# Perspective/Viewpoint

# Contemporary Mental Health Rehabilitation: Keeping it Simple in a Complex World

#### **Abstract**

A major driver during the era of 'deinstitutionalisation' was the change in societal attitudes towards people with mental illness, away from exclusion and marginalisation towards inclusion and participation in society. More recent mental health policy has tended to focus on promotion, prevention and early intervention, with little mention of those with more complex problems. However, despite the significant investment in early intervention services, long term studies consistently show that around a quarter of people newly presenting with psychosis do not do well. Nevertheless, there is good evidence that with appropriate treatment and support from specialist mental health rehabilitation services, even people with the most severe problems can achieve, sustain and enjoy a rewarding life in the community, yet many 'deinstitutionalised' countries fail to provide rehabilitation services, placing this group at risk of neglect, exploitation and institutionalisation. Happily, this situation is beginning to change. The publication of the first National Institute of Health and Care Excellence (NICE) Clinical Guideline on Rehabilitation for People with Complex Psychosis (NICE; CG 181, 2020) represents a sea change in the recognition of the needs of those with the most severe mental health problems and provides evidence-based recommendations about the treatment and support that should be provided. Alongside this, policy makers in many countries are beginning to recognise the need to include rehabilitation services in their mental health plans. It has been a long time coming, but mental health rehabilitation services are finally being acknowledged as an essential component of the mental health system.

**Keywords:** Contemporary, mental health, mental health rehabilitation, rehabilitation

Contemporary mental health rehabilitation services in the UK and many other countries can trace their origins to the era of deinstitutionalization in the latter half of the 20th century, a period where people were assisted to move from the large asylums on the periphery of towns and cities to smaller, local supported accommodation services and helped to participate in their local communities. Over the subsequent 50 years or so, community mental health services have become increasingly specialized with teams that focus on people with particular diagnostic profiles, teams for those in the early stages of development of psychosis, and teams that provide short-term support to people at home during periods of crisis to try to prevent hospital admission. In this context, mental health rehabilitation services have evolved an increasing focus on people with more severe, complex, and longer term problems.

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In 2005, a survey of UK mental health rehabilitation practitioners was conducted to gather perspectives on the remit of their services. Responses were collated into a widely adopted definition of contemporary mental health rehabilitation:

"A whole systems approach to recovery from mental illness that 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." [1]

This definition emphasizes that rehabilitation is not a single intervention delivered in a specific setting, but rather a highly complex intervention delivered through collaboration between various components of the mental health system, working together to support an individual's recovery, often over many years. This "whole system approach" needs to include inpatient and community-based services provided by statutory (health

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and social care), nonstatutory (voluntary sector/ nongovernmental organization), and independent sector providers of health, housing, welfare benefits, education, and employment services. The definition also highlights the focus on enabling function rather than addressing clinical symptoms (though both are important). It also incorporates the crucial ingredient of "therapeutic optimism" – holding hope for the person's recovery when other parts of the mental health system, the service user themselves, and their family may have lost any belief that things can improve.

Holloway<sup>[2]</sup> noted that the majority of people who require mental health rehabilitation services have a primary diagnosis of a psychotic disorder such as schizophrenia, schizoaffective disorder, or bipolar affective disorder, with symptoms that have not responded to usual treatments. Severe negative symptoms and cognitive impairments associated with longer term psychosis (particularly those that affect executive functioning, i.e., motivation and organizational skills) will often present greater problems for this group than positive symptoms such as hallucinations and delusions. For some, recovery is further complicated by additional mental health problems that may predate the development of the primary mental health problem (such as personality or attachment difficulties, below-average intellectual functioning, or developmental disorders like those on the autism spectrum) or develop alongside it (such as depression, anxiety, and obsessive compulsive symptoms). A significant number will have coexisting substance misuse issues that can exacerbate symptoms further. Long-term physical health problems are highly prevalent (such as obesity, diabetes, cardiovascular problems, and chronic pulmonary disease) due to a range of factors, including side effects from medication, inactivity associated with negative symptoms of the illness, lifestyle choices (like smoking), and lack of access to a healthy diet and opportunities for exercise. These problems impede recovery and impact negatively on the person's social and everyday function to such a degree that they often require recurrent and/or lengthy hospitalizations and have high support needs in the community. Studies from England have also shown that a large proportion (up to three quarters) are vulnerable to sexual and/or financial exploitation and/or significant self-neglect.[3,4]

Despite the complexity of their problems, a number of studies have shown the benefits of mental health rehabilitation services for this group. Harding *et al.*<sup>[5]</sup> found that half to two-thirds of people who received mental health rehabilitation had improved or fully recovered 32 years later. Similarly, national research programs in England have shown that around two-thirds of people with complex psychosis who receive inpatient mental health rehabilitation achieve a successful discharge from hospital within 12 months, without subsequent readmission or community placement breakdown.<sup>[6]</sup> Furthermore, over 40% continue to progress in their recovery in the

community over subsequent years such that they are able to graduate from higher to lower supported accommodation successfully.<sup>[7]</sup> A longitudinal study of the users of inpatient mental health rehabilitation and supported accommodation services in London also found that two-thirds progressed successfully to more independent settings over a 5-year period, with 10% achieving fully independent living.<sup>[8]</sup> A number of "before and after" studies have also shown that inpatient service use is reduced when people have access to mental health rehabilitation,<sup>[9-11]</sup> and this reduction is associated with significant reductions in costs of care.<sup>[12]</sup> These results provide consistent evidence that when people with complex mental health problems have access to mental health rehabilitation services, there is a good reason for therapeutic optimism.

