Complex individuals in a complex society; how complex needs services should be the quality benchmark for mental health care

Helen Killaspy

Professor and Honorary Consultant in Rehabilitation Psychiatry

University College London and

Camden & Islington NHS Foundation Trust, London

h.killaspy@ucl.ac.uk

The origins of the asylums

- Stow's 1720 Survey of the Cities of London and Westminster:

"*those that are raving and furious and capable of Cure: or, if not, yet are likely to do mischief to themselves or others: and are Poor and cannot be otherwise provided for.*"

- By mid 1900's – hundreds of thousands of people across the world were living in asylums

The origins of community mental health care (UK)

19th Century

- **1808** – **Wynn's Act** 'for the ***better care*** and maintenance of lunatics being paupers or criminals'
- **1845** – **Shaftesbury Acts** 'for the ***regulation of the care and treatment*** of lunatics'
- **1890** – **Lunacy Act** established admission criteria (97% certified)

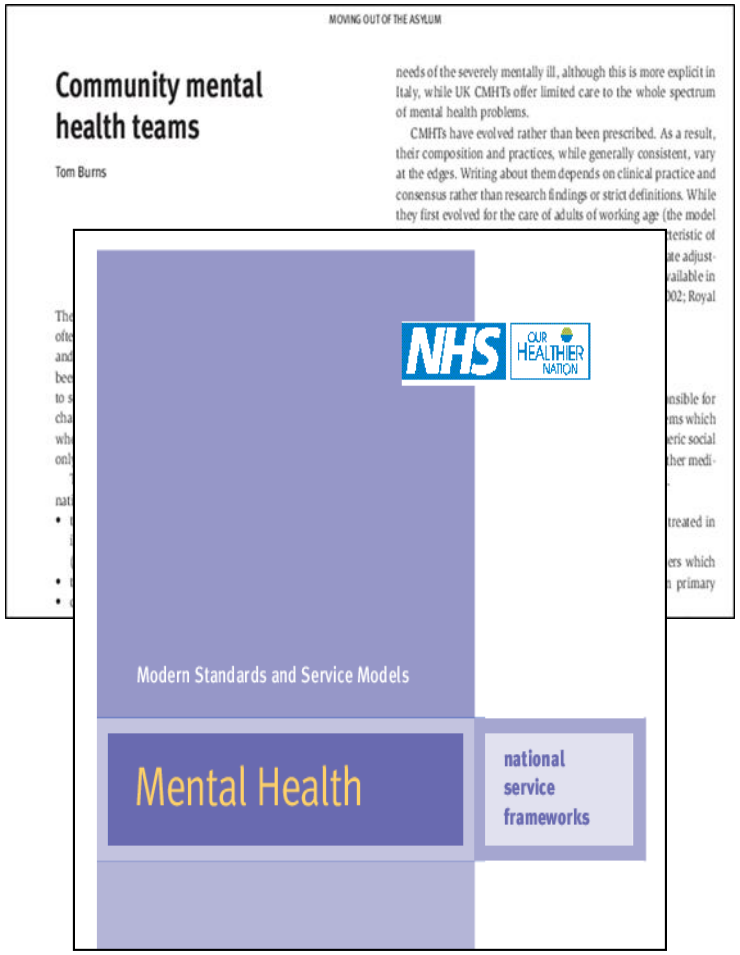
20th Century

- **1930** – **Mental Treatment Act** - extended voluntary admission to asylums as well as 'registered' hospitals.

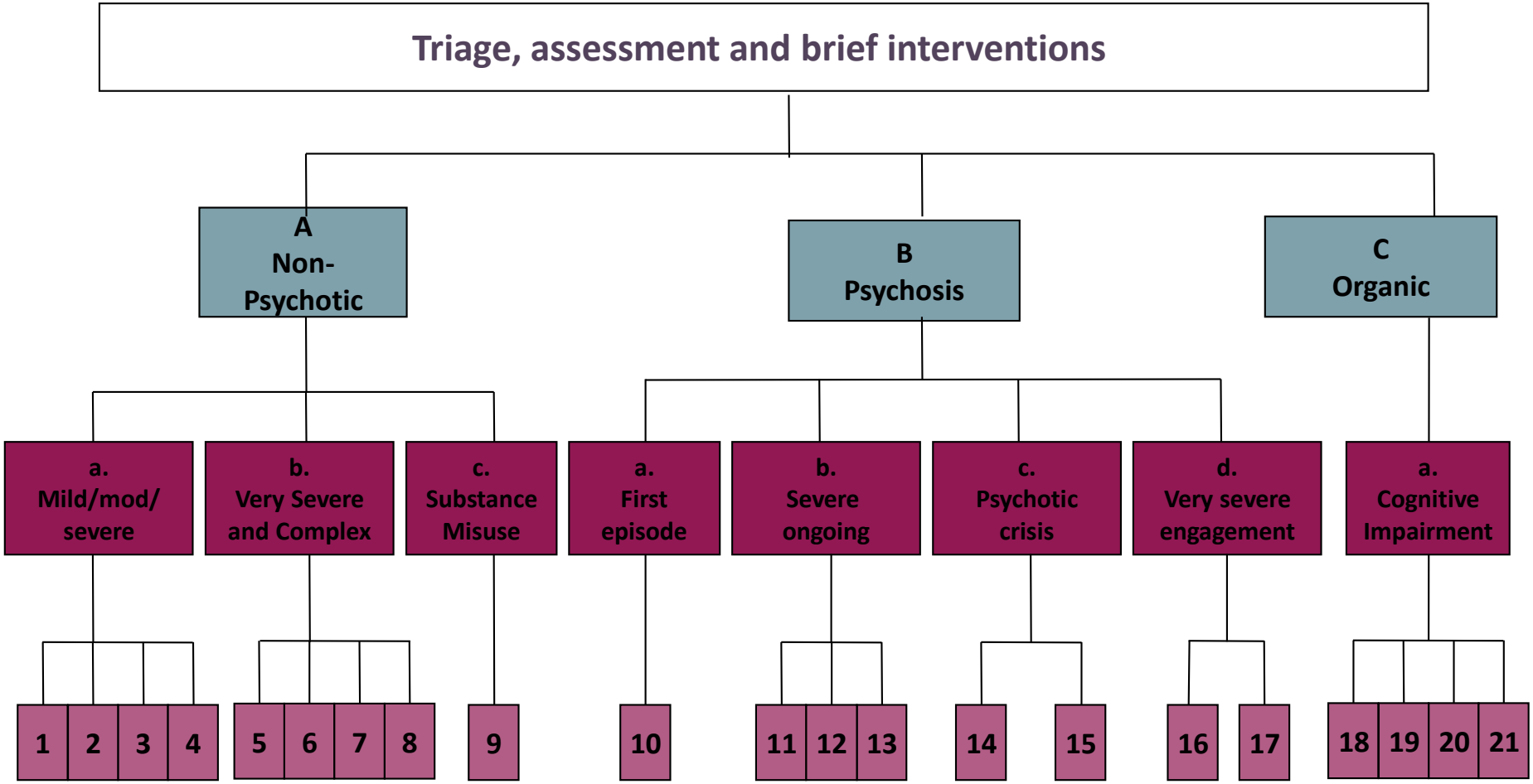
  - established outpatient clinics to assess patients' suitability for voluntary admission
- **1946** - NHS established – funding responsibility for asylums
- **1950's** – phenothiazine drugs

