In sight and in mind:
Making good on the promise of mental health rehabilitation

February 2020
Foreword

A small but significant proportion of people who develop severe mental health conditions, such as psychosis, relapse and need long term care. This group often develop functional impairments and has a high risk of suffering from both physical and mental health illness. Rehabilitation services are specifically geared up to meet the complex and enduring needs of this group. When provided early as an integrated whole system service, they can improve the outcomes and social participation of many people with severe mental health conditions. As such, they are a vital part of the mental health service offer.

Yet, despite this, there has been a concerning decline in NHS provided rehabilitation services in recent years. The resulting gap in provision has been met by the private sector on an ‘as needed’ basis. Without adequate local services there has been a big increase in out of area care for patients.

Recent data has shown that, as well as being widespread, out-of-area placements have longer admissions that lead to far higher average costs per stay. A major focus of rehabilitative care for patients is on social inclusion, meaning local services are far more able to maintain and build links with family support networks and with services in the community. There is a very strong case to end out-of-area rehabilitation and to reinvest the money in locally provided services, including adequate beds, community rehabilitation teams and supported housing that can meet complex needs.

With little publicly available data on mental health rehabilitation services in England, the Royal College of Psychiatrists and the charity Rethink Mental Illness joined together to research these services in more depth. One striking barrier was the inadequate information that was provided in response to our Freedom of Information (FOI) requests and it was, therefore, difficult to build a complete picture of rehabilitation services across England.

This is extremely concerning as this means vulnerable people are effectively invisible in the system and may not be getting the vital care they need. Reports by Care Quality Commission (CQC), as well as the British Medical Association (BMA) and leading newspapers, have laid bare how woefully inadequate the care of people with longer-term severe mental health illness has become in some parts of the system. This needs to change.
While there are new discussions taking place about system improvement and funding of services for people with severe mental illness – and this recognition among NHS leadership of the need for change is most welcome – often the voices of service users and carers are missing. Many are left to manage their care needs within a fragmented rehabilitation system, and their needs may be being neglected. It is essential that the care experiences of people with high support and treatment needs are heard and used to form the basis of future policy.

As the adage goes, “the true measure of any society is the how it treats its most vulnerable members”. It is vital that the needs of one of the most marginalised and vulnerable groups in our society – people with severe mental illness – are no longer neglected. Now is the time for concerted action.

Dr Rajesh Mohan, consultant psychiatrist and chair of the Faculty of Rehabilitation and Social Psychiatry at the Royal College of Psychiatrists

Mark Winstanley, chief executive of Rethink Mental Illness
Introduction

This report is the result of a collaboration between Rethink Mental Illness and the Royal College of Psychiatrists and its Faculty of Rehabilitation and Social Psychiatry.

In order to investigate current provision of mental health rehabilitation services across England and the use of out-of-area care for people who require these services, we sent a Freedom of Information (FOI) request to all Clinical Commissioning Groups (CCGs) and NHS mental health trusts across England. We also discussed rehabilitation care with clinicians, patients and carers.

There was significant variation in the responses provided to our FOI request questions. In some cases, we were informed that the data requested had simply not been collected locally and answers to our questions could not be provided.

As such, we present these findings as an imperfect snapshot of the system, rather than a scientific analysis. Yet, despite these limitations, we have identified gaps in the system and outlined priorities for change and how to achieve. Our report makes suggestions as to how these could be achieved and we hope it will spur greater consistency and transparency within the mental health rehabilitation system and will bring the different partners involved in fixing it together.

Our main findings were:

- Commissioners and providers generally considered the majority of cases where they had sent patients out of area to be ‘appropriate’. Yet, there is no clear national definition of what constitutes an ‘appropriate’ out-of-area mental health rehabilitation placement and we strongly doubt that these figures on the appropriateness such placements can be consistent with good practice.

- While sending rehabilitation psychiatry patients out of area is costly and can damage recovery chances, most areas did not have a plan to reduce the number of rehabilitation patients sent out of area.

- Fewer than one in four mental health trusts employed a dedicated community mental health rehabilitation team.

- CCGs and mental health trusts reported that 333 mental health rehabilitation beds have been decommissioned in the last five years, and there are plans to decommission a further 53.

