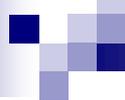# Personal health budgets and recovery

**Vidhya Alakeson
and
Rachel Perkins**

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

- No formula ... but 3 things seem to be important: hope, control and opportunity
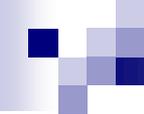
- **Hope** – believing that a decent life is possible

- **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

'Recovering a life' NOT 'recovery from an illness'

- No the same as 'cure'

- Not a theory about the cause of mental health conditions

- Not a professional intervention

'the lived or real life experience of people as they accept and overcome the challenge of the disability. They experience themselves as recovering a new sense of self and of purpose within and beyond the limits of the disability.' (Deegan, 1988).

A recovery approach and personalisation both require a fundamental change in **culture, approach and balance of power** within mental health services
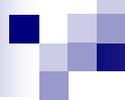
A fundamental change in culture and approach

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
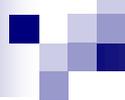
Is this change in culture and approach happening?

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**
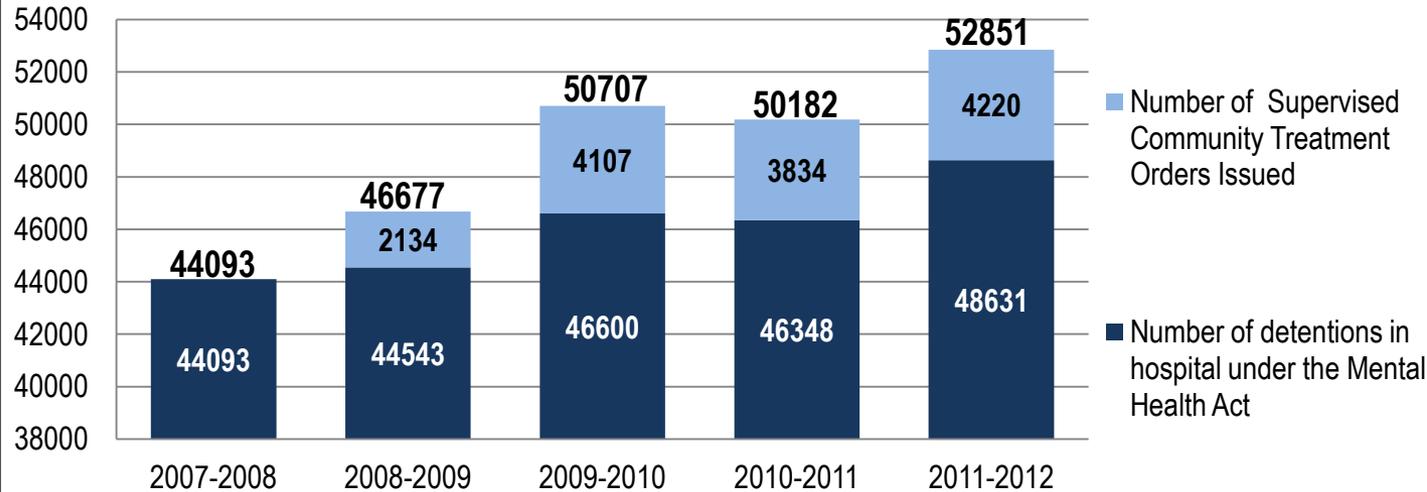
- ☐ recovery becomes 'getting better'
- ☐ recovery models, recovery interventions, recovery teams

