

Recovery for people with severe and complex mental health problems in Northern Ireland

A guide for trusts and
commissioners of
rehabilitation services

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Introduction

How effective are our rehabilitation services in treating serious and complex mental illness in Northern Ireland?

Rehabilitation service users are usually people with schizophrenia, schizoaffective disorder or bipolar disorder. Around 10% of service users presenting for the first time with a psychotic illness will go on to require rehabilitation services because of the severity of their illness and its debilitating effect on their lives.

Creating the best mental health service for Northern Ireland – a united view across sectors

The need for vastly improved rehabilitation services is shared across mental health organisations and services from both the third sector and the public sector. This is a truly collaborative briefing paper developed over a number of months, shaped and informed by a rich and diverse range of perspectives: service users, carers, leading mental health charities and clinicians.

With major change ahead for health and social care services heralded by Transforming Your Care, the shared aim of this briefing is to call for a review and improvements in our provision of rehabilitation services in Northern Ireland.

We will be faced with many commissioning choices in the future. Choosing to keep rehabilitation services as they currently exist in Northern Ireland undermines our capacity and potential to improve the lives of people most affected by mental illness across our communities.

Maire Grattan
Chief Executive
CAUSE

Key messages for trusts and commissioners

- 1 In spite of the developments in mental health service delivery over the past 30 years in Northern Ireland, there remains a small group of service users whose needs cannot be met by standard services. Because of the severity and complexity of their illness, they need longer timeframes and intensive intervention to recover.
- 2 This group requires a specialist service: rehabilitation. Rehabilitation is a highly effective treatment. It can transform lives and mean the difference between true recovery and institutionalisation. It is cost-effective and is in line with current strategy, philosophy and values in mental health (the Bamford review, the Transforming Your Care programme and the Implementing Recovery through Organisational Change programme).
- 3 Rehabilitation is not a new service. It exists in some form in all trusts. However, although in line with current strategy, it has not been included in strategy. The result is that these services have not been valued or developed. There is no incentive for trusts to do so. Rehabilitation services are patchy, inadequate to meet the need and seen as an easy place to make savings.
- 4 The absence of rehabilitation in our mental health services has serious consequences for service users, their families and the public purse. Without rehabilitation, the most severely ill and vulnerable members of our society will not have the opportunity to recover and lead meaningful lives. They are at risk of a new form of institutionalisation, stuck in acute (mental health) wards or in out-of-area placements with the associated high costs.
- 5 Meeting the Transforming Your Care goal of ending institutional care by 2015 can only be achieved if there is a pathway to recovery for people with the most severe and complex illness. This needs to be acknowledged and incorporated into mental health strategy in Northern Ireland. Trusts must be held accountable for how they plan to develop their rehabilitation services to meet the needs of this group.

What are mental health rehabilitation services?

Mental health rehabilitation is a whole-system approach to recovery

It maximises an individual's quality of life and social inclusion by fostering their skills, promoting independence and autonomy in order to give them hope for the future, and aiding successful community living through appropriate support (Box 1, page 7).

It is a specialist mental health intervention with both in-patient and community components. It is an essential care pathway to enable recovery for a group of patients with severe and complex mental health needs. It has the joint aim of minimising symptoms of illness and promoting social inclusion.

Because of the complex nature of their patients' problems, mental health rehabilitation services often work with their service users over many years, enabling them to gain (or regain) confidence and skills in everyday activities and in managing their mental health symptoms.

Who uses mental health rehabilitation services?

Clients of mental health rehabilitation are usually people with schizophrenia, schizoaffective disorder or severe bipolar illness who have not

recovered with the help of general mental health services.

The pathway to this service can involve many years of illness. People might have experienced lengthy periods of acute hospital stay or repeated 'revolving door' admissions.

The barriers to recovery for some people with mental illness can be complex:

- persistent, troubling symptoms of psychosis
- severe negative symptoms
- cognitive impairment
- comorbid mental and physical health problems
- substance misuse
- functional impairment
- challenging behaviours.

