

Enabling Recovery for People with Complex Psychosis

Helen Killaspy

Professor and Honorary Consultant in Rehabilitation Psychiatry

University College London and

Camden & Islington NHS Foundation Trust, London

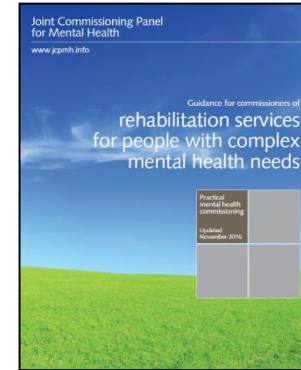
h.killaspy@ucl.ac.uk

Complex Psychosis

- **15-27% of people with first episode psychosis develop complex problems**
(Craig et al., 2004; Menezes et al., 2006; Friis, 2011)
 - Treatment resistant ‘positive’ symptoms, severe ‘negative’ symptoms
 - Cognitive impairments
 - Co-existing problems
 - intellectual disability/developmental disorder/trauma-attachment problems
 - physical health comorbidities, other mental health symptoms, substance misuse problems
- Severe difficulties in social and everyday **function (ADLs and community)**
- Highly **vulnerable** to self-neglect (49-72%) and exploitation (25-41%) (Killaspy et al., 2013; 2016)
- Long periods in hospital and high community support needs
- Absorb up to **50% of mental health/social care budget** (Mental Health Strategies, 2010)

The 'whole system' mental health rehabilitation pathway

*“A **whole system** approach to recovery from mental ill health which maximizes an individual’s **quality of life and social inclusion** by encouraging their skills, **promoting independence and autonomy** in order to give them **hope** for the future and which leads to **successful community living** through appropriate support.”*
 (Killaspy et al, 2005)



- Complex medication regimes
- Physical health
- OT – ADLs and occupation
- Psychosocial interventions
- Recovery orientation
- Therapeutic optimism
- Long term view

Referrals

- Acute inpatient wards (80%)*
- Forensic units (20%)

Inpatient and community rehabilitation units

Mental health supported accommodation

- Residential care
- Supported housing
- Floating outreach

Clinical Input

- Community Rehabilitation Teams
- Primary Care

Greater autonomy

> 10 years

1-3 years

> 5 years



Good evidence for rehabilitation care pathway

Most people with complex psychosis do well when they have access to a rehabilitation pathway (inpatient rehabilitation, supported accommodation services, community teams)

Case control study - Ireland

- **Lavelle et al (2012) – 5 centres**
 - 8 times more likely to be discharged from hospital than controls
 - Greater improvements in social and everyday functioning than controls

Cohort studies - England

- **Killaspy et al (2016) – REAL Study (50 inpatient rehabilitation units, >350 service users)**
 - 57% successfully discharged from inpatient rehabilitation services to supported accommodation within 2 years (+ 14% ready for d/c)
- **Killaspy et al (2018) – QuEST Study (90 supported accommodation services, >600 service users)**
 - 38% progressed successfully to more independent accommodation over 30 months
- **Killaspy and Zis (2012) – North London**
 - 67% sustained successful community discharge over five years
 - NB - only 10% achieve fully independent accommodation

Drivers of better outcomes in mental health rehabilitation

Predictors of outcome	OR (95% CI)	Study
Successful discharge from hospital associated with greater:		
• social skills	1.13 (1.04 to 1.24)	REAL
• engagement in activities	1.04 (1.01 to 1.08)	
• recovery orientation of service	1.03 (1.01 to 1.05)	
Successful move on to more independent accommodation associated with greater:		
• human rights promotion of service	1.09 (1.02 to 1.16)	QuEST
• recovery orientation of service	1.06 (1.00 to 1.11)	

Recovery orientation domain

- Therapeutic optimism
- Expected maximum length of stay
- Collaborative, individualised care planning
- Strengths based approach
- Supporting the person to gain/regain ADL skills
- Service user involvement in running the service
- Ex-service users employed in the service

Human rights domain

- Access to legal representative
- Access to advocate
- Assistance to vote in elections
- Privacy/dignity
- Confidential case notes
- Access to communication (phone, email)
- Complaints procedures



Cost benefits of rehabilitation services

Bunyan et al. *BJPsych Bull* 2016; 40:24-28

22 people discharged from inpatient rehabilitation unit

Mean (SE) bed days 2 year prior to inpatient rehabilitation = 380 (56) = £66,000/yr

Mean (SE) bed days 2 years after inpatient rehabilitation = 111 (52) = £18,000/yr

Mean (SE) bed days on rehabilitation unit = 700 (385) = £74,000/yr

Extrapolation

100 people with complex mental health needs

10 year trajectory (3 years before rehab, 2 years in rehab unit, 5 years post rehab)