Our recommendations for change are based not only our own findings, but also on work by the BMA’s magazine, The Doctor, and the CQC, as well as the experiences of the patients and carers who have experience of the mental health rehabilitation system and clinical experts who work within it.

Our aim is for the multiple parties involved to agree a joint ambition to properly define and then end inappropriate out-of-area placements, and allow the people who need in-patient rehabilitation services to get the support they need closer to home. As part of the the NHS Long Term, the Mental Health Implementation Plan raises the prospect
of delivering specialist services for people with rehabilitation needs in their communities as part of the new community model and if the moment is seized, it presents the ideal opportunity to make this happen.

**Box 1: Account of a carer of a mental rehabilitation service user**

“Mary has schizoaffective disorder and spent 8 months in a rehabilitation service in 2016. She was transferred there from an in-patient unit.

One of the great things about the rehab unit, was that it was still part of the hospital/trust, which meant that she could still keep her housing association council flat even though, temporarily, she was unable to live there temporarily. Because it was nearby, she was also able to go back there once a week and to visit us.

To us, the rehab service provided a good example of best practice in mental health service delivery. The team working with Mary set her goals that could be achieved through very gradual steps, and they did a really good job in rebuilding her trust. She was given a weekly budget to go out and buy her groceries each week, which she then prepared and cleaned up. Initially, she was assisted in taking her medication, but over time she was encouraged to take it by herself independently. Mary told us that from the moment she went into the rehab unit, the staff treated her as a person. This is unlike the hospital environment, where they often don’t see the whole person – just a patient – meaning you lose a lot of those life skills you need.

After Mary was discharged and went back home, someone who had worked with her in the rehab unit would visit her regularly, so the transition was smooth and successful. We felt that the local aspect of the services provided was a key reason why they were so successful in rehabilitating Mary back into the community. There’s no way that an out-of-area placement would have had the same result.”

**What is mental health rehabilitation?**

Some people living with severe and enduring mental health conditions – such as psychosis – do not respond quickly to treatment and struggle to manage everyday activities without support. Mental health rehabilitation services are vital to support this group of people to live a life that is as high quality and independent as possible.

Whilst some rehabilitation services are based in hospital sites, others are located in the community. Patients should move between these care settings, supported by a multi-disciplinary rehabilitation team comprising psychiatrists, nurses, occupational therapists, psychologists and social workers.

People are generally referred to in-patient rehabilitation services after their condition has failed to improve adequately on an acute ward of a mental health hospital – often following multiple admissions – and where the clinician in charge of their care does not believe they are well enough to live in the community. In the longer term, people with rehabilitation needs should receive specialist community mental health team support and will often also need specialist supported housing to enable their recovery.

Although each patient’s story will be different, the following diagram gives an overview of what the evidence shows is the most effective rehabilitation pathway, alongside the difficulties that arise when it is not in place.
Key challenges for mental health rehabilitation

There is good evidence that when local mental health rehabilitation services are provided, they are able to support the majority of people with the most severe, long-term mental health conditions, enabling them to enjoy a good quality of life in the community. However, the lack of provision of these services means that many people are simply unable to access them.¹

This report examines some of the key challenges within the mental health rehabilitation system today.

1. Out-of-area placements are now routine, despite their negative impacts.

“When you’re a long way from home, people visit quite frequently early on, but over time people come to see you less and less. I don’t blame them. People have their own lives to be getting on with, but it is lonely. Leaving the hospital every weekend was also disruptive, as I missed out on the activities other patients did at the weekend. I think this slowed my recovery down, but I wanted to maintain connections with my friends and family, and leaving at weekends was the only way I could this. I shouldn’t have had to make that choice.”

— ‘Rebecca’ speaking of her experience of an out-of-area placement

The 2018 CQC investigation into the provision of mental health in-patient rehabilitation services\(^2\) showed that 63% of placements were in different geographical areas to the CCGs that arranged them. This is happening despite the negative impacts that out-of-area placements can have on the system (in terms of costs) and on the person receiving services (in terms of how they move between care settings and maintain their connections with loved ones and their community).