... and social exclusion continues unabated

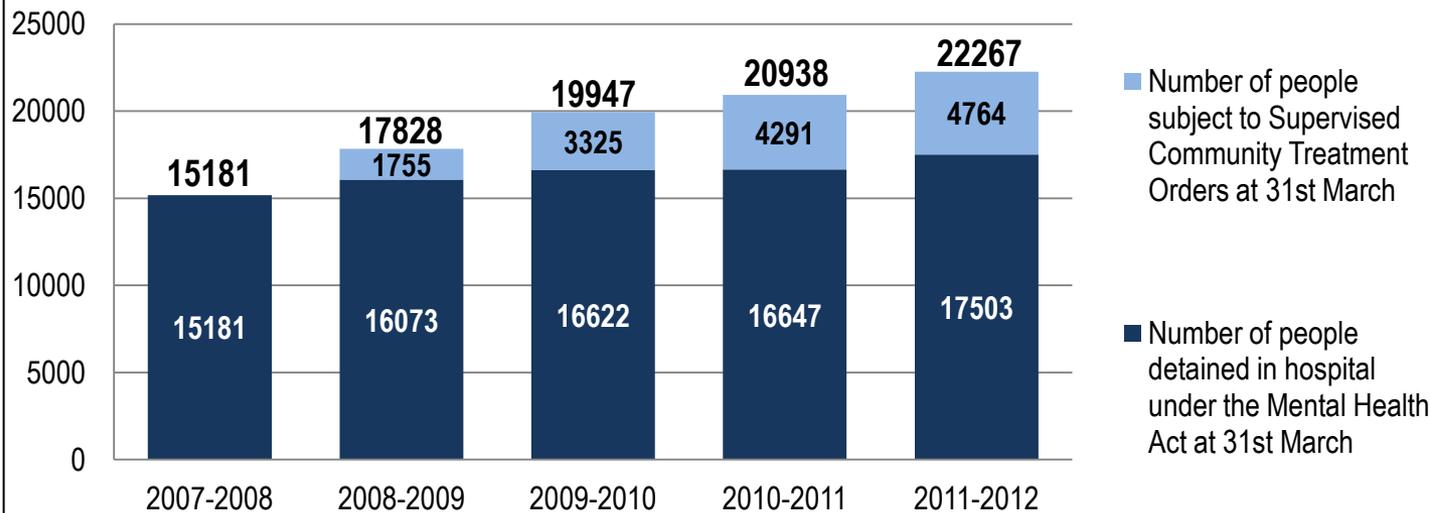# The balance of power has not changed

- 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**

Total number of uses of the 1983 Mental Health Act 2007-2012 (compulsory detentions in hospital and supervised community treatment orders issued)

Year	Number of detentions in hospital under the Mental Health Act	Number of Supervised Community Treatment Orders Issued	Total
2007-2008	44093		44093
2008-2009	44543	2134	46677
2009-2010	46600	4107	50707
2010-2011	46348	3834	50182
2011-2012	48631	4220	52851

Number of people compulsorily detained in hospital or subject to Supervised Community Treatment Orders at March 31st

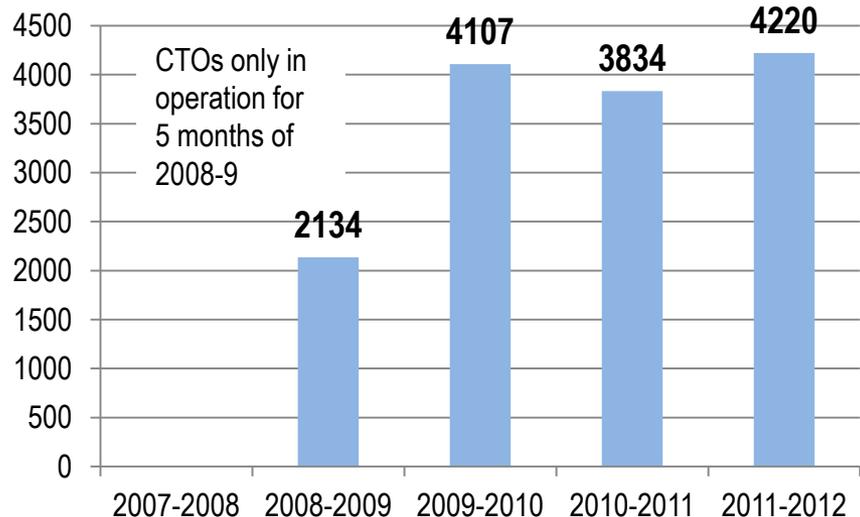| Year	Number of people detained in hospital under the Mental Health Act at 31st March	Number of people subject to Supervised Community Treatment Orders at 31st March	Total
2007-2008	15181		15181
2008-2009	16073	1755	17828
2009-2010	16622	3325	19947
2010-2011	16647	4291	20938
2011-2012	17503	4764	22267

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
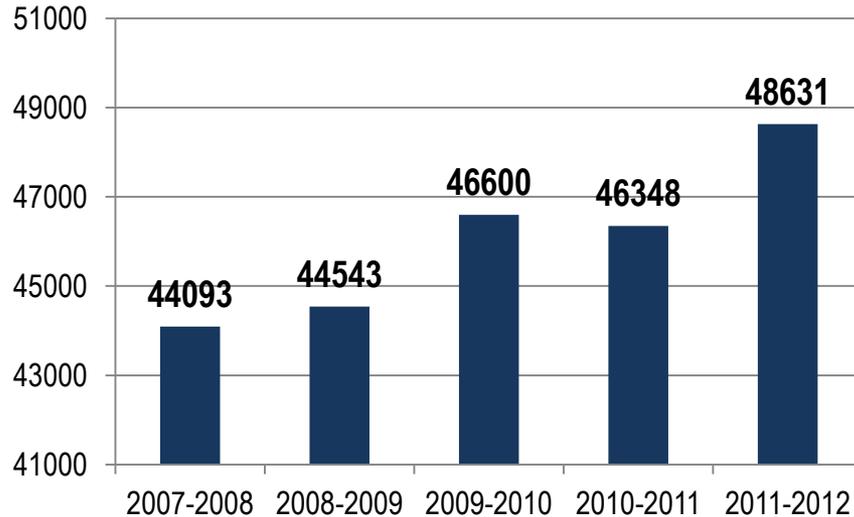
Number of Community Treatment Orders Issued