Development of community mental health care

- **1970s** on….addition of community nurses to outpatient clinics ⇒ development of **Community Mental Health Teams**
- **2000s - increasing specialisation**
  - Crisis resolution teams
  - Early intervention for psychosis
  - Assertive community treatment
- **2010s - super specialisation**
  - Personality disorder services
  - Post-traumatic stress services
  - Developmental disorder services
  - Inpatient specialists



Tariff based models; service by diagnosis and need



Specialisation and continuity of care

EDITORIAL
Killaspy Commentary on . . . How did we let it come to this?

Importance of specialisation in psychiatric services

Commentary on . . . How did we let it come to this?†

Helen Killaspy[1]

The Psychiatrist (2012), 36, 364–365, doi: 10.1192/pb.bp.112.039537

[1]Mental Health Sciences Unit, University College London and Camden and Islington NHS Foundation Trust, St Pancras Hospital, London
Correspondence to Helen Killaspy (h.killaspy@ucl.ac.uk)

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Summary In this issue, Dr Lodge makes a plea for continuity of care in the face of the increased specialisation of mental healthcare over recent years. However, continuity of care is not a straightforward concept and its relationship to clinical outcome is not established. The increased specialisation of mental healthcare reflects an evolving evidence base that has increased our understanding of mental illness and the treatments and delivery systems that are most effective. In other words, specialisation is the sign of a progressive field.

Declaration of interest None.

In his editorial in this issue of *The Psychiatrist*, Dr Lodge makes a plea for continuity of care, making a case that the increased specialisation of mental health services in recent years has led to fragmentation of patient care.[1] Dr Lodge suggests a return to the catchment area-based generalist approach. Although some may consider this a perfectly reasonable view, there are difficulties with this nostalgia and I present three main arguements to support my position.

Difficulties with the concept of continuity of care

First, continuity of care is not a straightforward concept. It is difficult to define and its association with clinical outcome is unclear. Over the past 10 years or so, the National Institute of Health Research has funded a series of research projects on continuity of care that has defined the concept as comprising six dimensions: the experience of a coordinated and smooth progression of care from the patient's point of view (experienced continuity); excellent information transfer (continuity of information); effective communication between professionals, services and with patients (cross-boundary and team continuity); flexibility to adjust to the needs of the individual over time (flexible continuity); care from as few professionals as possible (longitudinal continuity); one or more professionals with whom the patient can establish and maintain a therapeutic relationship (relational or personal continuity). Collation of the results of the studies identified that the most important of these for people with longer-term, relapsing and remitting conditions, including mental illness, was flexible continuity.[2] In addition, having a good relationship meant of different people. In other words, there seemed to be a willing trade off between seeing the same person and seeing the right person or people at the right time. It is also important to note that the studies did not establish whether better continuity of care was associated with better clinical outcomes.[2]