67/100 do well @ cost ~ **£30m**

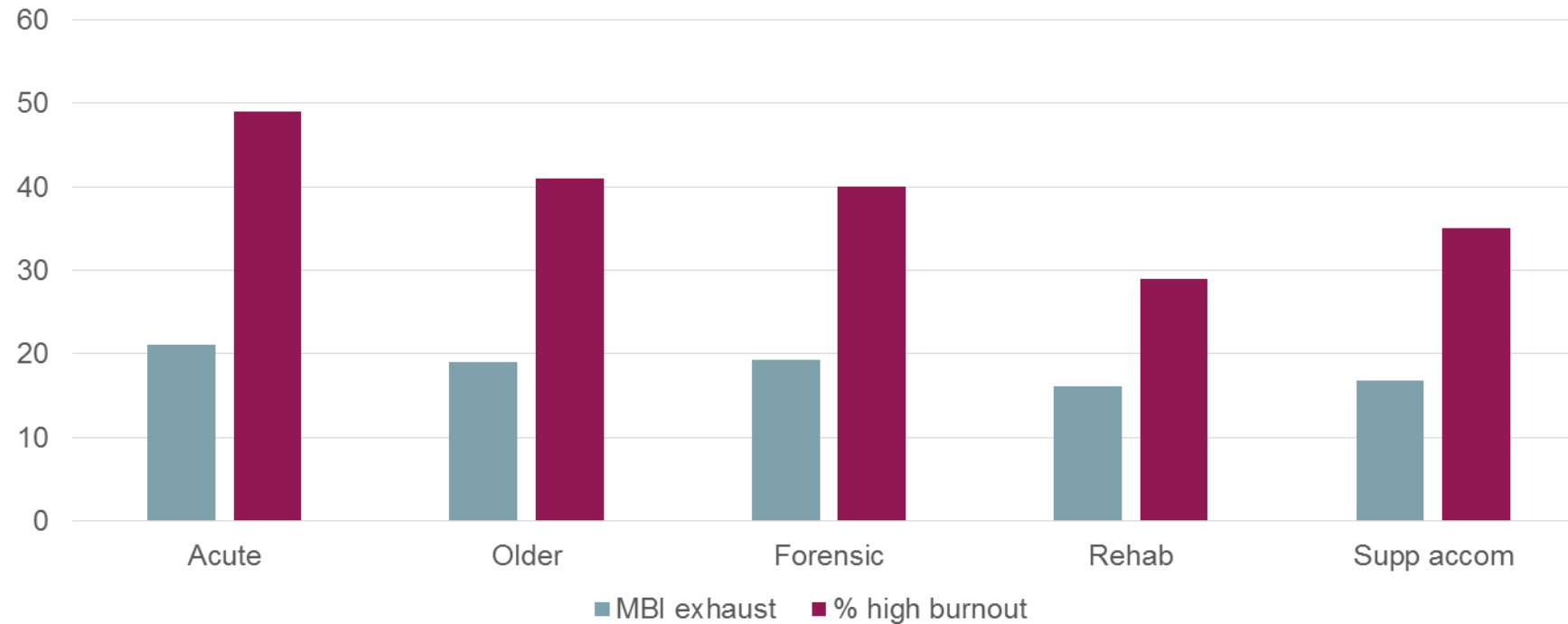
33/100 don't do well @ cost ~ **£22m**

Total cost for 100 people with rehabilitation services in place ~ £52m

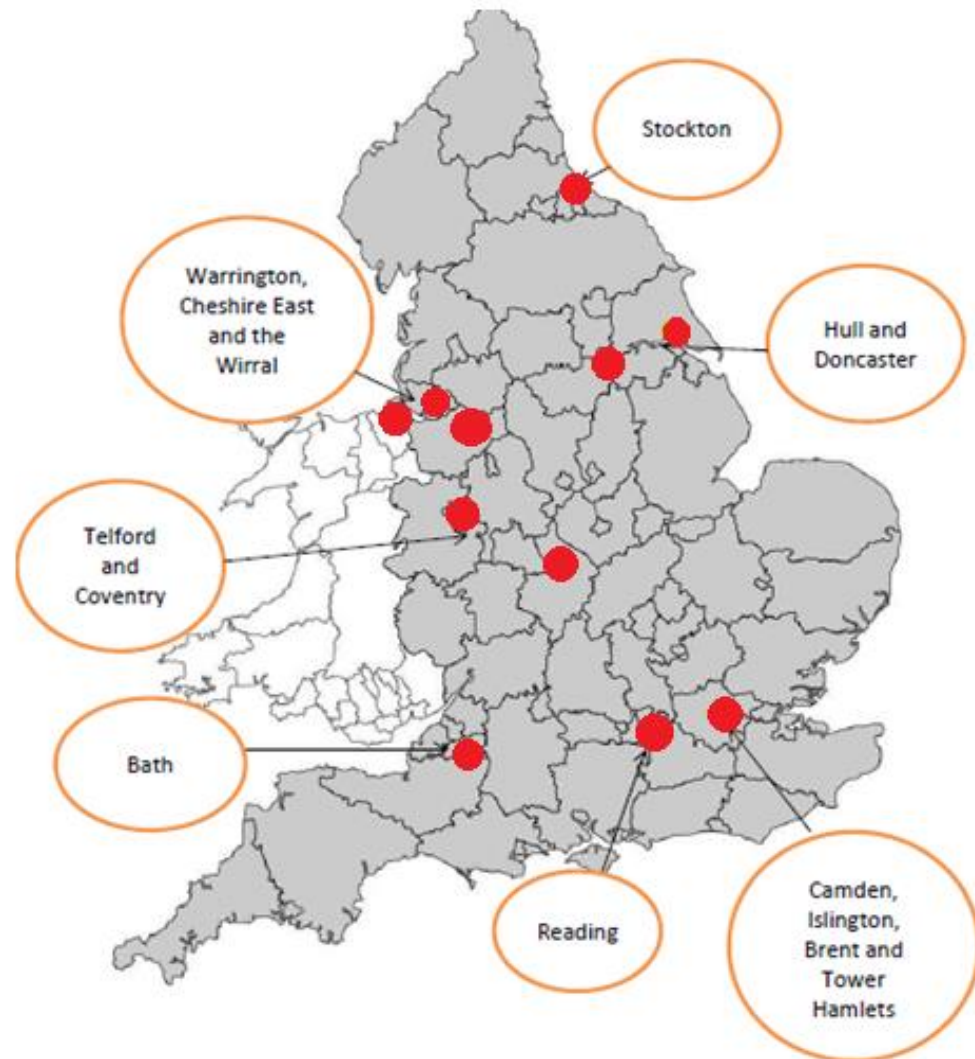
Total cost for 100 people with no rehabilitation services in place ~ £66m

Staff morale: mental health inpatient wards and supported accommodation* staff across England

Johnson et al, *BJPsych* 2012; *Dowling, PhD thesis (2020)



