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)
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
  - 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

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

Residential Care
Supported Housing
Floating Outreach
Visual analytics 2 – hierarchical clustering for services

Supported Housing Services

Level 1

Level 2

Level 3
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
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.’

‘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.’

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

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

- 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

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
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
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
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