

| Institution: University College London  |                             |                       |
|---|-----------------------------|-----------------------|
| Unit of Assessment: 4 Psychology, Psychiatry and Neuroscience                               |                             |                       |
| Title of case study: Improving provision of mental health rehabilitation services worldwide |                             |                       |
| Period when the underpinning research was undertaken: 2007-2019                             |                             |                       |
| Details of staff conducting the underpinning research from the submitting unit:             |                             |                       |
| Name(s):  | Role(s) (e.g. job title):   | Period(s) employed by |
|   |                             | submitting HEI:       |
| Helen Killaspy  | Professor of Rehabilitation | 2003 to present       |
|   | Psychiatry                  |                       |
| Period when the claimed impact occurred: 2012 to present                                    |                             |                       |

Is this case study continued from a case study submitted in 2014? No

# 1. Summary of the impact

The lifetime prevalence of psychosis in the UK is 1%. Around 20% of people with psychosis develop long term, complex problems that mean they require ongoing intensive interventions. This accounts for half the NHS and social care spend on mental health. Research at UCL has for the first time evidenced the potential of rehabilitation services to reduce this group's dependence on such interventions. The findings were included in the first NICE guideline on rehabilitation for adults with complex psychosis and influenced NHS England to improve provision and quality of rehabilitation services. The research generated service assessment tools that are recommended by the Royal College of Psychiatrists and used widely both within the UK and internationally to monitor the quality of care delivered to this vulnerable group.

#### 2. Underpinning research

Since 2007, a team led by Professor Killaspy at UCL has conducted major research programmes, funded by the European Commission (EC) and the National Institute of Health Research (NIHR) that have identified the key components of mental health rehabilitation services and the content of care that best support the recovery of people with complex psychosis. The team developed tailored, standardised quality assessment tools for these services and used them in large cohort studies, alongside cost-effectiveness analyses, patient and staff experience surveys, systematic reviews and modelling, to identify the aspects of care associated with better outcomes, and tested these in trials. Their findings constitute the first empirical evidence for contemporary mental health rehabilitation services since the deinstitutionalisation programmes of the 1970s.

Three main projects underpin this impact:

# 1). The DEMoBinc (Development of a European Measure of Best Practice) Study (2007-2010).

This EC FP6-commissioned UCL-led project aimed to develop an international, standardised quality assessment tool for longer-term mental health facilities across Europe. The project included 11 centres in 10 countries (Bulgaria, Czech Republic, England, Germany, Greece, Italy, Netherlands, Poland, Portugal, Spain) and incorporated a systematic review, an international Delphi exercise involving over 400 stakeholders (patients, carers, clinicians and advocates), and a review of national care standards to inform the tool content. Validation and inter-rater reliability testing were conducted with over 200 facilities and 1500 patients across the 10 countries. The final output of this research was an on-line tool, the Quality Indicator for Rehabilitative Care (QuIRC; https://quirc.eu/). Completed by the service manager, it provides ratings of the service's quality on seven domains of care (including living environment, therapeutic milieu, treatments and interventions, promotion of autonomy, human rights and social inclusion, and delivery of recovery-based practice) and suggestions on how to improve quality (R1). The domain ratings correlate well with patient experience and the tool is now available in 11 languages – those of the 10 participating countries plus Finnish.

#### 2. The REAL (Rehabilitation Effectiveness for Activities for Life) Study (2009-2015).

This NIHR Programme Grant for Applied Research (PGfAR) included a quantitative and qualitative survey of NHS inpatient mental health rehabilitation services across England (**R2**), a cohort study



to identify predictors of successful community discharge (R3), and the development and testing (through a cluster trial involving 40 services) of a staff training intervention to increase service user engagement in activities. Most patients had been in contact with mental health services for well over a decade and experienced multiple readmissions before they were referred to rehabilitation services. Two-thirds of those who received rehabilitation achieved and sustained community discharge, without readmission. This was associated with the degree to which services implemented recovery-based practice (collaborative, person centred, optimistic) and with patients' social skills and engagement in activities.