Mental healthcare services in England



Mapping Local Service Delivery in 14 Local Authorities in England

Residential Care

22/28 Services

Supported Housing

35/85 Services

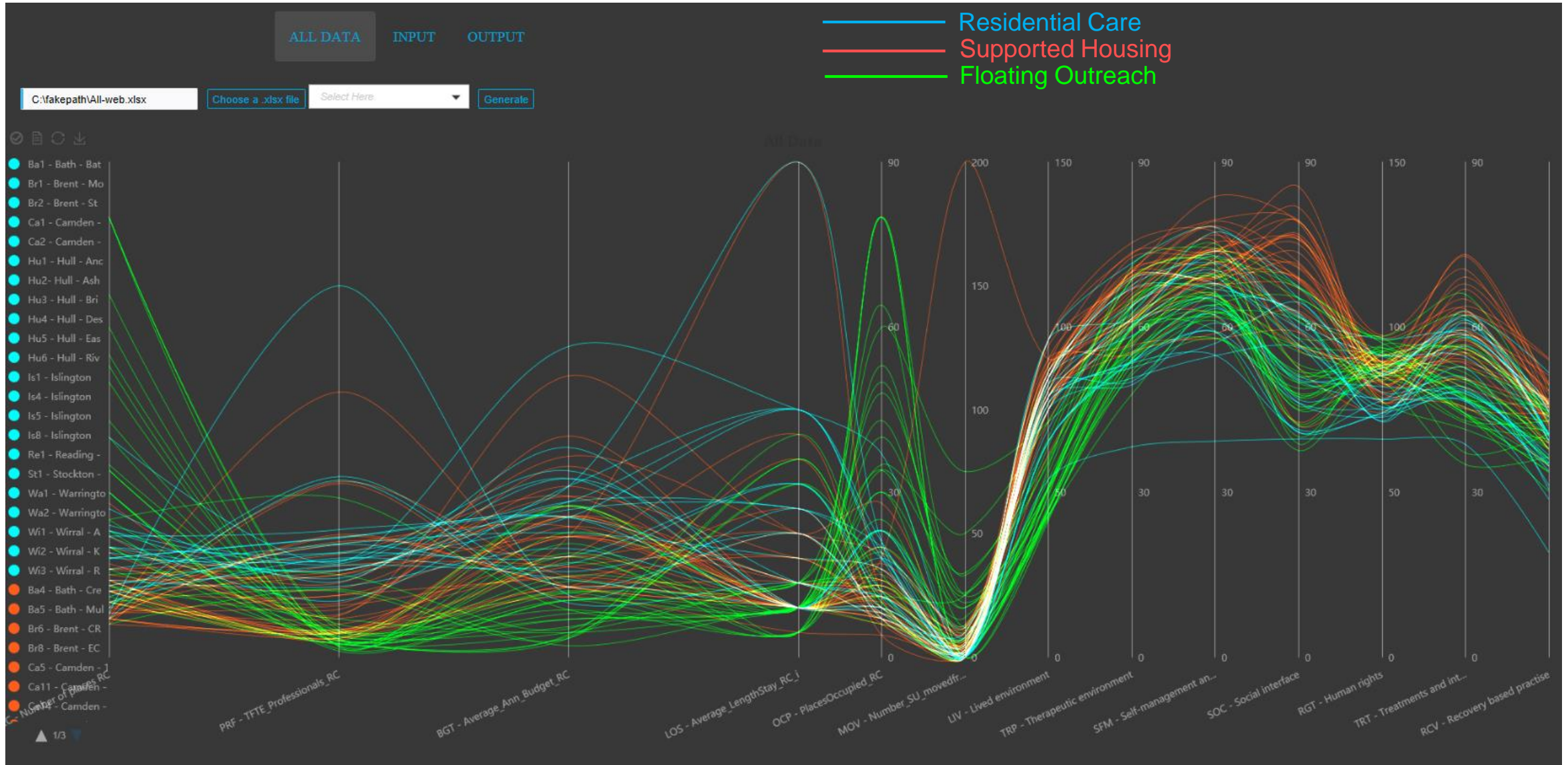
Floating Outreach

30/35 Services

In order to support evidence-informed decision-making process for better resource provision and care delivery:

- Understand service patterns using visual analytics approaches; and
- Analyse relative technical efficiency of services.

Visual analytics 1 – parallel coordinates for indicators



Visual analytics 2 – hierarchical clustering for services

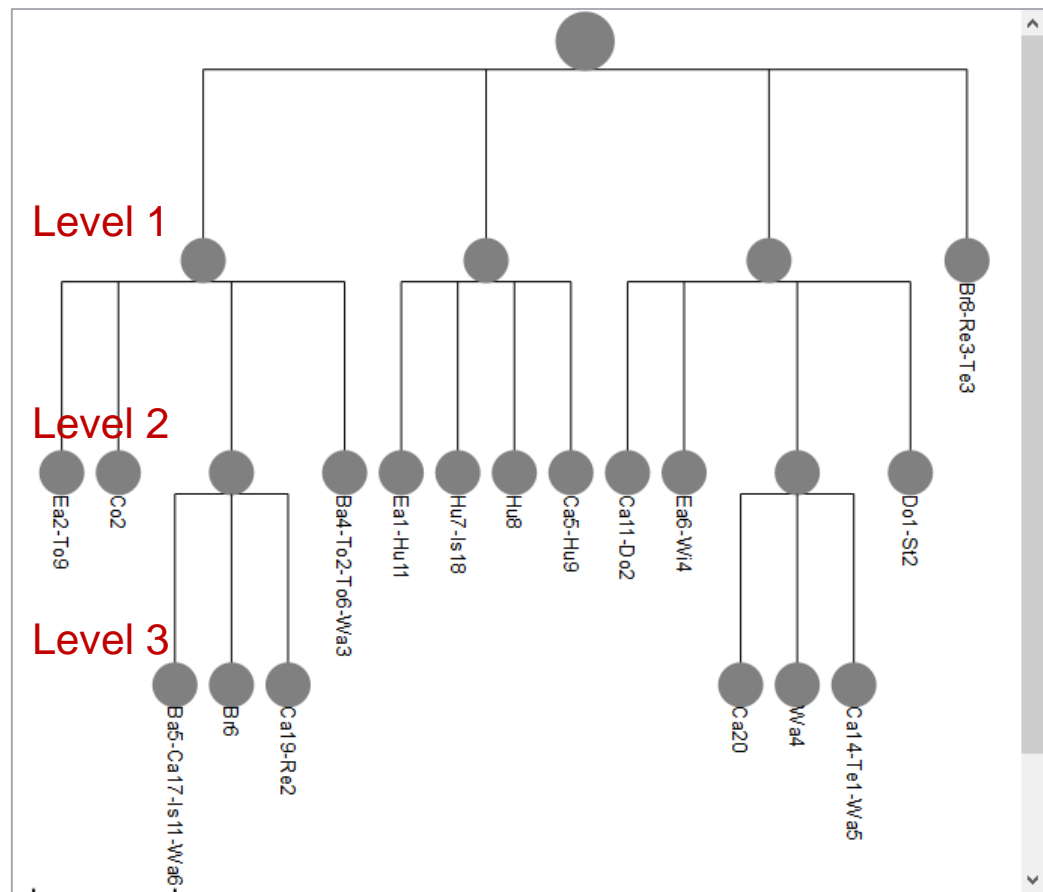
Visual Analytics and Decision Support Tool

File Run About



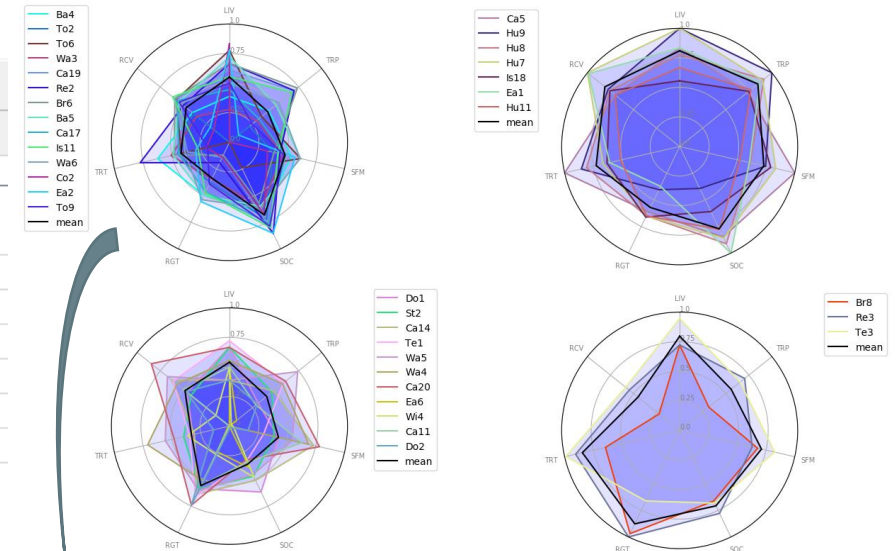
Supported Housing Services

View data View selected data View cluster tree



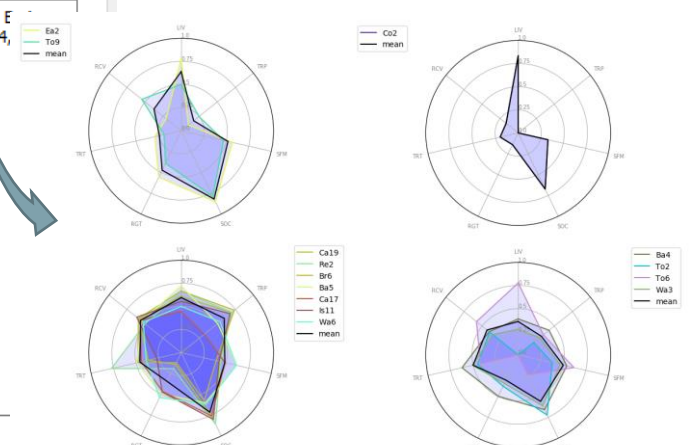
Variable	Min	Max
LIV	0.0	1.0
TRP	0.0	1.0
SFM	0.0	1.0
SOC	0.0	1.0
RGT	0.0	1.0
TRT	0.0	1.0
RCV	0.0	1.0

