

Rehabilitation Services

Recovery for People with Severe and Complex Mental Health Problems In Northern Ireland 2014



*A guide for Trusts
and commissioners
compiled in partnership
with Service Users
and Carers, voluntary
agencies and the Royal
College of Psychiatrists
(Northern Ireland)*

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1. In spite of the developments in how mental health services are delivered over the past thirty 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 may 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; Bamford, TYC and ImROC*.

3. Rehabilitation is not a new service. It exists in some form in all Trusts. However, It has not been included in current strategy. The result is that these services have not been valued or developed. There is no incentive for Trusts to do so. They are patchy, inadequate to meet the need and seen as an easy source of savings.

5 Key Messages for Commissioners and Trusts

4. The absence of Rehabilitation in our Mental Health services has serious consequences for people, 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 expensive Out of Area placements with the associated high costs.

5. Meeting TYC goals 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 to account for how they plan to develop their rehabilitation services to meet the needs of this group.

**Implementing Recovery through Organisational Change.*

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 and bi-polar disorder. Around 10% of service users presenting for the first time with a psychotic mental illness will go on to require rehabilitation services due to the severity of their illness and its debilitating impact on their lives.

Creating the best mental health service for NI – 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. In choosing to keep rehabilitation services as they currently exist in NI undermines our capacity and potential to improve the lives of people most affected most by mental illness across our communities.

Maire Grattan
Chief Executive
CAUSE

"I am 36 years old and I have had mental health problems for nearly 20 years. I have an illness called Schizo-affective disorder and I was unwell for many years. Throughout my 20's had numerous admissions into 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 into 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."

Robert

What are Mental Health Rehabilitation Services?

Mental Health Rehabilitation is a whole system approach to recovery from mental ill health.

It maximises 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.

It is a specialist mental health intervention with both inpatient 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 aims of minimising symptoms of illness and promoting social inclusion.

Due to the complex nature of their problems mental health rehabilitation services often work with their clients over many years, enabling them to gain/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 and severe bipolar illness who have not been able to recover with the help of general mental health services.

Typically the pathway to this service can involve many years of illness. People can 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 and include:

Persistent troubling symptoms of psychosis

*Severe negative symptoms
Cognitive impairment*

Co morbid mental and physical health problems

Substance misuse problems

Functional impairment

Challenging behaviours.

Around 10% of service users with a psychosis will go on to require rehabilitation services.

“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 that eventually he got 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, 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. Due to 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.”

A carers story.

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 high need group.

At any time around 1% of people with schizophrenia are in receipt of inpatient rehabilitation. While this is a relatively small proportion of all of 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.

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 five years and around 10% will achieve independent living.

(Ref: (2) P19)

A study in the Republic of Ireland demonstrated that when a group of service users accessing a rehabilitation service were compared with a group with similar problems waiting for the same service, the rehabilitation group were *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, therefore leaving Northern Ireland with a fragmented and very limited service. We would be left with generic acute inpatient 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 both in the mental health and quality of life of these patients but also in economic terms. People can become ‘stuck’ on acute wards due to the lack of an available service to meet their needs. This leads to problems for the individual; distress and institutionalization, 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.

Having no rehabilitation service has serious consequences:

Service related:

Increased re-admissions 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. The consequences of this may be tragic in some cases with harm to self or to others. Institutionalisation.

Learning From the Experience of Others.

In England and Wales, psychiatric hospital closure took place rapidly in the latter part of the last century and was virtually completed by the late 1990s. Rehabilitation services were not developed in parallel and there was disinvestment in this area. While 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 periods 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. (Ref: (11) P19)

In 2004-2005 the cost of out-of-area placements to the NHS was £222 million. This problem has now been identified and investment in local rehabilitation pathways has improved. Patients are being 'repatriated' to effective services in their local Trusts leading to better outcomes and considerable cost savings.

Although some elements of the mental health services in Northern Ireland are highly developed and among the best, from the perspective of hospital closure, we are in a similar position to England ten to fifteen 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 patient's 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 result is potentially a new generation of institutionalized people who do not have the opportunity to recover and lead meaningful lives.



Delivering Transforming Your Care

The mental health goals of Transforming Your Care (TYC), in line with Bamford, include the closure of “long stay institutions”, reducing the numbers of people in institutional care and inpatient beds; this goal is shared by practitioners, service users and carers.

