Recovery, Personalisation
and the
Growth of the Non-government Sector

Mental Health Issues Workshop
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"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 ……

Are people with a mental illness prone to violence? 36% said yes

Do people with mental health problems need to be kept in a psychiatric hospital? 57% said yes

Should someone with a mental health problem be held responsible for their own actions? 48% said no

Do people coming into your neighbourhood to access mental health services raise fear? 34% said yes

Could women who have been treated in hospital for mental illness be trusted to babysit your child? 74% said no

Should people with a mental illness have the same right to a job as anyone else? 25% said no

Attitudes to mental illness 2010: 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. At times, trying to communicate with people who spoke too fast was difficult. 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."
"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 4½ 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?

- In the general health context, has been understood to mean getting back to the way you were before illness or accident affected you – either spontaneously or as a result of treatment ['clinical recovery'].

- 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.

- 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.

- ‘Personal recovery’ is not limited by the presence or absence of symptoms, disabilities, nor the ongoing use of services. Pivots around considerations of how to live well in the context of long-term mental health conditions.
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 the process of regaining active control over one’s life. This may involve discovering [rediscovering] a positive sense of self, accepting and coping with the reality of any ongoing distress or disability, finding meaning in one’s experiences, resolving personal, social or relationship issues that may contribute to one’s mental health difficulties, taking on satisfying and meaningful social roles, and calling on formal and/or informal systems of support as needed. Services can be important aspects of recovery but the extent of the need for services will vary from one person to another.”

CSIP, RCPsyh, SCIE [2007]. A common purpose: Recovery in future mental health services
Joint Position Paper 08
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.

And yet a big part of me says take the risk, step out into the real world, engage with those normal people that you are so frightened and sceptical of…..”
“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

- Recovery approach focuses on re-establishing self-esteem, identity, relationships and a meaningful role in society – not simply on symptom relief and relapse prevention.

- Symptomatic improvement is still important, and may well even play a key role in a person’s recovery, but quality of life, as judged by the individual is central.

- Change in staff role from ‘authority’ to personal ‘coach’.

- Provide person with the resources - information, skills, networks and support - to manage their own condition as far as possible.
Recovery Approach

Although the ‘recovery approach’ harnesses the value of current treatments, how such decisions are made is as important as the decision itself.

“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 in 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.

- Needs to be part of services’ work with people right from the start.

- 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. Within this framework, it can be conceptualised as three linked themes.

Personalisation

The service user, regardless of age or disability has -

Greater influence in decision making

Greater choice

Greater access to information
“Personalisation is people taking control of their own lives in order to becomes full citizens. It is about rebalancing the relationship between the citizen and the state”

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

'Professional Gift' Model

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

'Citizenship' Model

- Citizen
  - Negotiated support
- Government
  - Entitlement to funding
- Professional
- Community
  - Contribution via taxation

Simon Duffy
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 in Health

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

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

‘Soft’: Mindset/ Cultural Changes

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

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

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

‘Hard’: Structural/ Systemic Changes

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
Personalisation: Where Does it Fit ...... ?

- Society
- Services
- Social Inclusion
- Personalisation
- Individual
- Recovery
Finding a Shared Language

- Personalisation
- Patient-centred care
- Person-centred planning
- Independent living
- Personal budget
- Person-centre support
- Direct payment
- Self-directed support
Self-Directed Support

- National strategy developed in the social care in UK to help take the personalisation agenda forward
- Used to describe how people are able to design the support or care arrangements that best suit their specific needs
- Puts people in the centre of their support planning process and recognises that they are best placed to understand their own needs and how to meet them
- Up-front allocation of money available to achieve outcomes, adjusted following development of support plan
- 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
Self-Directed Support in Health

As a recent NHS policy document states:

“By Putting Power in the hands of the people we have created a powerful engine for reform. Where once we had to rely on National targets to drive improvements, we can now drive change through the influence of patients. This will be the basis on which we renew our vision for the future.”

NHS 2010 – 2015 from Good to Great, DH 2009

A small but growing number of pilot programs are now experimenting with self-directed support in the management of serious mental illnesses.
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.
Direct Payment and Individual 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
Uses of Self-Directed Support

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

- All agencies have to be registered with the Care Commission and meet certain minimum standards.

- 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].
Uses of Self-Directed Support

Some examples of how the money might be used include:

- Employing a personal assistant
- Buying support from a care or support agency of choice
- Getting access to community-based activities
- Buying services from any local council
- 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
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
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
Values and Principles

Inclusivity
Everyone, no matter what level of impairment, is capable of exercising some choice and control in their living, with or without support by others.

Dignity
Everyone is to be treated with dignity at work, at home and in the community.

Equality
Everyone is an equal citizen of the state.

Enablement
Everyone is supported to maximise their aspirations and potential, training and education.

Fairness
Everyone is empowered to take control of their own lives and make decisions about their care.

Control
Everyone is supported to participate freely in all aspects of society, in the same way as other citizens.

Freedom
Everyone is provided with unbiased information about the choices available to them.
“Community sector organisations do not just offer greater cost-efficiency and improved service quality. Freed from excessive controls and reporting, they have the will, proximity, connection to their clients and flexibility to drive social innovation in meeting citizens’ needs.”

Putting the Public First: Partnering with the Community and Business to Deliver Outcomes.

Summary Report, Economic Audit Commission, October 2009
Growth of the Non-Government Sector

“As far as the State Government is concerned …... We happen to believe ..... that services for people - human services - are often best delivered by community-based organisations ..... 

[They] tend to be far closer to those that they are assisting ..... more adaptive, more flexible, able to respond to huge changes in circumstances and they are also far more successful than government in bringing in broader community support, whether it’s through corporate support, volunteers, family members or whatever else.”
Growth of the Non-Government Sector

“If you look within the services provided through the West Australian Government, the Disability Services Commission is a stand-out performer. Something like 60 per cent of all government spending in the disability area is channelled through non-government community-based organisations .... and is a model that I would like to see replicated across other areas of government service ......

We've also established a Mental Health Minister and a Mental Health Commission and ...... The philosophy in mental health will be along the lines of that in disability.”

Premier, Opening of WACOSS Conference, 13 May 2010
It's time to change the way services for people with disabilities are funded and structured in Australia.

Almost every Australian has cared, or is caring, for a family member with a disability, or knows of a family doing so. Many of these families fall through a huge gap in Australia's social services network.

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. With its inbuilt focus on lifetime needs and claims management would be much more effective and efficient, as well as fair.”

National Disability and Carers Alliance
Challenges

Striking a balance

- Choice and clinical treatment ['Not for Service' (MHCA), Low Prevalence Survey (Jablensky)]
- Clinical services and disability supports

Finding a world beyond mental illness – the real challenge of social inclusion

Technical challenges to introduction

- Structures
- Changing professional roles
- RAM

Challenges

Transforming the workforce
- Training both present and future [public, NGO, private]
- Workforce mix [health professional/those with ‘lived experience’]

Role of Government and NGO sector
- Individual/small providers [viability and quality]
- ‘Purchasing’ health and support services
- Coordination/partnership

Whole of Government - whole of community
- Partnerships [National MH Strategy]
- Community attitudes
Changing the Rules ....

“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

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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%20choice.pdf

International Developments in Self-Directed Care
Vidhya Alakeson


Paths to Personalisation in Mental Health
National Mental Health Development Unit

www.nmhdu.org.uk/news/paths-to-personalisation-whole-system-whole-life-framework