Specialisation as a reason for celebration

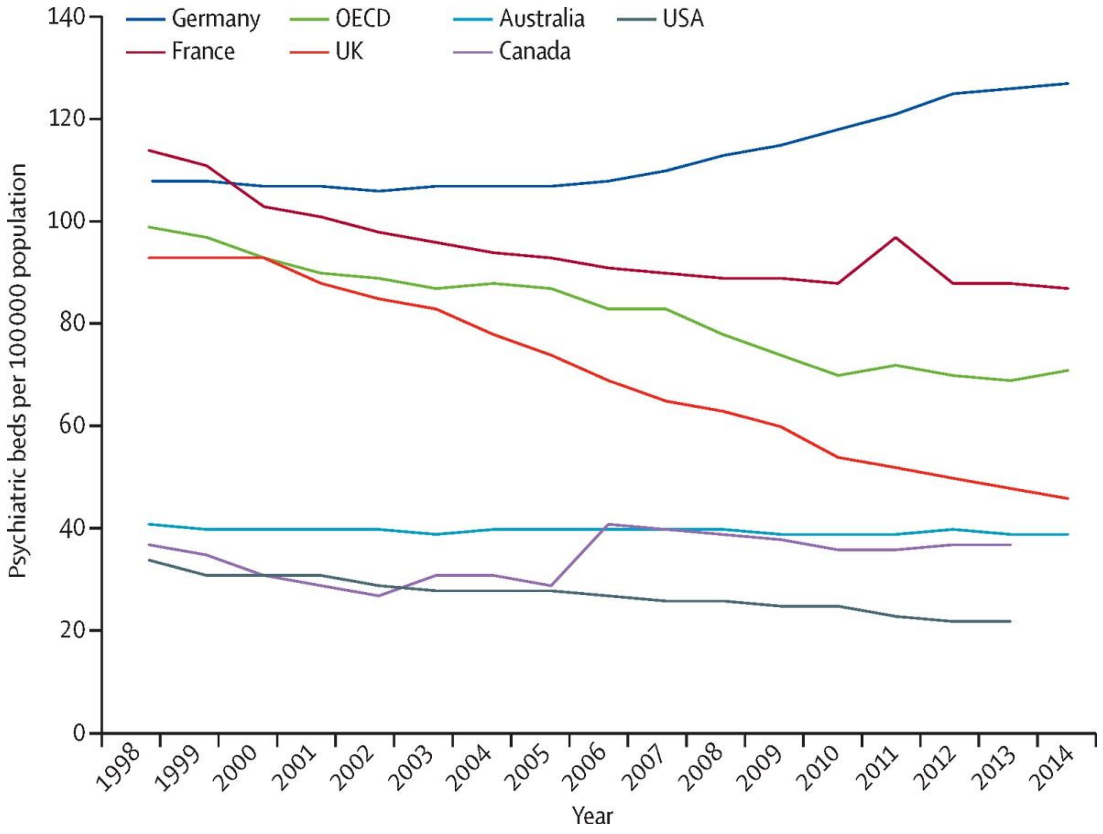
Second, the fact that psychiatric services have become more specialised is a reason for celebration rather than complaint. It suggests an evolution in our understanding of mental health problems, appropriate treatments and the configuration of services that can support people experiencing these problems to recover and regain control over their lives. This understanding has been informed by evidence from research. The National Institute for Health and Clinical Excellence (NICE) distils results from multiple trials to guide NHS investment in the most effective treatments and service delivery configurations. As our evidence base expands, providing us with a better and deeper understanding of exactly what works best and for whom, it becomes increasingly unrealistic to expect every psychiatrist and other mental health professional to remain fully informed and competent to treat all mental health conditions in accordance with the best available evidence.

The decision to implement crisis resolution, early intervention and assertive outreach services through the National Service Framework for Mental Health[3] was based on the international evidence available at the time. The impact of these new services on clinical outcomes was then

- Specialisation is a cause for celebration
- Flexible continuity - flexibility to respond to a person's changing needs over time
- Service users want the right person/team at the right time
- Willing trade off between continuity and specialist intervention
- Therapeutic rapport is vital

Mental health bed numbers

(Tyrer et al, letter to *The Lancet*, Jan 2017)



Policy shift - prevention and promotion

- 2014 - Five Year Forward View (UK)
- 2016 - EU Framework for Action on Mental Health and Wellbeing
- 2013-2020 - WHO Action Plan for Mental Health

➢ Focus on mental health promotion, prevention, early intervention, integration of community services, parity of esteem, stigma

➢ Little mention of inpatient care or complex needs group

However…..

- So far, trials of Early Intervention have not shown sustained benefits (LEO @ 5 years - Gafoor et al., 2010; OPUS @ 10 years - Secher et al., 2015)
- ….even when the specialist intervention is sustained beyond 2 years (Chang et al, 2017)
- 15-27% of people newly diagnosed with schizophrenia develop complex, long term problems (Craig et al., 2004; Menezes et al., 2006; Friis, 2011)
- Associated with: male, younger age of onset, insidious onset, more negative symptoms
- Promotion and prevention strategies unlikely to impact on this

People with more complex psychosis.....

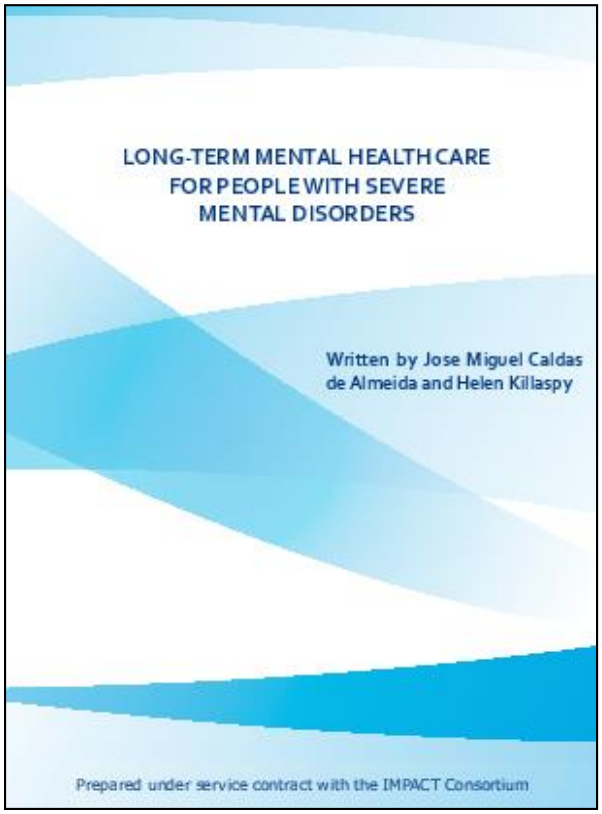
- Treatment resistant symptoms
- Severe negative symptoms (amotivation, apathy)
- Cognitive impairment (especially executive functioning)
- Pre-morbid intellectual disabilities/developmental problems
- Co-morbid mental and physical health problems
- Co-existing substance misuse problems

- Severe difficulties in everyday function
- Vulnerability to self-neglect (49-72%) and exploitation by others (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)


RECOVERY
Expectations
Reality

Successful deinstitutionalisation includes planning services for those with complex needs