Despite these encouraging findings, until recently, there was no consensus on the specific care that mental health rehabilitation services should provide. As a result, there is a considerable heterogeneity in approach, and many individuals with complex psychosis across the world do not receive adequate support to facilitate their recovery and maximize their independence. However, in August 2020, the first clinical guideline on mental health rehabilitation was published by the National Institute for Health and Care Excellence.[13] The guideline provides evidence-based recommendations on the organization of mental health rehabilitation services and the specific treatments and support they should provide to address people's mental health, physical health, and social needs. It includes recommendations on how to assess the local demand for mental health rehabilitation services to inform the number and type of rehabilitation services (inpatient rehabilitation units, supported accommodation services, and community rehabilitation teams) required to meet the needs of the local population and tailor these into a local rehabilitation care pathway. Most of the recommendations made in the guideline are relevant in any country or setting. For example, it emphasizes the provision of recovery-based practice, since rehabilitation services that provide a greater recovery orientation have been shown to be more successful at supporting people to progress successfully.[6] It recommends specific interventions that help people to gain/regain skills for community living, such as providing a range of group and individual activities within the service and supporting people to engage with leisure, educational, and work-related activities in the local community as they progress in their recovery. It also recommends provision of reflective practice and supervision for staff to assist them in managing the many challenges that working with such a complex service user group can present. This is critical in ensuring that any negative countertransference is addressed, and therapeutic optimism is maintained.

Despite the growing evidence for the effectiveness of mental health rehabilitation services, people with more severe and complex mental health problems have been missing from the national and international mental health policy in the recent years, which has tended to focus on public mental health promotion and early intervention.[14,15] However, robust evidence from long-term cohort studies shows that around a quarter of people newly diagnosed with psychosis who access early intervention services still go on to develop the kinds of severe and complex needs that require specialist rehabilitation services.[16,17] The lack of focus on mental health rehabilitation in policy in the recent years has led to a lack of investment in these services, which in turn, has led to a process of (re) institutionalization of those with more complex mental health needs in many countries, including those that were at the forefront of deinstitutionalization. For example, in Italy, concerns have been raised about the growth of "community residences" provided by the independent sector that provide care to this group, but offer a little in the way of rehabilitation.<sup>[18,19]</sup> In Australia, where nonstatutory services play a major role in the provision of community mental health care, inadequacies in the treatments available to people with more severe psychosis, including under the use of clozapine and psychosocial interventions like supported employment, have been identified.[20] In 2017, the hospital inspectorate for England and Wales reported major concerns that disinvestment in local NHS rehabilitation services had led to thousands of people with complex mental health problems being treated in hospital settings provided by the independent sector, often many miles from their home, with inadequate focus on rehabilitation and community integration and no clear plan of how they would be discharged.<sup>[21]</sup> Across Europe, it has also been shown that the reduction in inpatient psychiatric beds associated with "deinstitutionalization" has been more or less matched by a rise in the number of beds in the forensic mental health system and other forms of more institutional care. [22] These issues are, at least in part, due to the significant economic constraints facing health systems. Providing a longer term, specialist inpatient rehabilitation and supported accommodation is expensive. In the UK, it has been estimated that people with complex mental health needs absorb up to half of all the health and social care resource allocation for mental health.<sup>[23]</sup> It is perhaps no surprise then that inadequacies in services for people with complex mental health problems are exacerbated by perverse incentives that shunt the costs of care from one provider or sector to another, as well as disinvestment in rehabilitation services.

Encouragingly, we seem to be entering an era that recognizes that this situation cannot continue. The latest mental health policy in England includes reference to the need for rehabilitation services for those with the most complex needs,<sup>[24]</sup> and has been accompanied by investment in community rehabilitation teams as a part of the "Community Framework" program.<sup>[25]</sup> In Australia, mental health rehabilitation services are being developed

in New South Wales through the Pathways to Community Living Initiative, [26] and similar recommendations were made in a recent Royal Commission Review of community mental health services in Victoria, Australia. [27] These developments are hugely welcomed and represent public recognition of the ongoing need for specialist mental health rehabilitation services. It remains essential from a political, clinical, and economic perspective that people with complex mental health problems have access to the most effective approaches, models of care, treatments, and interventions that can help them in their recovery, and we, now, have a key tool to deliver this internationally in the form of the National Institute for Health and Care Excellence Guideline on mental health rehabilitation. [13]

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