejection, Stigma, and Hope
Psychiatric Rehabilitation Journal, 22, p185
“When I inquired about returning to school, he [my psychiatrist] cautioned me to dismiss the idea of ever returning to academic pressures. He said I should realise that I was ill and had to take things easy. I asked about looking for work, and he stressed that this too was out of the question for me.”

Marcia Lovejoy, Director Project Overcome, Minneapolis. Schizophrenia Bulletin, Vol 8, No.4, 1982
"I finally have been able to live a full and happy life. After 10 hospitalisations over the course of 12 years of treatment, I have finally learned how to survive, and have not seen the inside of a psychiatric hospital for 4\frac{1}{2} years. ..... 

My experiences .... have taught me that regardless of the cause[s] of mental illness, progress towards recovery cannot occur when there is no hope. Negative expectations and stereotyping are amongst the greatest obstacles to recovery, and keep many mentally ill persons immobilised by defeat and despair."

Marcia Lovejoy, Director Project Overcome, Minneapolis. Schizophrenia Bulletin, Vol 8, No.4, 1982
What is Recovery?

- It emerged from the writings of people who used services in the 1980s [US] and 1990s [UK] – coping with symptoms, getting better and regaining a sense of personal identity not defined by illness experience.

- In mental health, it has been applied to the experience of ‘personal recovery’ in people with persistent or recurrent mental illness that can occur in the context of continuing symptoms or disabilities.
What is Recovery?

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

What is Recovery?

‘Recovery is a process, a way of life, an attitude, and a way of approaching the day’s challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again…

The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work and love in a community in which one makes a significant contribution.’

Pat Deegan
“When I got the flat that I am in now, for the first time it was my house and it was my space and I could fill it with my memories and, you know, there wasn’t any baggage there ..... And it was a place where nobody knew me, nobody knew that I had mental health problems, nobody knew who I was. I was just a person who had moved into this flat ....”

Consumer, Scottish Recovery Network
“I feel a bond with the world of mental illness which provides me with identity security, friendship, acknowledgement, communion and respect. .... I don’t want to leave my world behind, my identity of illness and difference has been informed by my experiences over the last two decades.

These years have reinforced the message that this is the safest place to be. It’s where I find my friends, it’s where I earn my income, it’s where I meet people who understand me - I really don’t want to leave it, I fear a world without illness. “

Graham Morgan, prominent mental health activist. SRN Conference 2007
“The request I had found so offensive became a token to light my way and provide new and invigorating ways in which to see the world, to take that big leap in self-definition and see myself as whole rather than damaged and shattered”

Graham Morgan, prominent mental health activist. SRN Conference 2007
The Principles of Recovery

- Building a meaningful and satisfying life as defined by the consumer
- Discovering or rediscovering personal identity.
- Focus on health, strength and wellness.
- **Hope** is central.
- Self-management is encouraged and facilitated.
- Clinician becomes a ‘coach’ on journey.
- People do not recover in isolation - family and other supporters are crucial.
Recovery Approach

“My journey of recovery is still ongoing. I still struggle with symptoms, grieve the losses I have sustained ..... I am also involved in self help and mutual support and still use professional services including medication, psychotherapy and hospitals.

However, I do not just take medications or go to the hospital. I have learned to use medications and use the hospital. This is the active stance that is the hallmark of the recovery process.”

Recovery within a ‘Community Framework’

“Promoting tolerance and community acceptance of persons with psychiatric disorders, although necessary, is no longer sufficient.

We need to .... [promote] social inclusion .... [which] requires that society and its institutions actively promote opportunities for the participation of excluded persons, including persons with psychiatric disabilities, in mainstream social, economic, educational, recreational and cultural resources.

This concept has .... emerged as a way of framing the social aspect of a recovery movement that has seemed at times to be overly focused on the subjective experience of recovery.”

Thompson, K [2010]. Taking Issue. Psychiatric Services, Vol61 No8
Connecting with Communities

*Social inclusion* agenda requires:

- Services to find out what kind of participation in the wider community would have meaning and value for the people who use their services and assist them to engage.

- While some people may only need simple information and encouragement, others will require detailed planning and intensive support to retain, build/rebuild their life.

- Includes supporting participation in services and communities beyond mental health – getting away from the ‘whole of life’ approach that has often characterised mental health services.
“The Commission intends to commence supporting people via individualised funding in 2010/11”
It is a broad philosophy, which started in social care, but has expanded to encapsulates policies across a range of public services – including transport, leisure, education, housing, employment and health.
Personalisation

Personalisation means:

- Tailoring services and support to fit the specific needs of the individual
- Respecting the real and vital relationship the person has with family and friends
- Supporting people to take more control over their lives and their supports
- Enabling people to define the outcomes that are important to them
- Improving the responsiveness and flexibility of our services and supports
- Better involving communities and all stakeholders
“Personalisation is people taking control of their own lives in order to become full citizens. It is about rebalancing the relationship between the citizen and the state”