Because of these problems and their consequences, the individual, their family and even their supporting professionals can have low expectations and, at worst, may have lost hope. This is a low-volume but high-need group.

Around 1% of people with schizophrenia are in receipt of in-patient rehabilitation. While this is a small proportion of all those using mental health services, schizophrenia is a common illness, affecting approximately 4 people per 1000 at any time. This is a relatively small but not insignificant group.

Around 10% of service users presenting to mental health services for the first time with a psychotic illness will go on to require rehabilitation services owing to the severity of their functional impairment and illness.

Why are mental health rehabilitation services important to commissioners?

Mental health rehabilitation services work

A major aspect of the ethos of rehabilitation services is the continuous promotion of therapeutic optimism. There is good evidence that this optimism is neither idealistic nor misplaced.

Among those with complex problems, with appropriate rehabilitation the majority (60%) are able to progress to successful supported community living within 5 years and around 10% will achieve independent living (Joint Commissioning Panel for Mental Health, 2012: p. 19).

In a study in the Republic of Ireland, a group of service users accessing a rehabilitation service was compared with a group with similar problems waiting for the same service (Lavelle *et al*, 2011). The rehabilitation group was eight times more likely to achieve and sustain successful community living.

The absence of mental health rehabilitation has consequences

The alternative – resettlement without rehabilitation – is to close existing longer-stay wards with no development of rehabilitation services, leaving Northern Ireland with a fragmented and very limited service (Box 2).

We would be left with generic acute in-patient and community services and forensic services. Patients who neither recovered quickly nor committed serious offences, but had major deficits with essential life skills, would suffer. There would be serious negative consequences for the mental health and quality of life of these patients and also negative economic consequences. People can become ‘stuck’ on acute wards because of the lack of an available service to meet their needs. This leads to problems for the individual – distress and institutionalisation – and for the service.

Acute hospital care is expensive. The inappropriate use of acute beds (sometimes called ‘bed blocking’) leads to chronic bed shortages and problems accessing acute beds for those who need them.

Box 1 Robert's story

'I am 36 years old and I have had mental health problems for nearly 20 years. I have an illness called schizoaffective disorder and I was unwell for many years. Throughout my 20s I had numerous admissions to a psychiatric hospital for long periods of time. I was offered rehabilitation in a local facility and then supported living accommodation. Initially I wasn't sure about this but it has changed my life.

Before I was given this opportunity, I was living with my parents. My relationship with them was very poor and the situation at home was stressful for everyone. They were worried about what might happen when I was unwell. My admissions to hospital were becoming more frequent.

I am now living in an independent flat with support from staff. I have not had a hospital admission since 2006 and my mental health is good. I go out to work for a few hours every day. My mental health has never been better; I regularly exercise and attend football training weekly. My relationship with my parents and family is great now.

I hope to continue to live independently and enjoy an active, healthy life thanks to this great opportunity.'

Box 2 Possible consequences of having no mental health rehabilitation services

Service related

- Increased readmissions to psychiatric acute wards
- Delayed discharges
- Pressure on acute beds, leading to longer-term increases in cost
- High-cost out-of-area placements for people with complex needs who could have an effective local service

Person related

- Patients not being given the opportunity to recover life skills or recover from illness or to make a success of their lives
- Harm to self or to others
- Institutionalisation

Learning from the experience of others

In England and Wales, psychiatric hospital closures took place rapidly in the latter part of the 20th century and were virtually completed by the late 1990s. Rehabilitation services were not developed in parallel and there was disinvestment in this area. Although resources were concentrated on developing certain types of community service, these mostly met the needs of people with less severe forms of mental ill health. No real account was taken of the severity and complexity of illness experienced by a minority of service users.