**The impact of out-of-area placements on the cost of treatment**

The CQC estimated that two thirds of the £535m budget for mental health rehabilitation beds is spent on out-of-area treatment, with longer stays accounting for the higher costs. Most out-of-area beds are provided by the private sector, and the CQC also found that the average length of a stay in these wards is almost double that of an NHS ward.

**Out-of-area placements often do not follow recognised service models**

Out-of-area placements are more likely to take place in services that do not follow a recognised model of in-patient service. Two-thirds (64%)\(^3\) of all the CCG-funded beds provided by the independent sector are in what are referred to as ‘locked rehabilitation wards’, yet the Royal College of Psychiatrists does not recognise this model or term. While other forms of service, such as ‘high dependency,’ have a specific place on the rehabilitation pathway, with defined service standards, there is no equivalent specification for ‘locked rehabilitation’. This has caused concerns that out-of-area placements in these services can be used to ‘contain’ people, rather than provide the most effective possible treatment that is geared towards the patient’s recovery, highlighting the need for national action.

**The impact on transitioning between care settings**

Out-of-area placements can make creating and maintaining connections with services which are crucial for a person’s continued recovery (such as NHS, housing and social care) in patients’ home areas far harder. When the CQC asked the managers of rehabilitation wards to name the NHS mental health trust responsible for providing the aftercare of people in their service, managers in private hospitals, which provide the overwhelming majority of out-of-area treatment, could do so for only 53% of their patients. The figure was 99% for NHS services, which in turn are far more likely to be provided locally.

Crucially, long stays in out-of-area in-patient units can also mean that a person no longer meets the ‘local connection criteria’\(^4\) that are used by local authorities to determine access to housing, further delaying discharge.

The impact on a person’s connections with their loved ones and community

Out-of-area placements also have a personal impact on those using services. Being placed a long way from home can place a strain on individuals’ relationships with their

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\(^2\) CQC (March 2018) Briefing – Mental health rehabilitation inpatient services
\(^3\) CQC (March 2018) Briefing – Mental health rehabilitation inpatient services
family and friends, and runs counter to the core aim of rehabilitation services to support people to go back to their community.

Using FOI data, The Doctor calculated travelling distances from a list of more than 2,600 rehabilitation ‘out-of-area’ beds commissioned by the NHS over the past three years. It found that 1,313 people had been placed more than a two-hour round trip from their home and, of those, 141 were placed in a unit that was a round trip of seven hours or more. This makes maintaining contact with loved ones at a vital time extremely challenging – both emotionally and in practical terms – and we have heard first-hand accounts of how psychologically dislocating out-of-area placements can be.

One mother told us about her son’s experience:

“He was sent for care 30 miles away to a hospital in the middle of the countryside. It was the worst possible thing for him. He was the only young black man in the area, surrounded by countryside rather than the city buildings he had grown up with and felt comfortable around.

It was a terrible thing having to drive all that way to see my son and to not know who I’d find when I got there. Being sent so far from home sent his paranoia through the roof, and he admitted to me that he had begun to feel suicidal.”

2. Gaps in provision that can affect care and outcomes

We know that there are important gaps in the mental health rehabilitation system that can affect treatment and care outcomes, including the decommissioning of beds and a lack of specialist community services.

For many decades, rehabilitation services were the main point of liaison with forensic services to aid the return of patients from secure care back into their home area. In more recent years, as services have closed or seen a reduction in the support offered, this link has been all but lost in most areas, resulting in delayed discharges or challenges in find appropriate supportive care.

NHS mental health rehabilitation beds have been decommissioned

Our FOI request asked CCGs and mental health trusts to provide data on how many beds have been decommissioned and how many will be in the future. This allowed us to build a national picture of provision and explore any possible connection between this and out-of-area placements.

After adjusting for double counting across the CCGs and mental health trusts that responded, we found that there were 333 rehabilitation beds reported as having been decommissioned in the past five years, with plans for a further 53 beds to be decommissioned.

There can be good reasons for beds to be decommissioned, such as where better community services have allowed people to be discharged and effectively supported
in less restrictive settings. But while the data from our FOI identified some areas in which beds have been decommissioned and out-of-area placements are low (other factors discussed below such as supported housing and social care contribute to this too), there are other areas where beds have been decommissioned, or are planned to be, and there are significant levels of out-of-area treatment. Almost half (11 of 23) CCGs that reported having decommissioned beds confirmed that they had at least 11 patients out of area.