#### 3). The QuEST (Quality and Effectiveness of Supported Tenancies) Study (2012-2018)

This second NIHR PGfAR funded study investigated another crucial component of the mental health rehabilitation pathway, supported accommodation services. The programme included adaptation of the QuIRC for these services (QuIRC-SA) (R4), a national survey and cohort study involving over 600 service users (R5, R6), and a feasibility trial to compare two models of supported accommodation. The findings corroborated those of the REAL study, i.e. services that were more recovery orientated, and those that promoted people's human rights (e.g. enabling access to advocacy and legal representation), were more successful at helping them progress with their rehabilitation and 'move-on' to more independent accommodation, with associated cost savings for health and social care.

#### 3. References to the research

- [R1] Killaspy, H., White, S., Wright, C., et al. (2011). The development of the Quality Indicator for Rehabilitative Care (QuIRC): a measure of best practice for facilities for people with longer term mental health problems. BMC Psychiatry, 11:35. doi: 10.1186/1471-244X-11-35
- [R2] Killaspy, H., Marston, L., Omar, R. et al. (2013). Service quality and clinical outcomes: an example from mental health rehabilitation services in England. *British Journal of Psychiatry*, 202, 28-34. doi: 10.1192/bjp.bp.112.114421
- [R3] Killaspy, H., Marston, L., Green, N. et al. (2016). Clinical outcomes and costs for people with complex psychosis: a naturalistic prospective cohort study of mental health rehabilitation service users in England. BMC Psychiatry, 16:95. doi: 10.1186/s12888-016-0797-6
- [R4] Killaspy H, White, S., Dowling, S. et al. (2016). Adaptation of the Quality Indicator for Rehabilitative Care (QuIRC) for use in mental health supported accommodation services (QuIRC-SA). *BMC Psychiatry*, 16:101. doi: 10.1186/s12888-016-0799-4
- [R5] Killaspy H, Priebe, S., Bremner, S. et al. (2016). Quality of life, autonomy, satisfaction, and costs associated with mental health supported accommodation services in England; a national survey. *Lancet Psychiatry*, *3*(*12*), 1129-1137. doi: <a href="https://doi.org/10.1016/S2215-0366(16)30327-3">10.1016/S2215-0366(16)30327-3</a>
- [R6] Killaspy, H., Priebe, S., McPherson, P. et al. (2020). Predictors of move-on from mental health supported accommodation in England; a national cohort study. *British Journal of Psychiatry*, 216(6), 331-337. doi: 10.1192/bjp.2019.101

#### 4. Details of the impact

By establishing that mental health rehabilitation services are effective, identifying the vital components of success for implementation, and developing and implementing standardised tools for monitoring and improving the quality of services, the research has changed policy towards rehabilitation services, shaped their design and enabled their improvement internationally.

#### 1) Establishing the effectiveness of mental health rehabilitation

Rehabilitation pathways support patients to stabilise and reintegrate back into communities successfully, negating the need for recurrent and more expensive readmissions. The evidence of clinical- and cost-effectiveness provided by the REAL and QuEST research has been disseminated widely to policy makers and practitioners through publications, national and international conferences, targeted stakeholder events, blogs (for the Centre for Mental Health



and the Mental Elf website) and an expert webinar co-ordinated by the Royal College of Psychiatrists and hosted by the Mental Elf **[S1]**. In 2016, the findings were included in NHS England's *Commissioning Guidance for Rehabilitation*, a key reference document for Clinical Commissioning Groups **[S2]**, which cited the Joint Commissioning Panel for Mental Health's 2012 *Guidance for Commissioners of Mental Health Rehabilitation Services*, which in turn cited Killaspy's research extensively **[R1, R2, R6]**. The UCL team's findings were cited 13 times, providing the scientific basis underpinning key recommendations.