The result was that many people who needed longer or more intense treatment were placed in non-NHS facilities far from their place of origin. Providers from the profit-making sector were quick to grasp this opportunity. This led to the existence of a 'virtual asylum' with placements costing 65–100% more than a locally provided NHS service (Edwards *et al*, 2012: p. 19).

In 2004–2005, the cost to the NHS of out-of-area placements was £222 million. Once this problem was identified, investment in local rehabilitation pathways improved. Patients are being 'repatriated' to effective services in their local trusts, leading to better outcomes and considerable cost savings.

Although some elements of mental health services in Northern Ireland are highly developed, from the perspective of hospital closure we are in a similar position to England 10–15 years ago. The cost of allowing the private sector to move in to plug the gap in provision is more than just financial. These services are often situated far from patients' social contacts, lack any incentive to help people to achieve timely discharge and are not linked to networks of supported living and community services. The potential result is a new generation of institutionalised people with no opportunity to recover and lead meaningful lives.

Delivering Transforming Your Care

The mental health goals of Transforming Your Care (Box 3), in line with the Bamford review, include the closure of long-stay institutions and reducing the number of people in institutional care and in-patient beds; this goal is shared by practitioners, service users and carers.

The challenge is to align these goals with an understanding of the severity and complexity of schizophrenia and related illnesses, and to develop a modern mental health service for Northern Ireland that meets the needs of this group. If we don't, we risk the creation of a new population of 'virtually institutionalised' patients.

A recovery-based approach is essential. Many patients with psychotic illnesses are appropriately and successfully treated by acute mental health services and community mental health teams. There is, however, a small but important minority of people who live with schizophrenia whose recovery is harder to achieve and who require a specialist service (Box 4).

Many individuals with rehabilitation needs have significant histories of repeat or protracted acute hospital admissions (sometimes called 'revolving door syndrome'). Acute ward environments do not

meet the needs of this group of patients, leading to poor outcomes and institutionalisation.

According to the Vision to Action summary in Transforming Your Care, we need to reduce institutionalisation: rehabilitation services are the means to deliver this goal.

Box 4 A carer's story

'Our son developed paranoid schizophrenia aged 22; he is now 44. At first, attempts were made to treat him in the community, which in our view was an absolute fiasco. The staff tried but did not have specialised training and there were not adequate facilities to care for people with severe mental illness. Only when we insisted that our son be transferred to hospital did he eventually get the specialised care he needed.

The care he has received in rehabilitation has been wonderful: caring staff, a tremendous and insightful care package with his need as a priority, and he has been treated holistically and not as an illness! The whole care package, which included Mindwise and various other agencies, has been of the highest quality. This has enabled him to regain a lot of his life and he is now living in the community with support. Because of the severity of his illness this has taken many years to accomplish.

It has given us all hope for his future. We just don't know what we would have done without this provision. We love our son, and are so very grateful for the provision of the excellent care and rehabilitation he has received.'

Box 3 A summary of *Transforming Your Care: A Review of Health and Social Care in Northern Ireland* (Health and Social Care Review Team, 2011)

- Greater self-care to avoid chronicity
- Secondary prevention
- Self-management: supporting individuals as they acquire skills and take control of their own care plan
- 'Introduction of re-ablement to encourage independence and help avoid unnecessary admissions of older people into hospital' (Health and Social Care Review Team, 2011: p. 70)

'It is clear that people with long term conditions require high levels of care. It naturally follows that the health and social care system needs to focus its efforts on how to deliver high quality care to these individuals. The objective is to ensure better outcomes for patients. It is also important to understand that better organisation of care pathways will improve quality and value for money' (Health and Social Care Review Team, 2011: p. 71).

These goals are clearly in line with those of mental health rehabilitation services and, in fact, cannot be effectively delivered without a pathway to recovery for patients most at risk of institutionalisation (Edwards *et al*, 2012: p. 19).

What rehabilitation services are currently available in Northern Ireland?

Statutory services

All mental health services in Northern Ireland have some kind of rehabilitation service, but this has tended to be an almost accidental by-product of the hospital closure programme. These services are patchy, considered low priority and often delivered in poor-quality environments.