CTOs only in operation for 5 months of 2008-9

Year	Number
2007-2008	0
2008-2009	2134
2009-2010	4107
2010-2011	3834
2011-2012	4220

Number of detentions in hospital under the Mental Health Act 2007 - 2012

Year	Number
2007-2008	44093
2008-2009	44543
2009-2010	46600
2010-2011	46348
2011-2012	48631

"This is the third, and largest, randomised trial of CTOs, and, similar to its predecessors, did not find any evidence that CTOs achieve their intended purpose of reducing readmission in so-called revolving door patients with a diagnosis of psychosis. The evidence is now strong that the use of CTOs does not confer early patient benefits despite substantial curtailment of individual freedoms."
(Burns et al, 2013, *The Lancet*)

Number of uses of Place of Safety Orders (s136 and s135)

Year	Number
2006-2007	6387
2007-2008	7538
2008-2009	8759
2009-2010	12300
2010-2011	14399
2011-2012	15240
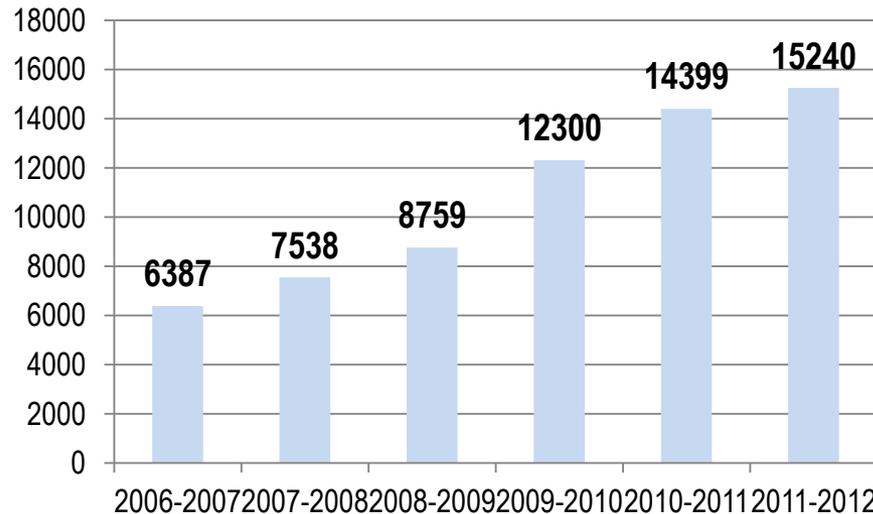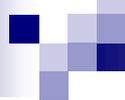
Recovery and Personalisation: a shared vision

- Rooted in lived experience
- Goal of equal citizenship for disabled people
- Beyond care and cure to focus on rebuilding lives
- Challenge mental health system to see 'patients' as people
- Rebalance the importance of clinical treatment alongside self care and other supports

What is a personal health budget?

- An allocation of NHS resources to meet identified health needs

- A route to increase individual choice and control in decision-making about healthcare

- A means to create greater shared decision-making in the NHS

- A tool to support individual recovery

5 features of a PHB as defined by the Department of Health

- The person with a PHB:

  1. Is able to choose the health and wellbeing outcomes they want to achieve
  2. Knows how much money they have for their health care and support
  3. Is enabled to create their own care plan
  4. Is able to choose how their budget is held and managed
  5. Is able to spend the money in ways and at times that make sense to them

What a personal health budget is NOT

"the main goal of personalisation is not to turn people into consumers of public services, but to encourage them to become participants and investors in their own care." (Leadbeater and Lownsbrough, 2005)

- Not the value of your entire year's NHS spending

- Not for all types of treatment and situation

- Not dependent on your own income

- Not an alternative to professional expertise

Positive findings from the national PHB evaluation

- Significant improvements in care-related quality of life and psychological well being

- But no impact on health status or on clinical measures

- No significant differences by age, sex or socio-economic status

- Lower costs of inpatient care compared to the control group.

- Overall more cost effective than conventional service delivery

- Particularly positive effects for CHC, mental health, for larger PHBs over £1000 and for PHBs that were implemented flexibly.