These findings are reinforced by research by The Doctor magazine, which found that NHS mental health rehabilitation wards have disappeared entirely from 18 CCGs and NHS trusts in England, leaving five million people in those areas reliant entirely on out-of-area private sector provision5.

Community rehabilitation treatment is rarely delivered by specialist teams

Community mental health rehabilitation teams are a crucial component of the rehabilitation system. They provide ongoing specialist clinical support for people when they are discharged from in-patient rehabilitation services into the community.

A case-control study in Ireland found that service users who had access to a rehabilitation system (which included support from a community rehabilitation team when they moved from in-patient rehabilitation services to supported accommodation), were eight times more likely to sustain their community placement and avoid readmission than people who were on a waiting list for rehabilitation services.6

Despite this, our FOI request found that only 12 of the 50 trusts that responded to our request (24%) provided a specialist community mental health rehabilitation team. Several others told us that they provided specialist community rehabilitation care, but through generic community mental health teams (CMHTs).

Generic services cannot provide the same level of specialist care that people with severely complex needs require and there have also been serious concerns7 in recent years that CMHTs are overstretched and underfunded, further limiting their ability to provide adequate support people with rehabilitation needs. It is therefore essential for those who need specialised community mental health rehabilitation services to have access to these teams.

Wider challenges around supported housing and social care

Although not the primary focus of this report, it is widely recognised that the lack of supply of specialist supported housing and social care support for people discharged from in-patient mental health rehabilitation services is a major barrier to discharge and recovery.

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6 Lavelle E, Ijaz, A, Killaspy H et al (2011) Mental Health Rehabilitation and Recovery Services in Ireland: a multicentre study of current service provision, characteristics of service users and outcomes for those with and without access to these services.
7 APPG on Mental Health (2018) Progress of the Five Year Forward View for Mental Health: On the road to parity
The National Housing Federation has estimated a general shortfall of nearly 35,000 supported housing places in 2020/21 that will rise to 47,000 by 2024/25.8 Within the overall supply of supported housing (of which around 5% is provided for people with a mental illness)9 there is a need for specialist provision with clinical input to give people with complex mental health needs the best chance of a sustainable recovery.

Likewise, the fact that those who use mental health rehabilitation services often have long-term care needs means that the well-known pressures on adult social care can have a substantial detrimental impact on this group. In its Fair Funding for Mental Health report, the Institute for Public Policy Research (IPPR) estimated that a minimum of £1.1bn of mental health social care spending per year will be required by 2030.10

Action beyond the NHS will be required to address the issues if we are to ensure that the complete mental health rehabilitation pathway is delivered. The current Government review of costs in supported housing provides an ideal opportunity to address this.

3. Ensuring the mental health rehabilitation system is fit for purpose requires greater national and local focus

A dearth of data on out-of-area placements in mental health rehabilitation, and the lack of clarity as to what constitutes an ‘inappropriate’ out-of-area placement, makes addressing these issues through national and local strategies challenging.

There is no national strategy to end out-of-area placements and few local plans

Since 2016, data have been collected nationally and locally on the number of mental health in-patients sent out of area for treatment in acute mental health services. Also, the government has set a national ambition to eliminate inappropriate acute out-of-area placements (where patients with acute non-specialist needs are admitted to a bed outside of their local care network) by 2020/21. Unfortunately, there is no equivalent national strategy to end inappropriate out-of-area placements in mental health rehabilitation services.

The results of our FOI request show that local-level plans to do so are also rare, with only 46 of the 191 CCGs and 12 of the 54 mental health trusts that responded having strategies to minimise rehabilitation out-of-area placements. Where strategies do exist, it is hard to assess whether they are sufficiently ambitious without a national framework to measure them against.

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10 IPPR (2018), Fair funding for mental health: Putting parity into practice, IPPR: London
There is a lack of routine data on out-of-area placements and no shared definition of when an out-of-area placement is appropriate

While we know that a large proportion of people receiving in-patient rehabilitation treatment are out of area, a lack of consistent data collection means that it is challenging to make meaningful comparisons between areas or to map changes over time. This, in turn, hampers efforts to plan improvements or assess their effectiveness.