Level 1



Level 2 of Level 1.1

To9, Ea2, Co2, Wa6, Is11, Ca17, Ba5, Br6, Re2, Ca19, Wa3, To6, To2, F, Hu11, Ea1, Is18, Hu7, Hu8, Hu9, Ca5, Do2, Ca11, Wi4, Ea6, Ca20, Wa4, Te1, Ca14, St2, Do1, Te3, Re3, Br8



Reductions in NHS mental health rehabilitation services (Royal College of Psychiatrists' Rehabilitation Faculty surveys)

Since 2003:

- 61% of UK NHS inpatient rehabilitation services report **disinvestment**
- Around **half of all NHS rehabilitation units closed** (~75)
- **Shift in provision** to supported accommodation services with clinical input from community teams
- Increased implementation of **community rehabilitation teams** (from 15% to 51% of NHS Trusts)
- **Expansion** of inpatient rehabilitation services in the **independent sector**

Care Quality Commission, 2018

Comprehensive inspections of all mental health providers 2014-2017

There are a 'high number of people in 'locked rehabilitation wards'. 'These wards are often situated a long way from the patient's home....In a number of cases we found that these hospitals did not employ staff with the right skills to provide the high-quality, intensive rehabilitation care required to support recovery.'

- 5000 rehabilitation beds
- > 50% in private sector
- Total cost > £500m
- Length of stay and cost in private sector = **twice** local NHS rehabilitation services

'Too often, these...rehabilitation hospitals are in fact long stay wards that institutionalise patients, rather than a step on the road back to a more independent life in the person's home community.'



The myth of deinstitutionalisation in England

BMJ 2017;358:j4279 doi: 10.1136/bmj.j4279 (Published 2017 September 27)

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ANALYSIS

Figures

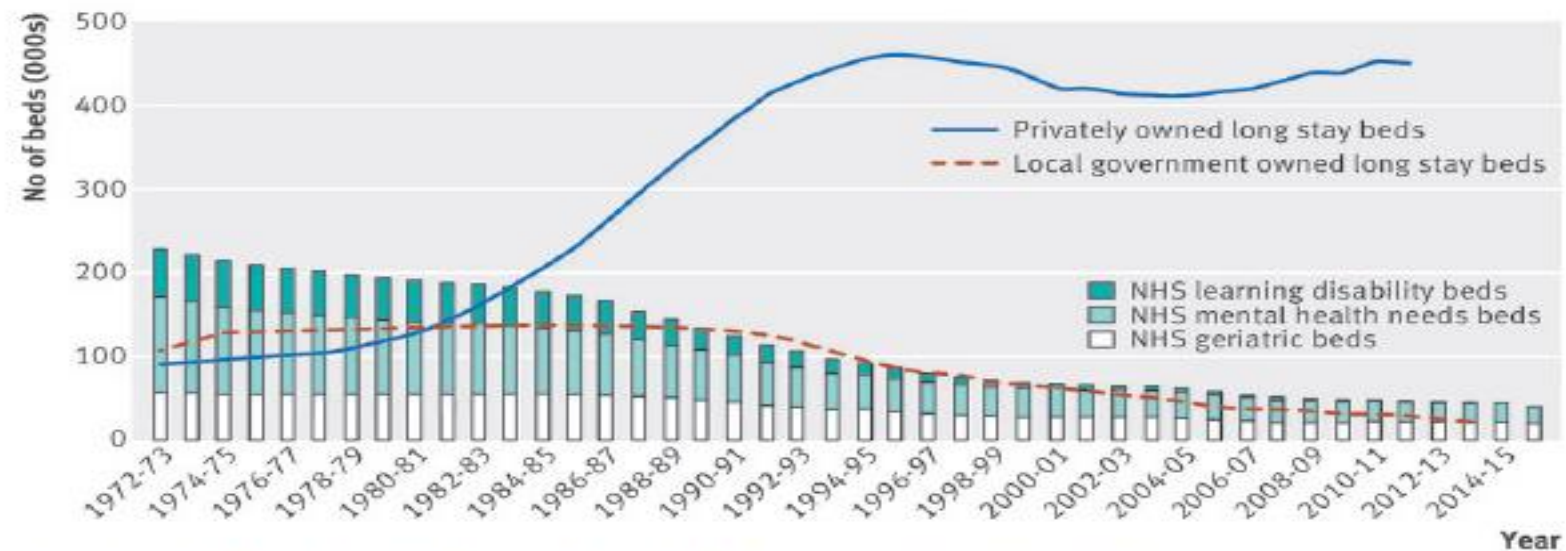
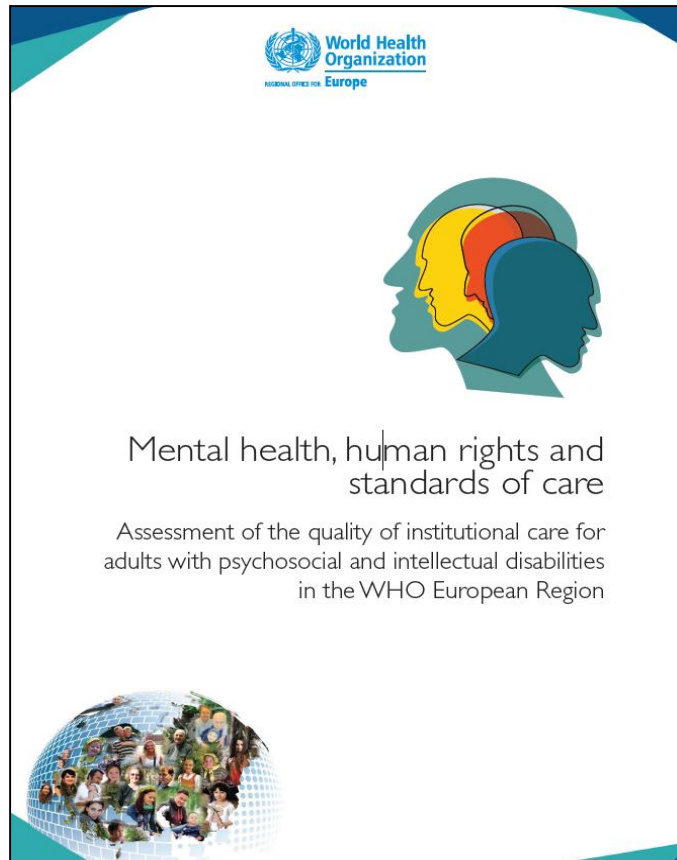