NHS mandate commits to roll out

- By April 2014, everyone eligible for CHC entitled to ask for a PHB instead of conventional care

- Includes parents of children with special educational needs or disabilities (SEND pathfinders)

- By 2015, 'patients who could benefit [with long term conditions] will have the option to hold their own personal health budget…as a way to have even more control over their care'.

Examples from national pilot programme

- Recovery budgets in Merseyside
- PHBs for dementia in continuing healthcare
- IAPT pilot in Eastern and Coastal Kent
- Alcohol detox pilot in Southampton
- Community mental health team pilot in Northamptonshire

Alex's story in his words

USPN	Total cost of care (excluding medication) 2010/11	Total cost of care (excluding medication) first 12 months following PHB implementation Sept 11-Sept 12	Cluster 2011
120021	£9,686.66	£4,242.84	7
220029	£5,859.16	£11,186.26	7
220035	£6,667.32	£10,867.50	4
220047	£35,236.71	£45,062.04	11
Totals	**£57,449.85**	**£71,358.64**	

USPN	Total cost of care (excluding medication) 2010/11	Total cost of care (excluding medication) first 12 months following PHB implementation	Cluster 2011
120008	£ 19,464.75	£14,207.36	8
120031	£56,291.89	£16,903.11	8
120057	£ 6,263.24	£11,068.84	3
120058	£ 40,934.71	£4,259.08	1
120065	£ 15,527.88	£3,056.16	8
Totals	**£138,482.47**	**£49,494.55**	
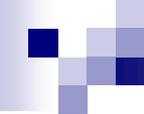
The opportunities

- Stimulating innovation towards more recovery-oriented mental health system that responds to the individual

- Better prevention of acute episodes through more personalised care, reducing hospitalisation

- Better management of crises by linking joint crisis plans to PHBs to reduce hospitalisation, including compulsory detention

- Integration of PHBs and social care personal budgets – RCPsych and ADASS commitment

Reducing compulsory detention - the evidence base: Joint Crisis Plans

"The Joint Crisis Plan is developed by seeking agreement between the patient and their mental health team about what to do if they become unwell in the future. An independent person (or "facilitator") helps the patient and the team to reach agreement and makes sure that the patient's voice is heard. The Joint Crisis Plan can include things like an individual the patient would like to have contacted in a crisis; treatments that have been helpful or unhelpful in the past; treatment preferences or refusals, and practical arrangements."

More than halved subsequent rate of compulsory detention:

Joint crisis plan group – 13% compulsorily detained in 15 month follow-up period

Control group – 27% compulsorily detained in 15 month follow-up period

Reducing compulsory detention ... A role for personal health budgets?

Even with Joint Crisis Plans

❑ major choices available are limited: for most – acute admission or home treatment

❑ pressure on services means that both are often restricted to those who are already in crisis rather than early intervention to prevent the build up of a crisis

If personal health budgets were available in conjunction with Joint Crisis Plans

❑ possibility of intervening early to obviate the need for admission

❑ range of possibilities available could be increased:

But in the longer term ...

- The Mental Health Act is intrinsically discriminatory
- Contravenes Human Rights legislation – the United Nations Convention on the rights of disabled people (See Annual Report of the High Commissioner for Human Rights 2009)
  - 'respect for inherent human dignity and individual autonomy including the freedom to make one's own choices' (article 3)
  - 'enjoy legal capacity on an equal basis with others in all aspects of life' (article 12)
  - 'the existence of disability shall in no case justify a deprivation of liberty' (article 14)

The challenges

- Freeing up resources from existing services to make choices possible

- Integrating PHBs into other changes in NHS eg. Any qualified provider, PbR, CCGs etc

- Implementing necessary infrastructure without additional funding

- Keeping the implementation as simple as possible to limit bureaucracy

- Culture change for individuals and clinical professionals to enable real shared decision-making
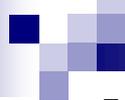
More fundamentally both recovery and personalisation require a different model for understanding the challenge...

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**
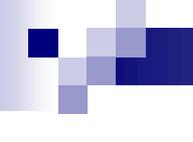
"It is society that disables people. It is attitudes, actions, assumptions – social, cultural and physical structures which disable by erecting barriers and imposing restrictions and options ... **The social model of disability is about nothing more complicated than a clear focus on the economic, environmental 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':**
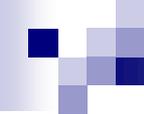
"All disabled people having the same choice, control and freedom as any other citizen – at home, at work and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves' but it does mean that any practical assistance people need should be based on their 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

Thank You
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