The fact that there is no agreed definition between the different agencies involved in this area of care as to what constitutes an ‘inappropriate’ out of area mental health rehabilitation placement adds to these problems.

We knew that without such a definition of appropriateness, this term may be interpreted differently by different local areas. In asking CCGs and mental health trusts to identify how many of their out-of-area placements they considered to be ‘appropriate’, we therefore used the CQC guidance on how this is defined. The threshold for when an out-of-area placement should be considered appropriate is aptly very high.

Box 2: Definition of appropriate out-of-area mental health rehabilitation placement (as used in our FOI requests)

| If a person requires treatment in a ‘highly specialist in-patient rehabilitation unit’ as defined by the CQC as being for people with very specific and complex mental health needs and comorbidities (e.g. psychosis plus acquired brain injury, severe personality disorder, or autism spectrum disorder), as these are usually provided at a regional or national level.” |

In a small number of the data returns from our FOI, CCGs and trusts highlighted patients with learning disabilities as part of their response, despite our questions focusing on mental health rehabilitation needs. It is unclear whether these patients had learning disabilities as well as mental health rehabilitation needs, or whether they were included because data on patients in mental health rehabilitation was not collected separately. This further illustrates the need for improved data collection and clearer, applied definitions within the system so that conclusive assessments can be made on whether a patient is in the most appropriate setting.

Of the 1,744 out-of-area placements reported to us, trusts and CCGs only considered 14% to be inappropriate. Our position, however, is that it is reasonable to expect the vast majority of mental health rehabilitation to be provided locally. Professor Helen Killaspy, consultant psychiatrist and honorary consultant in rehabilitation psychiatry at UCL and Camden and Islington, comments further on this:

“People who require treatment in mental health rehabilitation services should be treated in their local area in the vast majority of cases. We need to move to a system where out-of-area treatment is seen as an exception that we are committed to tackling—as it is with acute mental health—rather than a norm we accept”.

Only 6% of acute out-of-area placements are currently considered to be appropriate by the government.\(^{11}\) We believe this provides a benchmark for how often out-of-area rehabilitation placements should be considered acceptable.

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\(^{11}\) NHS Digital (2019), Out of Area Placements in Mental Health Services, NHS Digital: London
Signs of change

The evidence in this report and previous research by others highlights the issues within the system, including high levels of out-of-area placements, a reduction in locally available beds, and a lack of community mental health services for those with the most severe and enduring mental illnesses. However, as well as knowing the problems, we are also able to suggest solutions.12

Encouragingly, there are signs of change emerging. In 2018, Dr Sridevi Kalidindi CBE was appointed Clinical Lead of the mental health rehabilitation workstream within the ‘Getting It Right First Time’ (GIRFT) programme. This was launched by NHS Improvement to tackle unwarranted variation in service and to share best practice amongst health providers. The programme has already highlighted good practice in several areas but importantly recognises, on a national level, that mental health rehabilitation is not functioning as it should. It also gives practical support to local areas that are seeking to improve their practice and areas told us in response to our FOI request that their work with GIRFT is changing their approach.

The NHS Long Term Plan’s Mental Health Implementation Plan specifically recognises mental health community rehabilitation as a “fixed, targeted deliverable” within plans for new community services for adults with severe mental illness. This means that those who need rehabilitation in the community should receive dedicated care that “spans core primary/community provision and dedicated community-based services… ensuring improved access to high-quality, evidence-based care and reduced waits”.13

Furthermore, the National Institute for Clinical Excellence (NICE) published its first draft guideline14 on rehabilitation for people with complex psychosis and other severe mental health conditions for consultation in January 2020. If followed across the system, the guideline offers a template that could transform the experience of the patients and families who rely on the rehabilitation services. NICE has emphasised that commissioners should “place people locally and limit the use of out-of-area placements wherever possible, except for people with particularly complex needs” such as people with psychosis and an acquired brain injury or autism.

It has also set out measures to:

- improve transparency in the system
- ensure patients maintain contact with their home area
- ensure patients are brought home as quickly and seamlessly as possible involve patients and their loved ones in decisions about their care.