Fig 1 Average daily number of NHS geriatric, mental health needs, and learning disability beds and number of available long term beds by provider, 1972-73 to 2015-16 (data from Health and Social Care Information Centre and LaingBuisson Care of older people UK market report, 27th ed)

Sutaria, Roderick, Pollock et al,
BMJ, 2017, 358; j4279

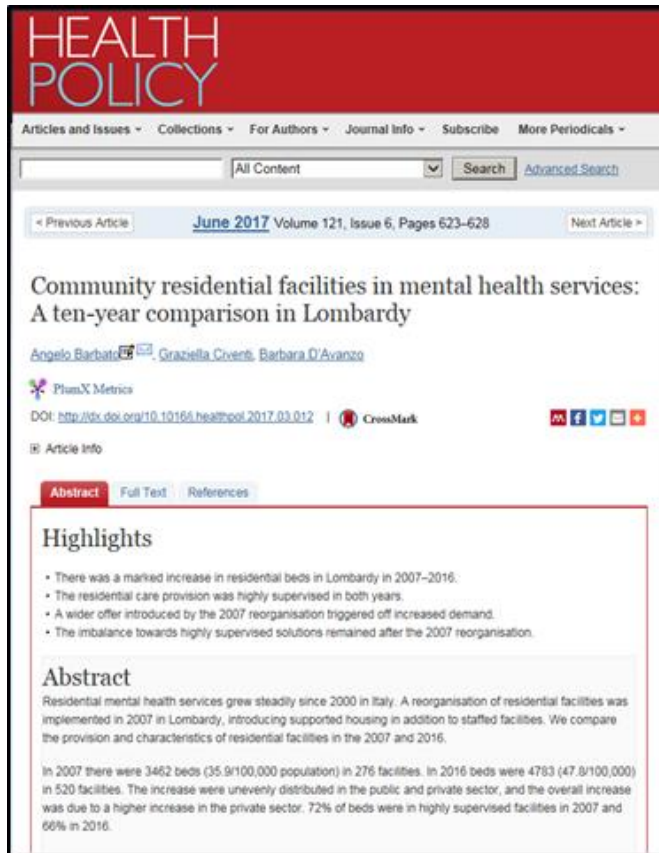
WHO 'Quality Rights' Survey: longer term mental health facilities in 25 European countries (WHO, 2018)



- Lack of knowledge about mental health and the protection of human rights
- Lack of a personalised approach to care
- Lack of rehabilitative activities
- Lack of legal provisions or legal representation
- Lack of community alternatives for move-on

Albania, Armenia, **Austria**, Azerbaijan, **Belgium**, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, **Denmark**, Estonia, **Finland**, Georgia, **Germany**, Hungary, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, **Luxembourg**, Poland, **Portugal**, Republic of Moldova, Romania, Serbia, Slovakia, Slovenia, **Switzerland**, the former Yugoslav Republic of Macedonia, Turkmenistan, Ukraine

Tendency towards institutionalisation, even in community settings



The screenshot shows the journal page for the article 'Community residential facilities in mental health services: A ten-year comparison in Lombardy' by Angelo Barbato, Graziella Cavers, and Barbara D'Avanzo. The page includes a search bar, navigation links, and a 'Highlights' section with the following points:

- There was a marked increase in residential beds in Lombardy in 2007–2016.
- The residential care provision was highly supervised in both years.
- A wider offer introduced by the 2007 reorganisation triggered off increased demand.
- The imbalance towards highly supervised solutions remained after the 2007 reorganisation.

The abstract states: 'Residential mental health services grew steadily since 2000 in Italy. A reorganisation of residential facilities was implemented in 2007 in Lombardy, introducing supported housing in addition to staffed facilities. We compare the provision and characteristics of residential facilities in the 2007 and 2016. In 2007 there were 3462 beds (35.9/100,000 population) in 276 facilities. In 2016 beds were 4783 (47.8/100,000) in 520 facilities. The increase were unevenly distributed in the public and private sector, and the overall increase was due to a higher increase in the private sector. 72% of beds were in highly supervised facilities in 2007 and 66% in 2016.'

Italy: survey of 'community residences' in Lombardy, Italy (Barbato et al, *Health Policy*, 2017)

- Last 10 years - 88% increase in community residences (276 to 520) and 38% increase in number of places (from 3462 to 4783)
- Most expansion in private sector (care vs treatment)
- Concerns about lack of rehabilitative and recovery ethos

Inadequate community care

Australia - Survey of High Impact Psychosis

(Morgan et al, *ANZJP*, 2016)


- Few inpatient services, increasing involvement of NGOs in providing community care
- Sub-optimal treatment
 - Polypharmacy (63%)
 - Under use of clozapine, employment support and other evidence based psychosocial interventions
 - Poor physical health and low access to physical healthcare
 - High rates of social isolation
 - Increasing levels of homelessness

ANZJP 50
1967-2017

Australian & New Zealand Journal of Psychiatry
2017, Vol. 51(2) 124-140
DOI: 10.1177/0004867416679738

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SAGE



Key Review

Responding to challenges for people with psychotic illness: Updated evidence from the Survey of High Impact Psychosis

Vera A Morgan^{1,2}, Anna Waterreus¹, Vaughan Carr^{3,4,5}, David Castle^{6,7}, Martin Cohen^{8,9}, Carol Harvey⁷, Cherrie Galletly^{10,11,12}, Andrew Mackinnon^{13,14}, Patrick McGorry¹⁵, John J McGrath^{16,17}, Amanda L Neil¹⁸, Suzy Saw¹⁹, Johanna C Badcock^{2,20}, Debra L Foley²¹, Geoff Waghorn¹⁷, Sarah Coker²² and Assen Jablensky^{2,20}

Abstract

Objective: The objective is to summarise recent findings from the 2010 Australian Survey of High Impact Psychosis (SHIP) and examine their implications for future policy and planning to improve mental health, physical health and other circumstances of people with a psychotic disorder.