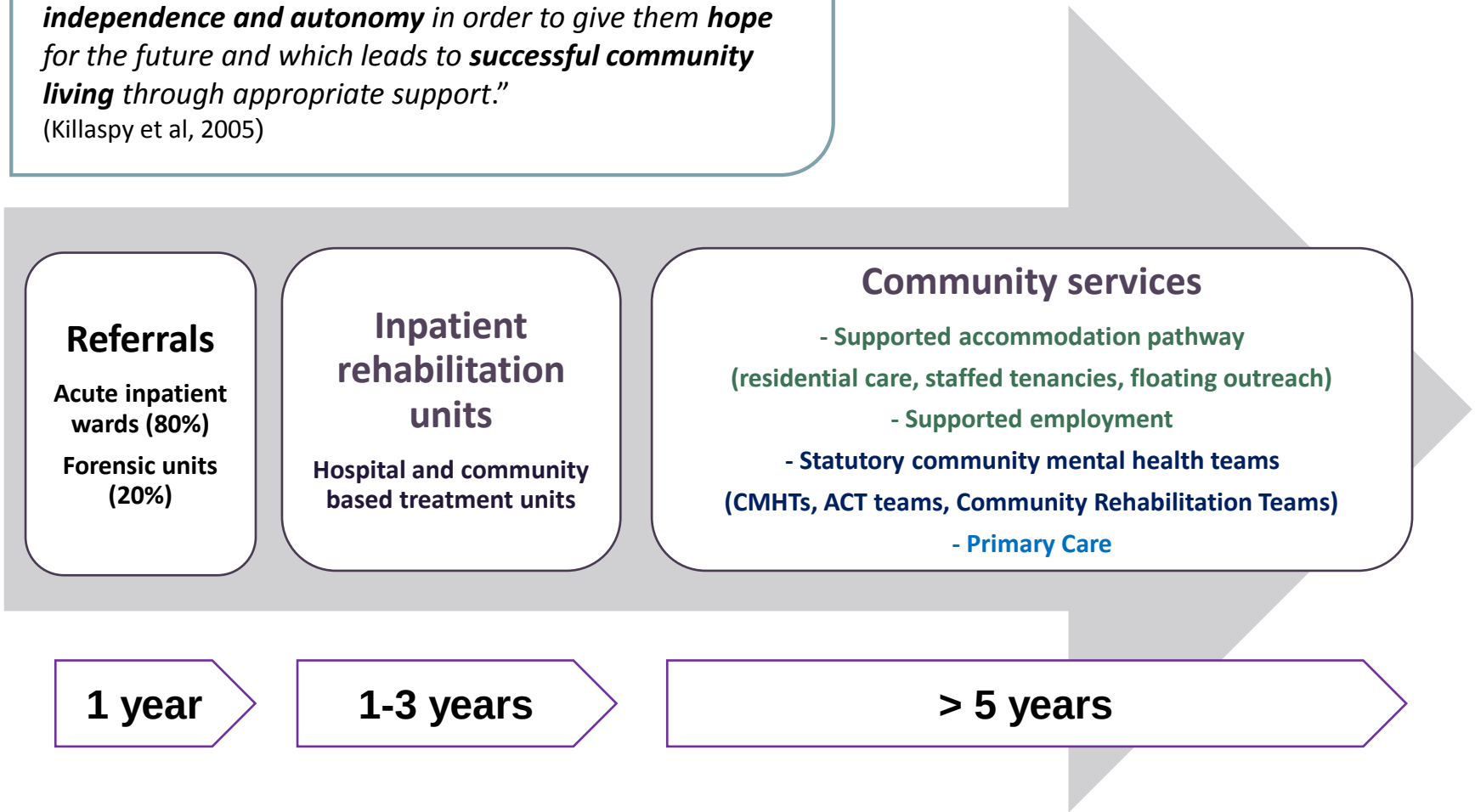
(Caldas de Almeida and Killaspy, 2011)



- **Balance** of community and inpatient **services** (Thornicroft & Tansella, 2004)
- **Specialised inpatient and community services for those with more complex needs**
- **Primary care** liaison
- Ensure access to **physical health care**
- Supported housing and vocational rehabilitation
- Staff training, including **recovery** approaches
- Addressing **stigma** and **social exclusion**
- Service user and carer **participation**
- Support to **families**
- Promotion of **research**

UK ‘whole system’ MH rehabilitation care 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)



Mental health rehabilitation

Interventions

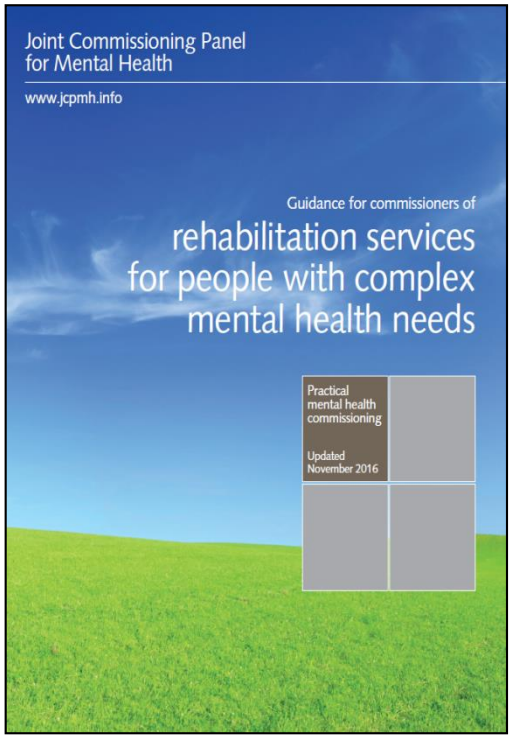
- Complex medication regimes
- Physical health care
- Occupational therapy - graduated, tailored support to gain/regain daily living skills
- Vocational rehabilitation/community activities
- Psychological interventions
- Family involvement and support

Multidisciplinary teams

- Rehabilitation psychiatrist
- Nurses
- Health care assistants/support workers
- Occupational therapists/activity workers
- Psychologists
- Social workers