Taken together, the guideline sets out a vision for the treatment of the most severe forms of mental illness that lives up to the inspiring idea behind mental health rehabilitation: that recovery is possible even for those who are the most unwell.

12 Joint Commissioning Panel for Mental Health (2016) Guidance for commissioners of rehabilitation services for people with complex mental health needs
14 NICE (2020), Rehabilitation for adults with complex psychosis and related severe mental health conditions
Conclusions and recommendations

The positive steps that have already been taken are very welcome. So too is the fact that many of those in local and national leadership positions within the NHS understand these problems and have committed to tackling them.

Now is the moment to improve the mental health rehabilitation pathway once and for all, and we have written this report to try to seize on current momentum. The recommendations below seek to build on progress already being made, taking us further and faster towards the aim of delivering the services vulnerable patients need as soon as possible.

We believe there are four priorities to deliver change, and that national and local leadership across all relevant policy makers and providers is critical in delivering these:

1 **NHS England, providers and commissioners must commit to end inappropriate out-of-area rehabilitation placements.**
   This needs to be evidenced with consistent collection and regular publication of data to track progress towards ending out-of-area placements and investing in high-quality locally based rehabilitation services.

2 **The commitment to end inappropriate out-of-area rehabilitation must include a whole system approach:**
   - The development and implementation of an ambitious national plan to reduce out-of-area care should be led by NHS England, and must be jointly developed by all relevant national bodies and clearly define the role that each part of the system will play. Local-level strategies and delivery plans need to be defined clearly. The current GIRFT programme for rehabilitation should be supported and strengthened to achieve implementation of this commitment across England.
   - A consensus statement should be developed that outlines an agreed, shared, definition of the specific circumstances in which out-of-area placements may be considered appropriate. A sufficient number of local rehabilitation beds should be provided in each area, assessed according to local need, This will effectively prevent people being sent out of area.

3 **Those who need rehabilitation mental health treatment in the community should be supported by local specialist rehabilitation services in each CCG footprint, as part of the implementation of the NHS Long Term Plan.**
   This will ensure that effective recovery-based care is available to proactively support people to progress from in-patient to community-based rehabilitation settings as soon as they are able. The skilled rehabilitation workforce needed to deliver this plan should be reflected in the upcoming NHS People Plan and must be further reinforced through central transformation funding.
4 Health, housing and social care must work together locally and nationally – both strategically and operationally – to ensure that support is available to allow quicker discharge.

While the primary responsibility for out-of-area placements and the drive to end them must come from Commissioners and NHS trusts, housing and social care will play a crucial role in making this a reality. There is scope for more imaginative solutions and partnership working, which should be taken up at local level and nationally by DHSC and MHCLG. Social care and supported housing must be properly funded according to local need, with improved data on the services provided, to make local rehabilitation a reality.

Appendix

FOI data

The lack of standardisation in reporting across local health economies makes it difficult to report numbers of out-of-area placements in a robust, consistent manner. Our experience of conducting a FOI request on these issues strengthened our view that responsibilities for reporting should be clarified as a matter of urgency to ensure a full picture is readily available to researchers and policy-makers, enabling trends to be analysed over time and between localities.

Notwithstanding this broader point, we took several steps to ensure that the data that we reported was as accurate as possible, and to reduce the potential for double counting, as follow:

- CCG groups were considered first, to ensure that numbers for constituent individual CCGs were removed from the total. In some instances (e.g. Redditch and Bromsgrove, South Worcestershire and Wyre Forest) each CCG reported the same data, which ran the risk of triple-counting. We therefore removed what we considered to be likely duplicate records. Remaining CCGs were then checked before we examined the data from providers. As trusts do not always map exactly on to CCG areas, we reviewed annual reports to clarify the funding CCGs in each case.

- There was inconsistency in responsibility for collecting data on rehabilitation placements between areas. In some cases, only the CCG or corresponding trust supplied data, but there were also instances where both provided data that appeared to overlap. To avoid double counting, in these cases we have compared the two numbers and deleted the lower of the two.

- To ensure the numbers accounted for beds and placements where organisations merely reported <5 or >5, these were always included as 3 and 8 respectively.