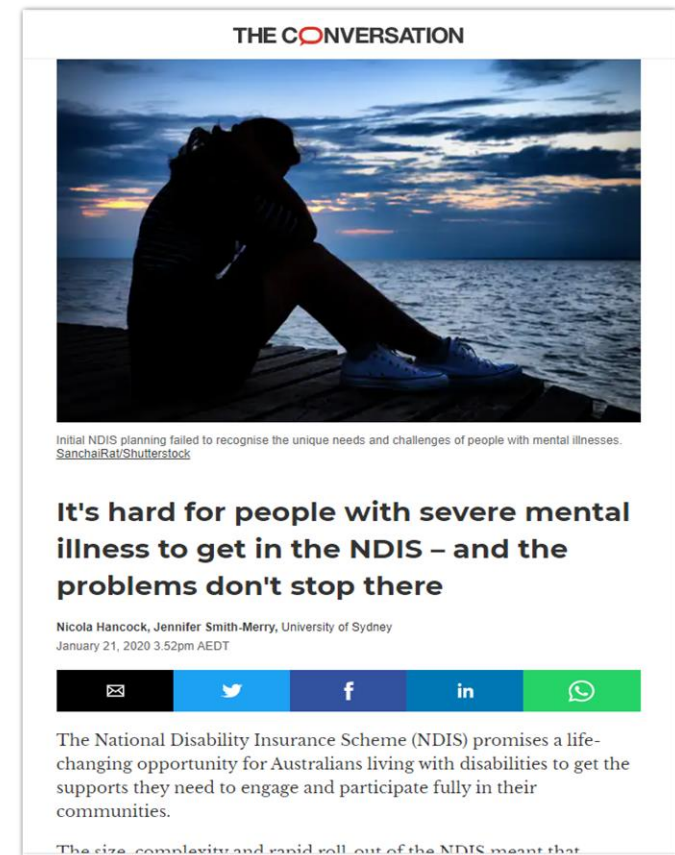
Methods: Survey of High Impact Psychosis collected nationally representative data on 1825 people with psychotic illness. Over 60 papers have been published covering key challenges reported by participants: financial problems, loneliness

¹Neuropsychiatric Epidemiology Research Unit, School of Psychiatry and Clinical Neurosciences, The University of Western Australia, Crawley, WA, Australia
²Centre for Clinical Research in Neuropsychiatry, School of Psychiatry and Clinical Neurosciences, The University of Western Australia, Crawley, WA, Australia
³Research Unit for Schizophrenia Epidemiology, School of Psychiatry, University of New South Wales, Sydney, NSW, Australia
⁴Schizophrenia Research Institute and Neuroscience Research Australia, Sydney, NSW, Australia
⁵Department of Psychiatry, University of Melbourne, Melbourne, VIC, Australia

Discriminatory welfare benefits systems



UK Govt data on 327,000 people who switched from DLA to PIP between 2013 and 2016: People with a mental health condition were 2.4 times more likely than those with diabetes, back pain or epilepsy to lose their entitlement.



Why are people with complex mental health needs so often marginalised?

Missing from policy

- Recent mental health policy has focussed on **public mental health promotion and early intervention**
- **Factors associated with developing more complex needs** are well known (pre/perinatal 'soft' brain injury, male, younger age of onset, insidious onset, severe negative symptoms, multiple co-morbidities) but most are **not amenable to this policy focus**
- By definition, those with complex needs require **longer term, specialist** approach that undermines aspirations of public health promotion and early intervention
- **Lack of service user/carer voice**
- Lack of acknowledgment of this group in policy has been **highly detrimental**



Barriers to appropriate service planning

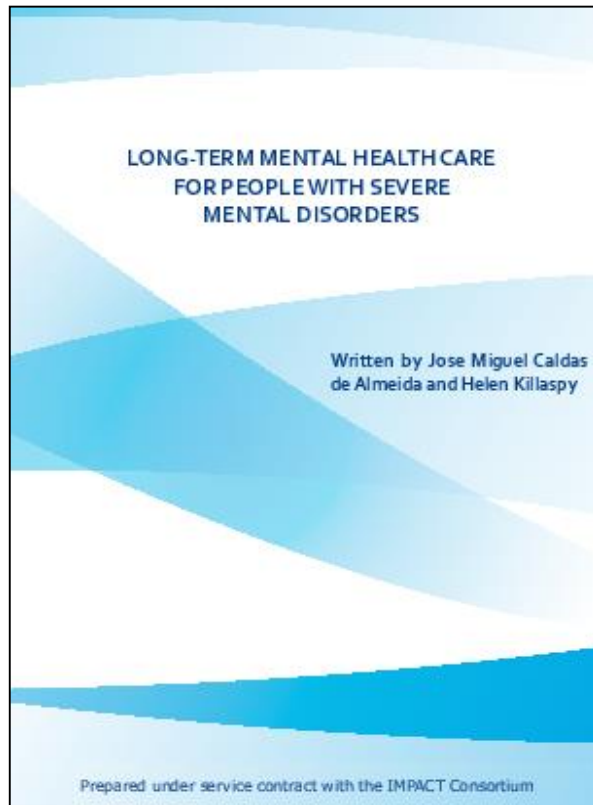
- **Service planners work to annual financial cycles** vs longer term planning
- **Economic constraints** - cuts and shifts towards 'cheaper' options
- **Cost shunting** - (in UK, from NHS Trusts to commissioning bodies)
- **Poor oversight of the whole system** and need for longer term pathway

Impact

- **Lack of specialist rehabilitation skills in local mental health services**
- **Inadequate treatment** and community support
- **Vicious cycle** of (re)institutionalisation
- **'As close to home'** and **'least restrictive'** treatment principles undermined

Successful deinstitutionalisation includes provision of specialist services for those with the most complex needs

(Caldas de Almeida and Killaspy, 2011)



- **Balance** of community and inpatient **services** (Thornicroft & Tansella, 2004)
- **Specialist inpatient and community rehabilitation for complex needs**
- **Primary care liaison**
- Access to **physical health care**
- **Supported housing** and **vocational rehabilitation**
- Staff training, including **recovery** approaches
- Address **stigma** and **social exclusion**
- Service user **participation**
- Support and inclusion of **families**
- Promotion of **research**

Adequate investment is vital

Taylor et al, *BJPsych*, 2017

- 171 longer term inpatient and community based mental health facilities in 8 European countries, 1471 service users
- % national health budget spent on mental health **positively associated with quality of longer term care and service user autonomy and satisfaction with care**
- Increase % national health budget spent on mental health to **10%**, quality of longer term care increased above pan-European average in all countries