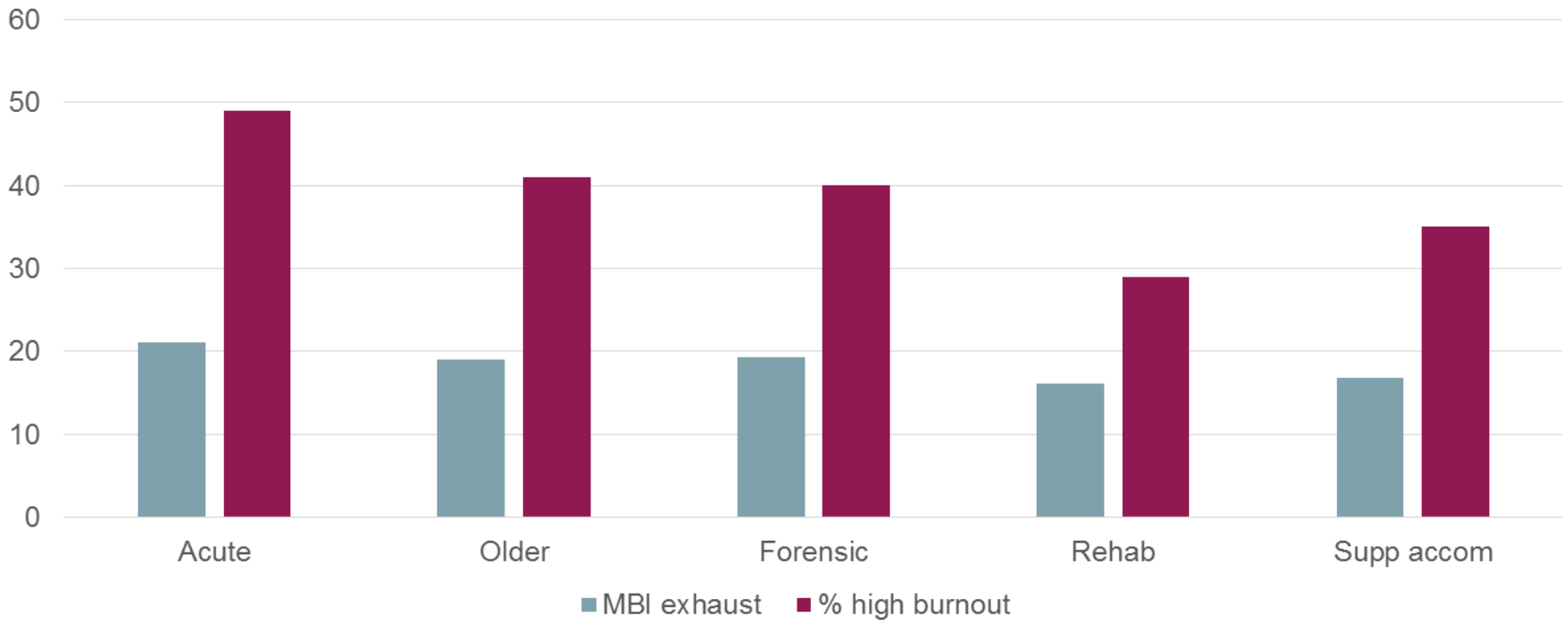
Culture

- Recovery based practice
- Therapeutic optimism
- High energy, low expressed emotion
- Long term view



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

Johnson et al, *BJPsych* 2012; *Dowling et al. in prep.



Good evidence for the rehabilitation care pathway

Case control study in Ireland - 18 month follow-up (Lavelle et al, 2012):

- Cases (126 receiving rehabilitation) **more likely (OR 8.44) to be successfully discharged** than controls (74 on waiting list) and more **improvement in social function**

Cohort study in North London - 5 year follow-up of 141 mental health rehabilitation service users (Killaspy & Zis, 2012)

- **Two-thirds did well:**

  40% moved forwards along pathway (10% achieved independent tenancy)

  27% stayed in same supported community placement

  33% readmitted/placement breakdown

National cohort study in England (REAL Study) - 12 month follow up of 362 users of 50 inpatient rehabilitation services (Killaspy et al, 2016):

- **57% successfully discharged (+14% waiting for supported accommodation**)

National cohort study in England (QuEST Study) - 30 month follow-up of 586 supported accommodation service users (Killaspy et al, in preparation):

- **41% successfully moved to more independent accommodation**

Cost benefits of MH rehabilitation services

Killaspy et al. *BMCPsych* 2016; 40:24-28
362 users of inpatient rehabilitation care across England
Median 12 years contact with mental health services and 4 previous admissions
57% successfully discharged to community over 12 month follow-up
Reduction in mean service use cost of £710 per service user/yr (95% CI –£888 to –£514).

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 on rehabilitation unit = 700 (385) = £74,000/yr
Mean (SE) bed days 2 years after inpatient rehabilitation = 111 (52) = £18,000/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 do well @ cost ~ **£30m**
33 don't do well @ cost ~ **£22m**
Total cost for 100 people **with rehab ~ £52m**
Total cost for 100 people **with no rehab ~ £66m**

Predictors of outcome

	OR (95% CI)	Reference
Successful (sustained) discharge from hospital associated with greater:		
• social skills	1.13 (1.04 to 1.24)	REAL study
• engagement in activities	1.03 (1.01 to 1.05)	Killaspy et al, 2016
• recovery orientation of service	1.04 (1.01 to 1.08)	
Successful move on to less supported accommodation associated with greater:		
• recovery orientation of service	1.06 (1.01 to 1.11)	QuEST study Killaspy et al.
No discharge/readmission associated with greater:		
• unmet needs	0.76 (0.66 to 0.88)	Lavelle et al, 2012
• challenging behaviours	0.51 (0.35 to 0.75)	
• substance misuse	0.13 (0.04 to 0.47)	
• medication non-adherence	8.60 (3.41 to 21.70)	Killaspy & Zis, 2012

Service quality assessment – QuIRC/QuIRC-SA

Recovery based practice

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

If you don't plan for those with complex needs…

Reinstitutionalisation in mental health care

This largely unnoticed process requires debate and evaluation

Since the 1950s mental health care in most industrialised countries has been characterised by deinstitutionalisation, with national reforms varying in their pace, fashion, and exact results.[1 2] The development of comprehensive community mental health care is widely regarded as not yet complete. In England the national service framework and NHS Plan aim at establishing new community based services—for example, for home treatment, assertive outreach, and early intervention. Yet despite the apparent evidence of ongoing deinstitutionalisation, we argue that a new era in mental health care has already started—reinstitutionalisation. It is displaying a synonymous pattern across Europe, as with deinstitutionalisation, but this time it has been occurring largely unnoticed by the scientific community and unscrutinised by politicians and the media.