In recent years, the emergence of the recovery paradigm has given rise to a belief in some quarters that rehabilitation is unnecessary. Partly because of this belief, many of the current rehabilitation services, minimal as they are, are under threat.

In fact, the core concepts of recovery are the key ingredients to successful rehabilitation: the development of a culture of empowerment, healing and hope.

In 2012, the Faculty of Rehabilitation and Social Psychiatry of the Royal College of Psychiatrists (Northern Ireland) undertook the first regional audit of the availability of facilities and services to support the rehabilitation of those with ongoing disabilities as a result of severe psychiatric illnesses such as schizophrenia. The audit tool was based on the standards for services as defined by Wolfson *et al* (2009).

As Tables 1 and 2 show, services are patchy, with very little in the way of designated rehabilitation services. Some rehabilitation services are in place only because of a belief on the part of staff that they are worthwhile and needed. They are being 'fitted in' to those parts of hospitals that remain open. Physical environments are in poor condition and services are considered as low value by trusts.

Table 1 Non-acute hospital and residential services in Northern Ireland^a

	Belfast	S. Eastern	Southern	Northern	Western
Step Down Beds scheme	None	Some	None	None	Some
Continuing care beds	Some	Some	None	Some	Some
In-patient rehabilitation unit	Service provided	None	Service provided	Service provided	None
Secure rehabilitation unit	Some	None	None	None	None
Adequate supported housing initiatives	None	None	None	None	None

a. Data collected between June and September 2012, using the audit tool.

	Belfast	S. Eastern	Southern	Northern	Western
Specialised community team for major mental illness	Some	None	Some	Some	Some
Voluntary-sector community resources	Service provided				
Designated community rehabilitation team	Some	Service provided	None	None	None
Trust day hospital	None	Some	Some	Service provided	None
Early intervention team	Service provided	None	None	None	None

a. Data collected between June and September 2012, using the audit tool.

They tend to be open to mislabelling as ‘old long stay’ and are threatened with closure.

Voluntary-sector services

Both hospital- and community-based rehabilitation rely hugely on the services provided by the voluntary sector. These include vocational rehabilitation, low-key social activities, supported accommodation, education and training, self-help, and life skills. Voluntary organisations have been at the forefront of service user and carer empowerment, ensuring service users have an effective voice. They are strongly recovery oriented and have battled over many years to reduce the stigmatisation and ghettoisation of people with mental health problems. These organisations have considerable expertise in providing services for this particular service user group.

In spite of their drive towards a recovery ethos, voluntary organisations express frustration at current models of funding and commissioning their services. They disagree with the emphasis on ‘throughput’ and time limits being placed on the recovery of individuals. They know that some service users will need their services for many years, or even indefinitely.

The funding dilemma

In recent years, the only available source of funding for supported community living has been through the housing budget, from a fund known as Supporting People. Trusts have sought to develop supported housing schemes through this mechanism. Some have been very successful. However, trusts have also sought to dismantle existing rehabilitation services and replace them with schemes funded through Supporting People. This has the aim of making efficiency savings, but is also disingenuously rationalised as recovery or community oriented. In fact, there are major problems in trying to deliver true rehabilitation services within the restrictions of a Supporting People scheme. The definitions of support are too rigid and inflexible to deliver what is essentially an active treatment.

The financial model of funding through housing benefit leaves service users with the unreasonable dilemma that, in order to access an essential treatment to aid their recovery, they have to give up their home. This dilemma creates a barrier to engagement and is antithetical to the entire ethos of a recovery-based service, which puts the service users’ personal goals at the core of the recovery plan.

Northern Ireland has no coherent plan for how to meet the needs of people with severe, complex mental health problems, who need recovery with specialist treatment over longer time periods.

What would a good mental health rehabilitation service look like?