BJPsych
The British Journal of Psychiatry
1-5. doi: 10.1192/bjp.bp.116.186213

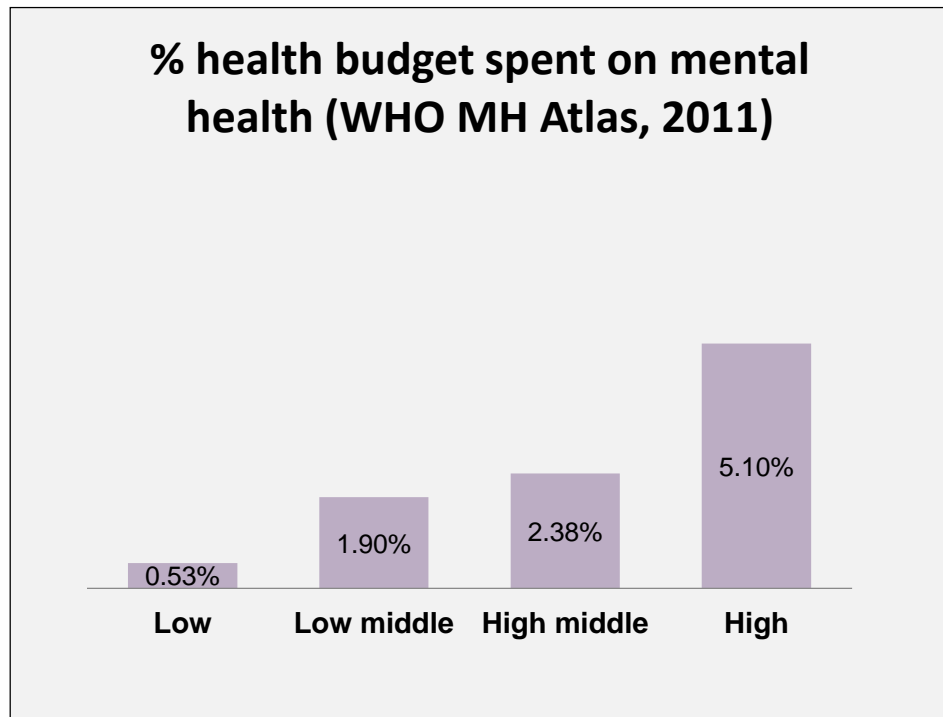
Relationship between national mental health expenditure and quality of care in longer-term psychiatric and social care facilities in Europe: cross-sectional study

Tatiana Taylor Salisbury, Helen Killaspy and Michael King

<p>Background It is not known whether increased mental health expenditure is associated with better outcomes.</p> <p>Aims To estimate the association between national mental health expenditure and (a) quality of longer-term mental healthcare; (b) service users' ratings of that care in eight European countries.</p> <p>Method National mental health expenditure (per cent of health budget spent on mental health) was calculated from international sources. Multilevel models were developed to assess associations with quality of care and service user experiences of care using ratings of 171 facility managers and 1429 service users.</p>	<p>Results Significant positive associations were found between mental health spend and (a) six of seven quality of care domains; and (b) service user autonomy and experiences of care.</p> <p>Conclusions Greater national mental health expenditure was associated with higher quality of care and better service user experience.</p> <p>Declaration of interest None.</p> <p>Copyright and usage © The Royal College of Psychiatrists 2017.</p>
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In its report entitled *Mental Health: New Understanding, New Hope*, the World Health Organization (WHO) highlights the need to prioritise mental health and the need to increase expenditure on promotion, prevention and treatment.¹ More recently, mental health has been included in the Sustainable Development Goals as one of the key health priorities.² Previous research examining the mental health facility expenditure and the quality of care they provide suggest a positive association.³ However, it is unclear whether or not greater mental health expenditure at the national level trickles down to better outcomes. The development of the Quality Indicator for Rehabilitative Care (QuIRC), the first internationally standardised tool to assess the quality of care provided in longer-term mental health facilities,⁴ has made it possible to estimate the relationship between national mental health expenditure and quality of care in longer-term mental health facilities. Facilities providing care exclusively to a specific subgroup of service users (for example older people, individuals with intellectual disabilities, patients in forensic settings) were excluded. Facility managers and a random sample of 5-13 service users in each facility participated in face-to-face interviews with a DEMoBinc researcher after providing informed consent to take part in the study. Service users were excluded only if they were not available at the time the researcher was recruiting participants, lacked mental capacity to provide informed consent or were unable to complete the interview. A detailed description of the sampling process is provided by Killaspy and colleagues.⁴ The DEMoBinc project was approved by the relevant ethics committee in each country (see online supplement DS1 for details).

Investment and availability of community mental health care



In 2011, worldwide, the median % of a country's health budget allocated to mental health was 2.8% (MH Atlas, 2011)

Key drivers required to deliver a whole system approach to mental health rehabilitation

- 1. Supportive policy**
- 2. Service planning principles**
- 3. Clinical Guidelines**
- 4. Integrated systems (health, social care and voluntary sector)**

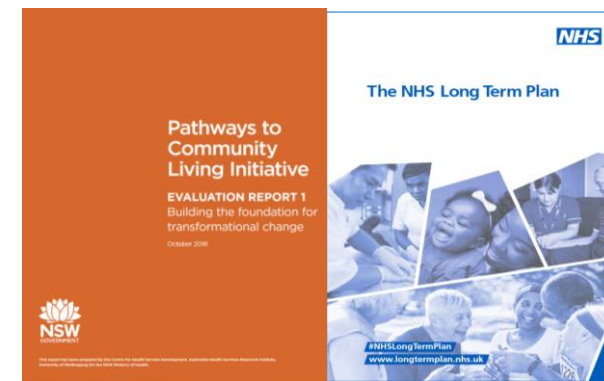
Key driver 1. Recent policy developments

England

- **NHS policy 2020** (NHS Long Term Plan): New integrated models of primary and community mental health care will include *‘maintaining and developing new services for people with the most complex needs’*
- National initiative to encourage development of local rehabilitation services (*Getting It Right First Time*)

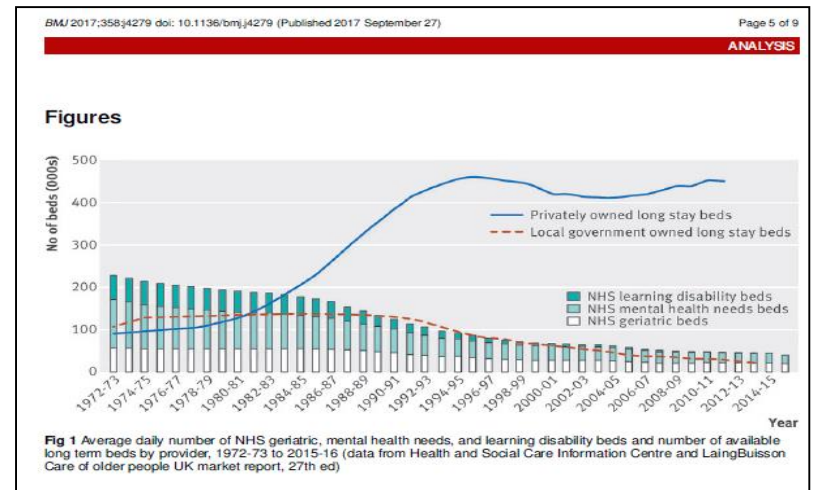
Australia

- RANZCP Section of Social, Cultural and Rehabilitation Psychiatry
- Australian Section - World Association of Psychosocial Rehabilitation
- Pathways to Community Living Initiative (NSW)



Key driver 2. Service planning principles

- Mental health systems **should include local rehabilitation services** for those with the most **complex needs**
- Rehabilitation takes time - need **long term service planning** for this group
 - Adjust procurement cycles
- **Avoid perverse incentives/financing structures** that lead to cost shunting, institutionalisation, reinstitutionalisation and marginalisation
 - Beware market forces
 - Resist economic pressures to cut longer term services
- **Be wary of fashionable trends**
- need both inpatient and community services
i.e. balanced care model (Thornicroft & Tansella, 2004)