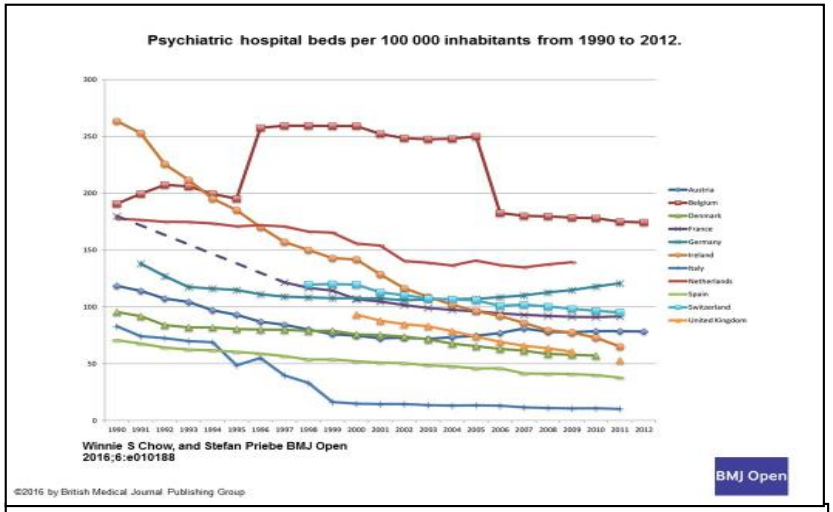
What are the signs of reinstitutionalisation? Firstly, the number of forensic beds is rising, in the United

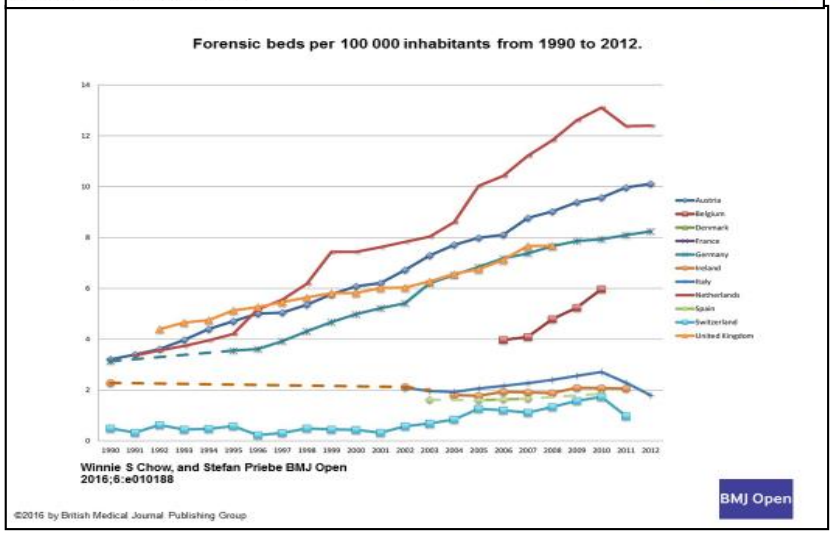
rates in mentally ill people.[3] Little systematic research has been conducted into the matter, although other countries, such as Germany and Austria, have also witnessed a steady increase in the numbers of forensic beds over the past 10 years.[4]

Secondly, attitudes to compulsory treatment have changed. The relative numbers of compulsory admissions of psychiatric patients across Europe vary by a factor of 20, but, independent of this mainly unexplained variation,[3] compulsory admissions have risen in many, although not all, European countries including the United Kingdom. In Italy, Bavaria, and the United Kingdom new legislation or new directives to handle existing legislation have been proposed, to widen the options for compulsory treatment.[6-8]

Thirdly, placements in supported housing at varying levels of dependence have increased enormously. Data as to how many and which patients are in what schemes and for how long are largely missing,

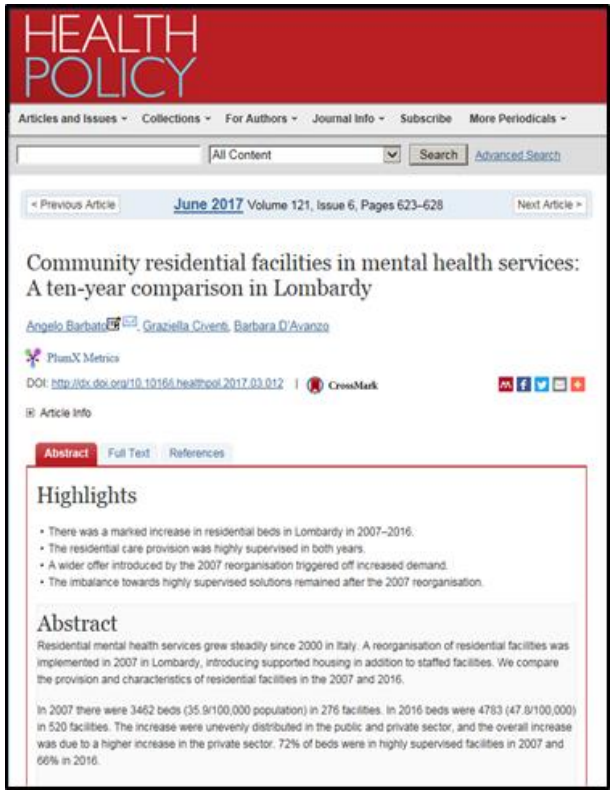
Priebe, S and Turner, T.
BMJ 2003;326:175–6





Community residences in Lombardy, Italy

Barbato et al, *Health Policy*, 2017



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Community residential facilities in mental health services: A ten-year comparison in Lombardy

Angelo Barbato, Graziella Civenti, Barbara D'Avanzo

PlumX Metrics

DOI: http://dx.doi.org/10.1016/j.healthpol.2017.03.012 | CrossMark

Article Info

Abstract · Full Text · References

Highlights

- 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.