(Duffy & Fulton, 2007)
‘Professional Gift’ Vs ‘Citizenship’ Model

- **Community**
  - Contribution via Taxation
  - Funding for Services
  - Professional
    - Assessment and Support
    - Person in Need

- **‘Citizenship’ Model**
  - Negotiated support
  - Entitlement to funding
  - Professional
  - Community
  - Government
  - Contribution via taxation

Simon Duffy
Personalisation is increasingly starting to emerge within Health [NHS] with new forms of practice:

- Person-centred planning
- Self-directed support
- Personal budgets
- Direct payments.
Personalisation as a Spectrum

Organisations & their employees place service users at the centre

Clinicians will employ new ways of working to increase the user's voice in Planning their care

A Care Plan is produced in collaboration between service user and clinician

The knowledge & expertise that both service users & professionals have about an individual's condition is drawn out

Service users have much greater flexibility, including a nominal budget which is held by a lead professional

The service user is able to ask the lead professional for information about different treatment choices before making decisions. New roles may emerge to facilitate this

Power & influence can only be transferred to a service user if they are given direct control over a budget

Service users commission their own care packages

‘Commissioners’ become overseers of a market

Adapted from Scoping for Personalisation, Skills for Health. Final Report [2009]
Pulling the Strands Together ....
Self-Directed Support

- Used to describe how people are able to design the support or care arrangements that best suit their specific needs.
- Up-front allocation of money available to achieve outcomes.
- People able to direct and control how the money available to meet their support needs is spent.
- Similar policies widely adopted - e.g. Germany, Netherlands, US and Australia.
At the heart of Self-Directed Support lies a simple yet powerful idea – the Personal Budget. Each person who needs support receives an individual allocation of money. They are empowered to decide how this resource is used to meet their needs.
Personal Budgets

- Direct Payment
- Money paid to an ‘agent’
- A user-controlled ‘trust’
- Individualised service fund
- Care manager

It includes a range of options for exercising choices
How it works …. 

- Consumers can buy services from any social-care agency they choose.

- Care agency draws up contract with consumers setting out what they can expect and what they can do if they are not happy with the service.

- Consumers can employ their own personal assistants, but then have legal responsibilities as an employer [can get independent advice and support].

- Flexibility of an individual budget allows consumers make use of a greater diversity of goods and services [e.g. 13 sites England found all continued to purchase traditional services but 60% also made non-traditional purchases].
Some examples of how the money has been used include:

- Employing a personal assistant
- Buying support from a care or support agency of choice
- Getting access to community-based activities
- Paying for transport [e.g. taxis]
- Paying for a break away for self or carer
- Buying a piece of equipment [e.g. computer]
- Paying for education or training
- Contributing to the costs of leisure and artistic activities
- Career guidance
- Complementary therapies
The Personal Plan

Best understanding of
a) My own needs
b) My preferences
c) My own resources
d) My networks & community

Expertise in
a) Needs, causes & evidence
b) Assessment or diagnosis
c) Services & treatments
d) Systems & entitlements
7 Steps to ‘Being in Control’

My Money: Finding out how much

Making my Plan

Seeing how it worked – What next?

Getting my plan agreed

Living life – In Control

Organising my money

Organising my support
“It’s time to change the way services for people with disabilities are funded and structured in Australia. ..... 

In place of Australia’s current crisis-driven, outmoded welfare-based approach to disability services, it's time for a modern, forward-thinking National Disability Insurance Scheme. .....”

National Disability and Carers Alliance
Benefits

- Redefines relationship between service agencies and consumer.

- Transfer of resources – give individuals and their carers/families greater say over the way in which their health and support needs are met.

- Greater flexibility in use of services.

- Increased personal responsibility [e.g. cheaper].

- Citizenship/social inclusion – ‘finding a world beyond mental illness’.
Challenges

- Technical challenges – setting up system, payments, information, planning support.

- ‘Early days’ in mental health BUT many potential problems not realised [Rita Brevis, A Voice and Choice. In-Control].

- Balancing ‘health’ and ‘disability’ needs.

- Changing roles of service providers [e.g. purchasing.

- Changing professional roles.
"If we really want to transform the quality and safety of healthcare, we can’t just do more of what we do now.

Even doing it more efficiently won’t be enough. We have to do different things and we have to do things differently. … the current system is designed around healthcare professionals. …. 

[What is needed is] a more desirable set of rules that puts patients at the centre of things ….. Now this means standing in their shoes and seeing things through their eyes.”

References

Personalisation in Mental Health
Simon Duffy
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Scoping for Personalisation
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Final Report [2009]


A Voice and a Choice
Rita Brewis
In Control

[www.in-control.org.uk/media/6235/a%20voice%20and%20a%20choice.pdf](http://www.in-control.org.uk/media/6235/a%20voice%20and%20a%20choice.pdf)

International Developments in Self-Directed Care
Vidhya Alakeson


Paths to Personalisation in Mental Health
National Mental Health Development Unit

Thank you!