Rehabilitation services form part of a pathway to recovery for people with schizophrenia and related psychoses. These services should be provided in a variety of settings, accepting referrals from acute wards and low secure wards through to in-patient rehabilitation units, community-based residential rehabilitation units and various levels of supported and independent living.

Community-based rehabilitation teams can offer a specialist outreach service to those who have severe functional impairment that is hard to address through traditional community mental health teams. See Fig. 1 and Fig. 2 for the key values and tasks of rehabilitation services.

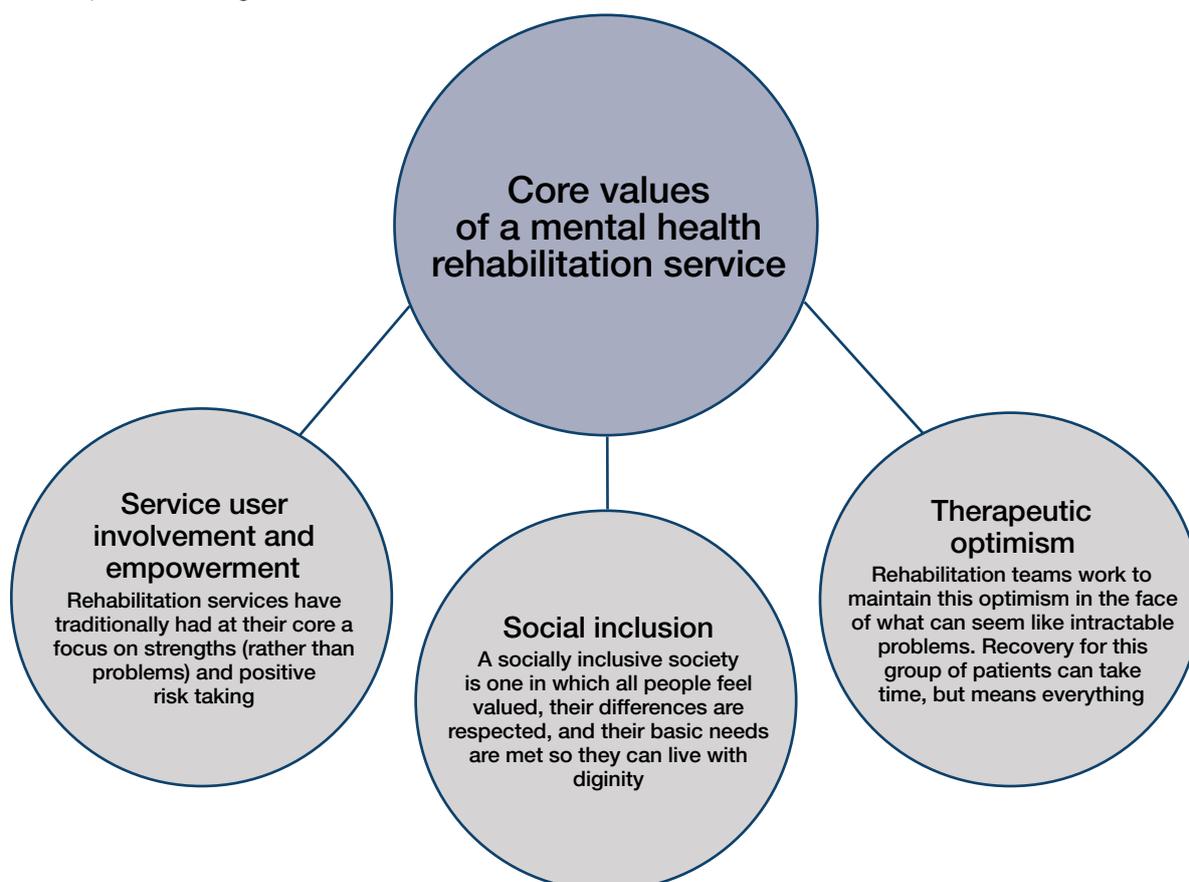


Fig. 1 The core values of a mental health rehabilitation service. These values require team members with the personal qualities needed for this kind of work.