Abstract

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.

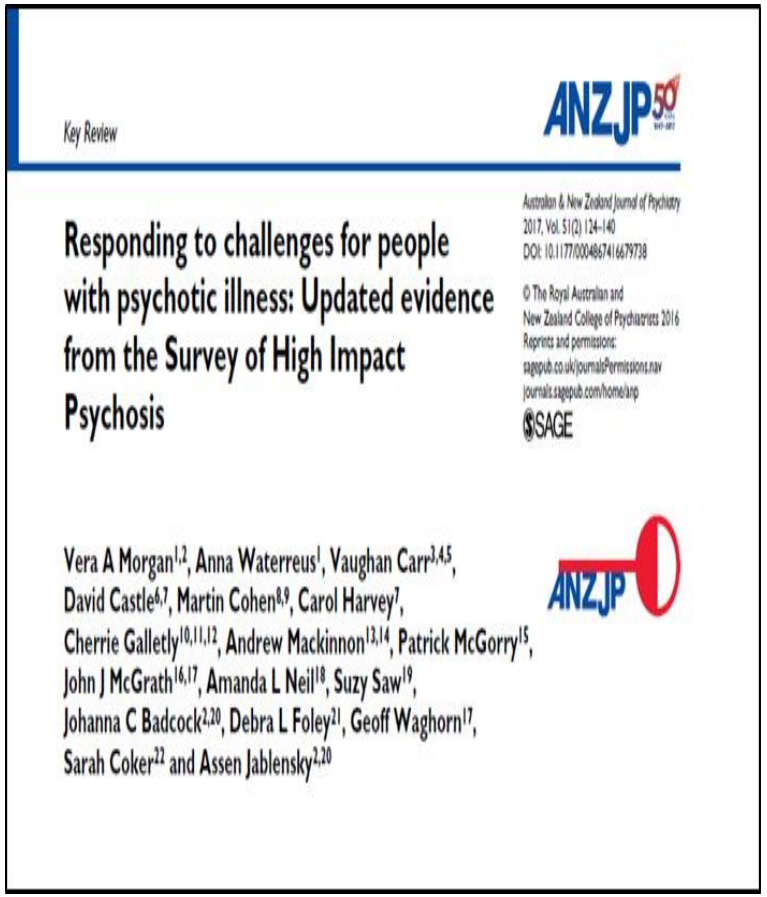
- Last 10 years - 88% increase in community residences (276 to 520) and 38% increase in number of places (from 3462 to 4783)
- Most expansion in private sector (care vs treatment)
- Concerns about lack of rehabilitative and recovery ethos

Australia - Survey of High Impact Psychosis

Morgan et al, *ANZJP*, 2017

- Highly deinstitutionalised, massive expansion of community care, including NGOs
- Sub-optimal treatment
  - Polypharmacy (63%)
  - Under use of clozapine, employment support and other evidence based PSIs
  - Poor physical health care
  - Increasing homelessness

➢ More integrated statutory and non-statutory services (health, education, employment, housing)