Killaspy's role as National Professional Adviser to the Care Quality Commission has driven a sea change in political support, at the highest level, for investment in NHS mental health rehabilitation services. The role included attendance at a series of meetings with the former Secretary of State for Health, Jeremy Hunt, where the findings were verbally acknowledged as challenging the national underinvestment in NHS rehabilitation services. It was agreed that NHSE would set up a *Getting It Right First Time* programme [S3] to support Clinical Commissioning Groups (CCGs) to invest in local mental health rehabilitation services for people with complex psychosis. The programme's Clinical Lead confirms that the research "has had a profound impact on the NHS' policy and guidance towards using these [rehabilitation] services in England.....Professor Killaspy's work and her clinical leadership, has been one of the key drivers in bringing rehabilitation services back to the centre of treatment pathways for people with complex psychosis. By so doing, she has helped to increase the use of rehabilitation as an effective tool to improve outcomes for this group, helping them to achieve and sustain the ultimate goal of successful community living" [S3]. This programme launched in late 2018 and after a successful initial pilot, has now been rolled out nationally.

#### 2) Identifying the key components of mental health rehabilitation

Whilst the concept of recovery has been strongly encouraged in mental health policy for many years, REAL and QUEST provided the first empirical evidence that services that adopt greater recovery orientation and facilitate patients' engagement in activities that help them build/rebuild their skills and confidence are more effective. Several specific recommendations derived from the results have been incorporated into the very first NICE guideline for mental health rehabilitation (NG181: Rehabilitation for adults with complex psychosis) published in August 2020 [S4]. This document is a critical lever for ensuring that CCGs and service providers implement evidence-based approaches that can help patients, through investment in appropriate services, staffing, training and supervision, and through the monitoring of their delivery (by the CQC, NHS benchmarking and NHSE) against NICE quality standards. NICE included the following overarching principles and organisational pathways in their recommendations, based on the UCL team's work:

- i) All local mental healthcare systems should include a defined rehabilitation pathway.
- ii) Rehabilitation should be offered to people as soon as it is identified that they have treatmentresistant symptoms of psychosis and impairments affecting their social and everyday functioning.
- iii) Rehabilitation services should: be embedded in a local comprehensive mental healthcare service; provide a recovery-orientated approach that has a shared ethos and agreed goals, a sense of hope and optimism, and an aim to reduce stigma; deliver individualised, personcentred care through collaboration and shared decision making with service users and their carers involved.
- iv) The rehabilitation pathway should include the following components, as informed by a local needs assessment: rehabilitation in the community, providing clinical care from a community mental health rehabilitation team to people living in supported accommodation (residential care, supported housing and floating outreach) and rehabilitation in inpatient settings, such as high-dependency rehabilitation units and/or community rehabilitation units [S4].

According to the Royal College of Psychiatrists (RCP): "There is no doubt that the guidance will improve care provision for a group of people with complex needs that have not previously had access to care guided by evidence. This will significantly galvanise commissioning of services in all areas and reduce variation in care. Ultimately, the benefits will be for patients and carers who



have long term complex needs. This means that many more patients now have an increased chance of progressing to independent living" [S5].

#### 3) Development of service quality assessment tools

As the only standardised quality assessment tool for mental health rehabilitation services, QuIRC [S6] has been used by over 1000 services across 19 countries. It was recommended by the RCP as a standardised routine audit tool for inpatient mental health rehabilitation services (comprising approximately 4000 beds in England) and incorporated into the RCP's Centre for Quality Improvement (QI) scheme for these services, AIMS-Rehab. Within the REF period, use has grown to around two-thirds of all NHS inpatient rehabilitation services (approx. 56,000 people) and a growing proportion of independent sector services who are now also members of AIMS-Rehab. The QuIRC provides each with an individualised assessment to inform their quality improvement programme [\$7]. According to the RCP, "A noteworthy feature of QuIRC... is the integration of human rights into the clinical care quality measure(s). This important innovation and approach, understandably has wider relevance for all other mental health services. Its other important features are patient centredness and recovery focus, both of which have further generalisability potential" [S5]. The QuIRC website has 485 users in the UK. Since there are around 250 NHS rehabilitation services in the UK, this represents extensive sector coverage. The website has users from across the globe: Europe (442), North America (19), South America (13) and the Pacific Rim (73) [S8].