Key driver 3. Clinical Guidelines

- In England and Wales, commissioners are accountable for contracting services that can deliver the treatments and interventions recommended by **NICE** (National Institute for Health and Care Excellence)
- Service providers are responsible for delivering them
- Commissioners and providers can be challenged about threats to existing services and lack of local provision

The first NICE Guideline for Mental Health Rehabilitation

Rehabilitation in adults with complex psychosis and other severe mental health conditions

In scope

- Primary diagnosis of psychosis **plus**
- Severe, treatment refractory symptoms (positive and negative) **and/or**
- Comorbid conditions (mild/borderline ID, developmental disorders, other mental health conditions, physical health conditions, substance misuse) **and**
- Impaired function - ADLs, interpersonal and occupational

Out of scope

- Primary diagnosis of common mental disorder (depression without psychosis, anxiety), personality disorder, obsessive compulsive disorder, eating disorder, substance misuse problems, or moderate to severe ID

Mental Health Rehabilitation NICE Guideline - areas covered

- **Identifying people** who would benefit most from mental health rehabilitation services
- **Organisation, function and structure of services** (inpatient and community rehabilitation units and community rehabilitation teams, supported accommodation)
- **Delivering optimised treatments** for people with complex psychosis and other severe mental health conditions to help recovery and prevent relapse
- **Collaborative care planning** and improving **service user and carer experience**
- **Therapeutic programmes specific to rehabilitation:**
 - activities of daily living (self-care, cooking, cleaning, shopping, budgeting, maintaining a tenancy)
 - interpersonal functioning and social skills
 - vocational rehabilitation (leisure, education and work)
 - healthy living (diet, weight, exercise, sleep, oral health, health monitoring, accessing health services, self-medication programmes, cessation programmes for smoking and substance misuse)
- Types of **supported accommodation** – features that promote successful community living
- Criteria and processes relating to **transition from rehabilitation services** to other parts of the mental health system or primary care

Key driver 4. Integrated systems

- **Integrated Care Systems** are all the rage in England!
- Aim to **encourage localism** and adapt resources to community needs
- Mental health services are **more advanced** with regard to integrating systems than physical health services
- **Organisational level** – shared vision/strategy, shared health and social care budgets – shared financial risks
- **Service level** – much less clear but key operational elements:
 - Clarity regarding each partner's remit and responsibilities
 - Regular interface meetings to discuss individual service users' transitions through the pathway, avoid silo thinking, build on the shared vision, avoid boundary disputes and cost shunting, support each other

Integrated rehabilitation service models – the way forward or a fashionable trend?

Tile House - an innovative partnership between statutory and non-statutory services

- 24 hour supported accommodation (sleeping night staff)
- Building and support staff provided by voluntary organisation
- 12 individual, self-contained one bedroom flats
- Clinical staff provided by NHS mental health Trust:
1.0 nurse, 0.025 psychiatrist, 0.2 psychologist, 0.4 OT
- Clients have tenancies and pay rent through housing benefit
- Clinical staff employed by NHS Trust (protects their pension and employment rights, access to CPD etc)



Tile House

Benefits

- Promotes common values and language
- Complementary staff skills and strengths
- Shared learning
- Greater and broader collaborative care planning with service users
- Enables clients with very complex needs to live successfully outside hospital
- Part funded by repatriation of people placed in out of area beds

Challenges

- Gatekeeping – who decides?
- Tensions between clinicians and non-clinicians in agreeing appropriate response to challenging behaviour
- Tensions in understanding the boundaries/remit of each others' roles
- Practical issues – lack of access to NHS electronic records
- Isolating for clinicians
- Expensive
- Lack of move-on and many relapses

Alternative approach to integration – community rehabilitation teams

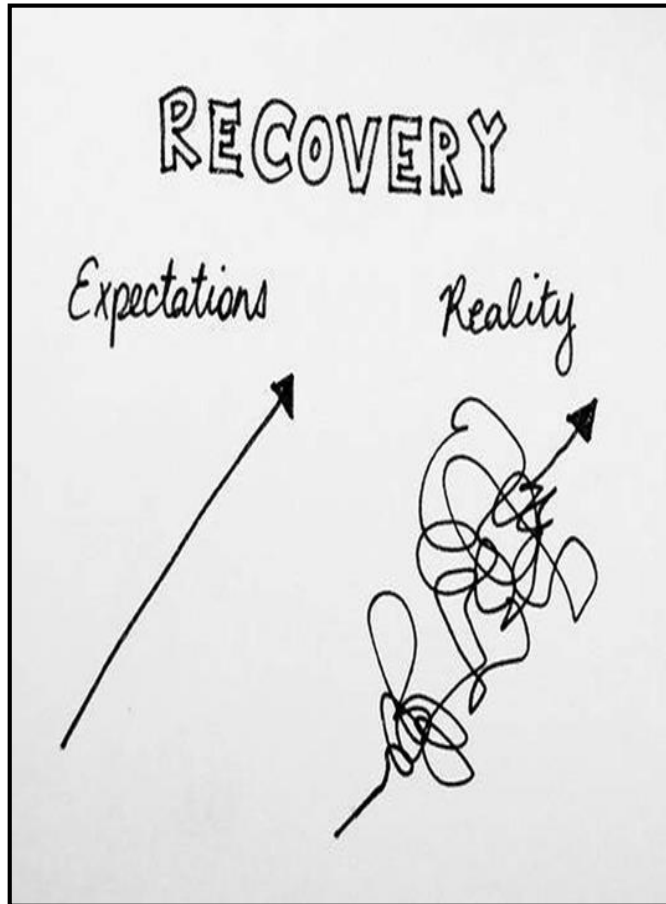
MDT with specialist rehabilitation skills and clear remit

- Care co-ordination of people with complex psychosis
- Hold health and social care statutory responsibilities – Care Programme Approach, S117 Aftercare, Safeguarding etc
- Proactively engage with inpatient, forensic and out of area services
- Liaison and in-reach to supported accommodation services
- In-vivo working with service users (and carers)
- Support supported accommodation service staff
- Liaison with primary/secondary physical health
- Facilitate ‘move-on’ through the whole rehabilitation care pathway

Summary

Enabling recovery for people with complex psychosis requires a whole system approach that includes:

- **Adequate** financial **investment** in mental health services
- **Acknowledgment** of the fact that some people have complex needs
- Commitment to **providing** adequate, **appropriate, longer term services** that can support people's recovery
- **Inpatient and community based** rehabilitation services
- **Health, social care and voluntary sector** working well together
- Appropriately trained and supervised, **recovery orientated staff**
- **Hypervigilance** on everyone's part to avoid systems and practices that lead to institutionalisation and marginalisation



**Don't forget to hold
the long term view!**

**Many thanks
for your attention
h.killaspy@ucl.ac.uk**