In-patient services

In-patient rehabilitation is an essential part of the pathway for service users whose mental health issues are severe and complex.

Service users whose needs are not well met in acute in-patient services need to be able to move seamlessly into an environment that supports their recovery. This environment should be able to support intensive and complex medical treatment with use of mental health legislation where appropriate.

In Northern Ireland, legislative restrictions mean that this part of the pathway will need to be hospital based. Although a hospital designation is necessary, there should be a clear understanding that length of stay may be several months, or even a year, and the environment and ethos must reflect this. For example, the environment should be comfortable, welcoming and homely, and it should be built to a high specification with appropriate facilities to enable privacy and dignity. An institutional feel should be avoided. Service users should have access to proactive primary healthcare (i.e. a GP).

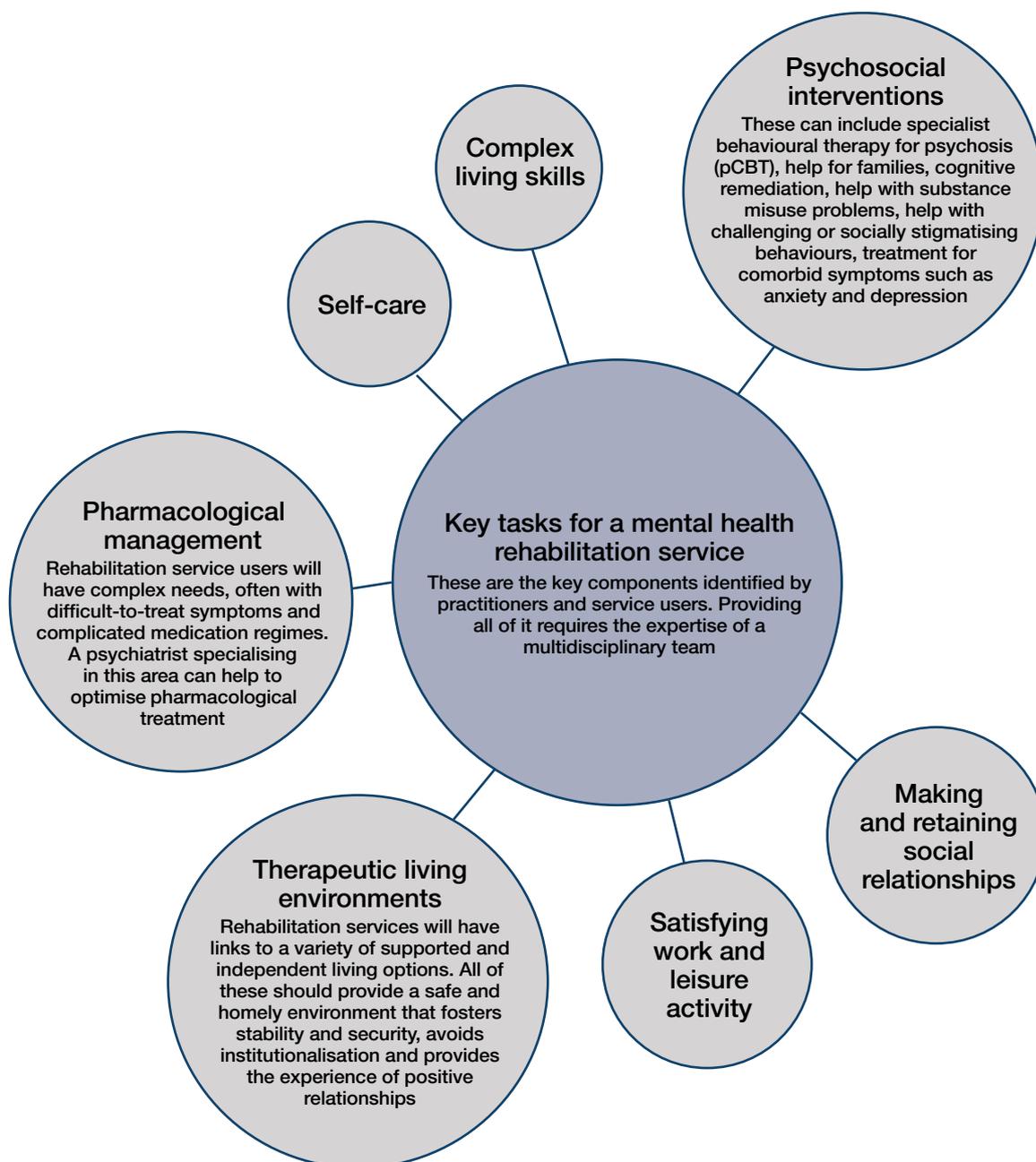


Fig. 2 The key tasks that a mental health rehabilitation service should achieve.

There may be more than one type of in-patient rehabilitation unit, depending on local need.

Community-based residential rehabilitation units

There is more than one model of provision for a community residential rehabilitation service. In some areas trusts provide these services and in some they are provided by voluntary agencies. There may be more than one type of residential facility, for example a facility suitable for higher-functioning service users. This kind of facility might provide a very intensive, active programme and link up strongly with local vocational services. Often this type of service will take referrals directly from acute wards or the community, as well as from in-patient rehabilitation units. Other units may be more suited to service users with ongoing severe,

complex needs, who would benefit from a slower and less pressurised recovery process.

It is vital to understand that there is a difference between community-based rehabilitation and supported living. Rehabilitation includes support, but it is considerably more than that.

Community rehabilitation teams

Community rehabilitation teams often work as extensions of in-patient or community-based rehabilitation units. They provide continuity of care and focus on functional and quality-of-life improvements for service users. Social inclusion is an important part of their role, and they often achieve life-changing reductions in social isolation. These teams have higher staff-to-patient ratios, which are justified economically by a reduced need for acute admissions.

Planning a mental health rehabilitation service in Northern Ireland

In England and Wales, nearly all mental healthcare trusts have an in-patient rehabilitation unit and about half of all trusts have a community rehabilitation team. According to the Royal College of Psychiatrists (Joint Commissioning Panel for Mental Health, 2012), a region equivalent to

Northern Ireland should have not just one tier but a range of local in-patient rehabilitation services that manage differing levels of complexity for different durations. Only a planned, regional approach could achieve this (Fig. 3).