QuIRC-SA [S6] is the only tailor-made standardised quality assessment tool for mental health supported accommodation services. It has been used across England (in over 150 services) and has been translated into Italian to assess services, initially in Verona and now across Italy [S9]. Like QuIRC, it is recommended by the RCP for use as a standardised routine outcome tool. The Chair of the RCP Faculty of Rehabilitation and Social Psychiatry says, "As a result there is now a system to enhance the quality of life of people living in community supported accommodation" [S5]. In November 2018, it was endorsed for routine use by the Housing Association's Charitable Trust, a voluntary organisation providing input to national policy and CPD activities for supported accommodation providers. Both QuIRC and QuIRC-SA are included in the August 2020 NICE Guideline NG181 [S4] as the only suitable service quality assessment tools for the inpatient and supported accommodation components of the mental health rehabilitation pathway. These highlevel endorsements are key to promoting adoption of these tools that help to drive up quality through individual service audits, quality improvement schemes (such as AIMS-Rehab), and national benchmarking through NHSE. QuIRC's uptake far exceeded expectations nationally and internationally, and use of both tools is increasing following publication of the NICE NG181 Guideline.

# 5. Sources to corroborate the impact

- [S1] Centre for Mental Health and Mental Elf blogs on mental health rehabilitation services. 2018. <a href="https://www.nationalelfservice.net/commissioning/service-review-and-improvement/in-sight-and-in-mind-improving-mental-health-rehabilitation-pathways-rehabpsych/">https://www.nationalelfservice.net/commissioning/service-review-and-improvement/in-sight-and-in-mind-improving-mental-health-rehabilitation-pathways-rehabpsych/</a>
- [S2] Commissioning Guidance for Rehabilitation, NHS England. 2016; Guidance for Commissioners of Mental Health Rehabilitation Services, Joint Commissioning Panel for Mental Health. 2012.
- [S3] Statement from the Director of NHSE's programme *Getting it Right First Time for Mental Health Rehabilitation Services*
- [\$4] Nice Guideline NG181, Rehabilitation for Adults with Complex Psychosis. NICE. 2020. <a href="https://www.nice.org.uk/guidance/ng181/resources/rehabilitation-for-adults-with-complex-psychosis-pdf-66142016643013">https://www.nice.org.uk/guidance/ng181/resources/rehabilitation-for-adults-with-complex-psychosis-pdf-66142016643013</a>
- **[S5]** Statement from the Chair of the Faculty of Rehabilitation and Social Psychiatry, Royal College of Psychiatrists
- [S6] QuIRC/QuIRC-SA website. <a href="http://www.quirc.eu/">http://www.quirc.eu/</a>



- [\$7] AIMS-Rehab website.

  <a href="https://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/ccqiprojects/rehabilitatio">https://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/ccqiprojects/rehabilitationservices.aspx</a>
- [S8] QuIRC user figures (as at August 2020).
- [S9] Martinelli, A., Iozzino, L., Ruggeri, M., Marston, L., & Killaspy, H. (2019). Mental health supported accommodation services in England and in Italy: a comparison. *Social Psychiatry and Psychiatric Epidemiology*, *54*(11), 1419–1427. doi: <a href="10.1007/s00127-019-01723-9">10.1007/s00127-019-01723-9</a>; Website for Italian survey (QuIRC-SA cited under Objective 2): <a href="www.diapason-study.eu">www.diapason-study.eu</a>.