Key Review

ANZJP

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

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

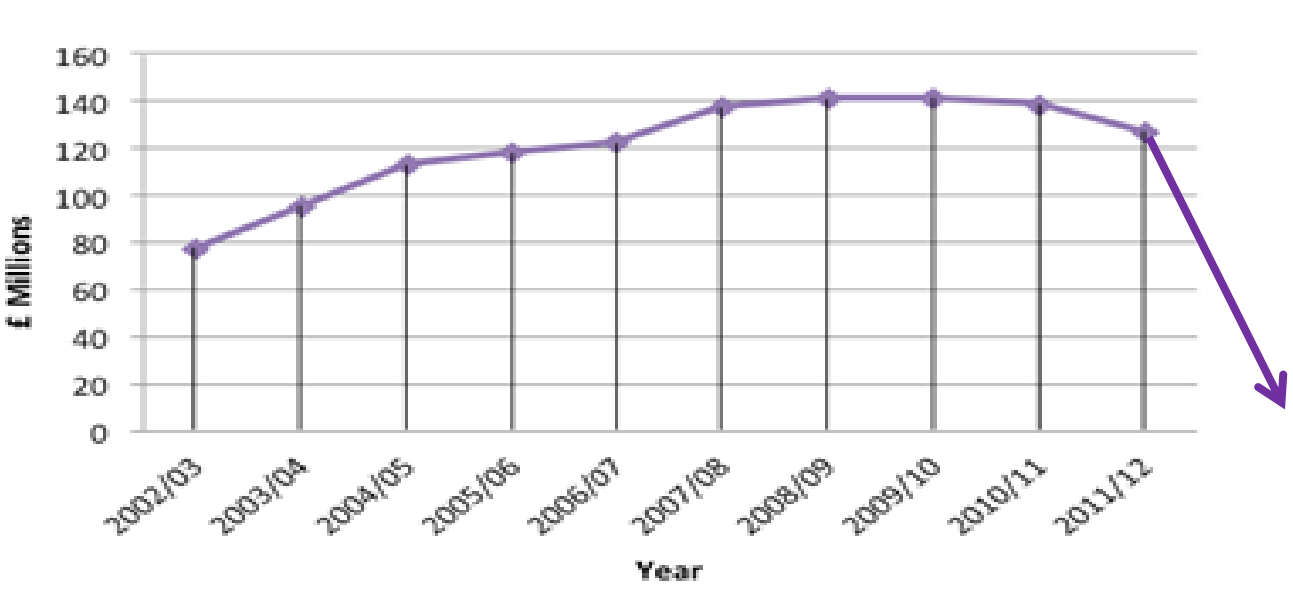
SAGE

Vera A Morgan[1,2], Anna Waterreus[1], Vaughan Carr[3,4,5], David Castle[6,7], Martin Cohen[8,9], Carol Harvey[7], Cherrie Galletly[10,11,12], Andrew Mackinnon[13,14], Patrick McGorry[15], John J McGrath[16,17], Amanda L Neil[18], Suzy Saw[19], Johanna C Badcock[2,20], Debra L Foley[21], Geoff Waghorn[17], Sarah Coker[22] and Assen Jablensky[2,20]

ANZJP

Investment in ACT in England

- ACT did not show expected benefits for complex needs group in settings where community care well developed and inpatient beds minimised (Killaspy et al., 2006; Burns et al., 2007; 2009; Dieterich et al., 2010; 2017)



Care Quality Commission report into the state of mental health care 2014-17

- Across England, 357 inpatient rehabilitation units inspected
- 4,936 rehabilitation beds
- 73% in locked units
- Majority of provision in private sector and most are many miles from the person's home

	Locked N=3587	Unlocked N=1349	Total N=4936
NHS	1152 (32%)	992 (73%)	2144 (43%)
Independent	2435 (67%)	357 (27%)	2792 (57%)

‘Out of area’ inpatient rehabilitation beds

- Social dislocation
- Disruption of care pathway
- Longer admissions than necessary
- Poor rehabilitative ethos in some
- Institutionalising
- Financial disincentives to repatriate to local services
- More expensive than local inpatient rehabilitation services (cost twice as much – Killaspy& Meier, 2010)

Out of sight, out of mind; (re)institutionalisation and abuse

Transforming care:

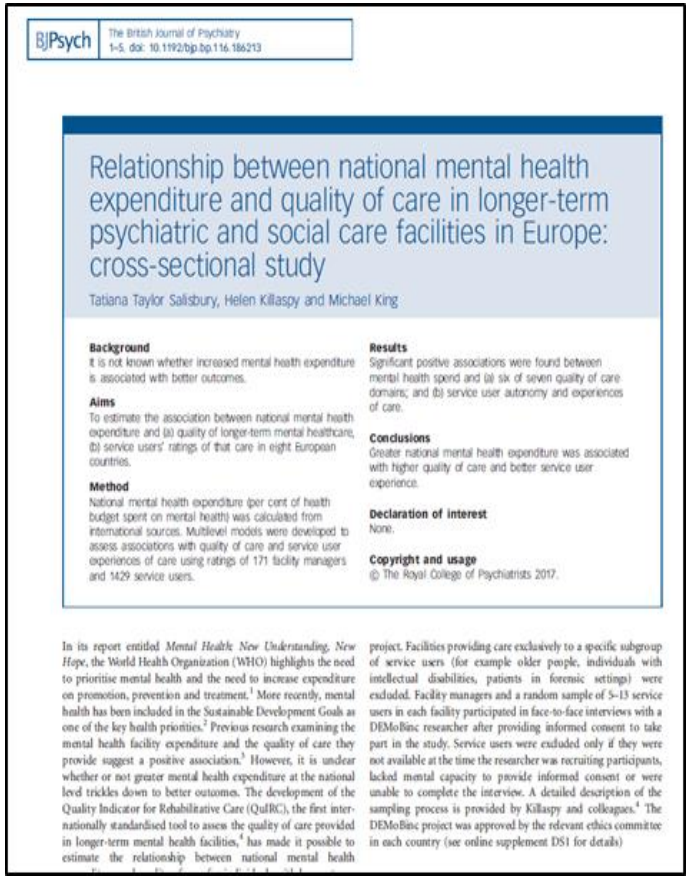
A national response to Winterbourne View Hospital

Department of Health Review: Final Report

Adequate investment is vital

Taylor et al, *BJPsych*, 2017

- 171 longer term inpatient and community based mental health facilities, 1471 service users, 8 European countries
- % health budget spent on mental health positively associated with quality of longer term care and service user autonomy and satisfaction with care
- Increase % 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

Background
It is not known whether increased mental health expenditure is associated with better outcomes.

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.

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.

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.

Conclusions
Greater national mental health expenditure was associated with higher quality of care and better service user experience.

Declaration of interest
None.

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

project. 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)

Under investment in services for people with complex mental health needs

- ‘Blind spot’ in contemporary service planning for high needs group
- Annual financial cycles
- Highly complex service systems
- Economic constraints - shifts in investment towards cheaper options at cost of specialist expertise
- ‘Unbearable’ nature of this group - undermines aspirations for promotion, prevention and being able to intervene early to prevent long term problems

➢ Lack of specialist skills and under use of effective interventions

➢ Vicious cycle of ‘exportation’ and (re)institutionalisation

➢ ‘As close to home’ and ‘least restrictive’ treatment principles undermined

Conclusions

- Need balanced approach in policy and investment between mental health promotion, prevention and provision to avoid marginalising those with most complex needs
- All mental health services should be recovery orientated **and** include local, specialist, longer term rehabilitation services for those with more complex needs
- Good evidence for whole system rehabilitation care pathway
- Rehabilitation takes time - need long term service planning
- Situation for this group getting worse, even in countries that were at the forefront of 'deinstitutionalisation'
- Modest, adequate investment is associated with good outcomes

Conclusion

If a society's greatness is measured by how it treats its most vulnerable…..

(Samuel Johnson, Mahatma Gandhi, various US presidents, Pope John Paul II)

Mental health services should be judged on the quality of their provision for those with the most complex needs

Thanks to….

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All the service users and staff who have participated in our studies

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