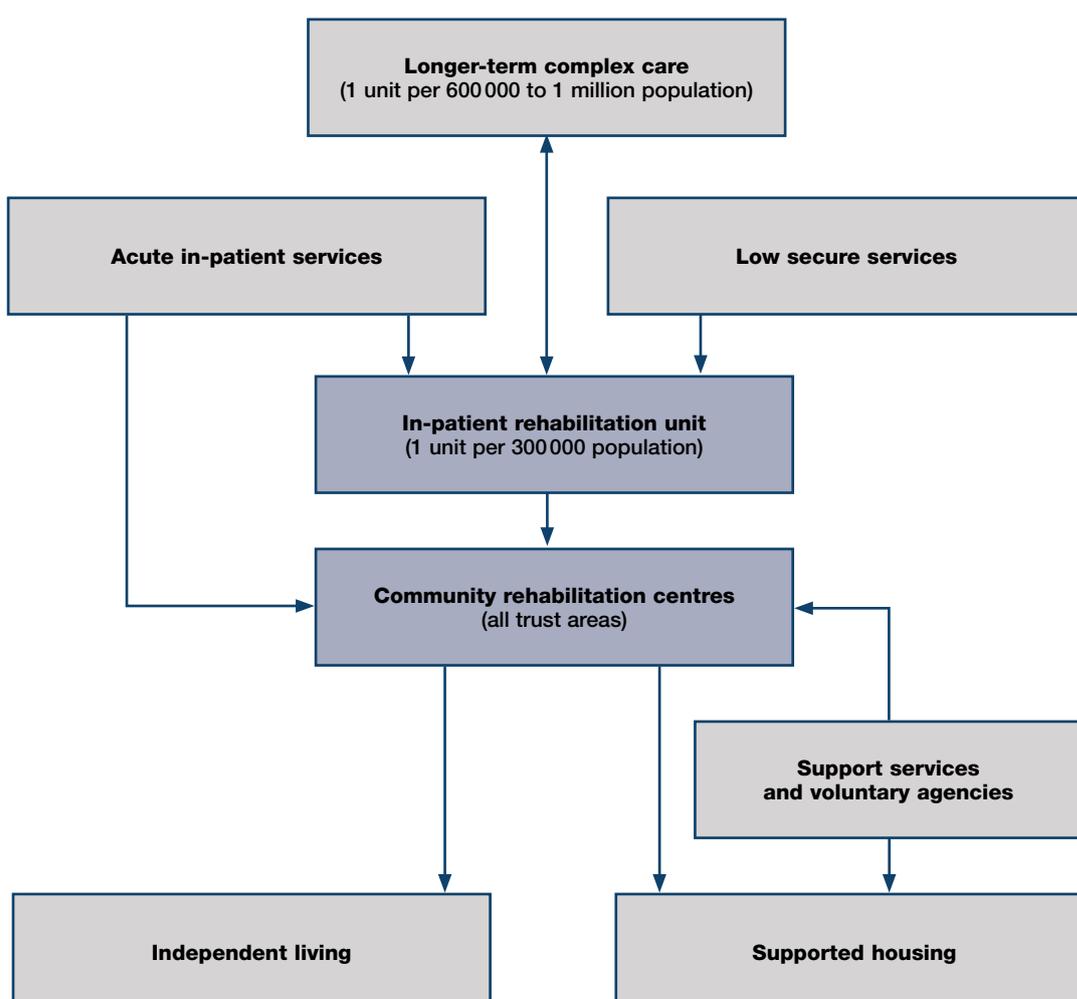


Fig. 3 The cooperation between various mental health medical and rehabilitation services.

Ideally, they should provide residential and non-residential programmes. They should have close links to non-statutory services, especially accommodation, advocacy, peer support and services to support work and occupation.

In-patient rehabilitation units

The recommendation is that there should be one unit for each 300 000 in the population; therefore, one per trust.

England and Wales are subject to different mental health legislation, and an in-patient unit of this type can be located away from a hospital site. Whether within a hospital or standing separately, an in-patient facility will have multidisciplinary staff and usually admit patients for 1–2 years. They usually have a mix of detained and voluntary patients. Some detained patients become voluntary during their in-patient stay.

Regional and sub-regional services

High-dependency and longer-term units are recommended per 600 000 to 1 million population and take patients for up to 3 years and more than 5 years, respectively.

High, medium and low secure services form part of the forensic network but link closely with rehabilitation and need to be developed in parallel.

Community rehabilitation services

All trusts should develop community rehabilitation services. These teams will work with service users over long periods, beginning with enabling discharge from in-patient services and supporting them in maximising independence and social inclusion.

What should happen now?

The needs of service users with the most severe forms of mental ill health must be considered as part of mental health strategy in Northern Ireland. The role of rehabilitation must be acknowledged and incorporated into this strategy. This must be urgently prioritised under the ongoing Bamford review and the implementation of Transforming Your Care.

Only then will trusts be incentivised to value, retain and develop these services. Trusts must be held accountable for developing a pathway to recovery for people with severe and complex mental health problems beyond the implementation of Transforming Your Care.

If this does not happen, we will not succeed in ending institutional care by 2015. We are in danger of creating a new generation of people at risk of poor outcomes and 'virtual institutionalisation'. The timescale of the Transforming Your Care goals creates an urgency, but also an opportunity.

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