The challenge beyond TYC is to understand the severity and complexity of Schizophrenia and related illnesses and develop a modern mental health service for Northern Ireland that meets the needs of this group. The alternative is 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 those people who live with schizophrenia whose recovery is harder to achieve and who require a specialist service.

Many individuals with rehabilitation needs have significant histories of repeat or protracted acute hospital admissions (Sometimes called “revolving door”). Acute ward environments do not meet the needs of this group of patients, leading to poor outcomes and institutionalisation.

Vision to Action summary says we need to reduce institutionalisation; Rehabilitation services are the means to deliver this goal.

Transforming your care (A Review of Health and Social Care in Northern Ireland December 2011) focuses on

- Greater self-care to avoid chronicity
- Secondary prevention
- Self-management. Supporting individuals to 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.” (Page 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.” (Page 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 those patients most at risk of institutionalisation.

(Ref: (11) P19)

“When I was living in the community I was “in the horrors.” I was drinking every day, getting into trouble and battling to live on my own or with my family. I was incontrollable.

I spent time in prison and then moved to a mental health hospital, where I was in a locked ward for over a year. Then I moved to a rehab ward. At first I was hurt leaving my mum, however this period of time in hospital allowed my mental state to settle and it helped me come off the drink.

When in hospital, I began to regain skills, such as cooking and developing the confidence to go into the local town. I was ready and waiting to move to supported living. It took me a while to adjust to the change of moving to supported living, however I am now well settled and I am benefiting from the balance of freedom and staff support. I have good relationships with staff and also now have an improved relationship with my mother.

My mental health is on the right pathway.”

Martin 39 suffers from Schizophrenia

What Rehabilitation Services are currently available in Northern Ireland?

Statutory Services

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

In the latter part of the last century rehabilitation came to be regarded as synonymous with resettlement of the long stay hospital population. It became unfashionable as a concept and the term rarely appears in mental health policy documents.

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

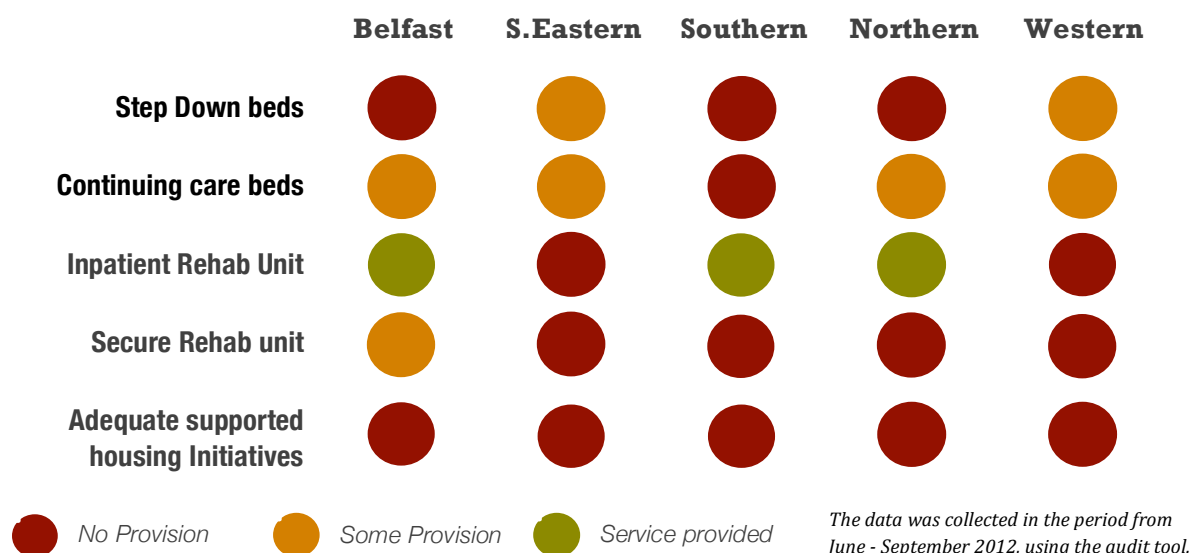
In fact the core concepts of recovery are the key ingredients to successful rehabilitation:

The development of a culture of empowerment healing and hope.

In 2012 the Faculty for Social and Rehabilitation Psychiatry Royal College of Psychiatrists Northern Ireland, undertook the first regional audit of the availability of facilities and services to support the rehabilitation of those in our community who had ongoing disabilities as a result of severe psychiatric illnesses such as Schizophrenia

The audit tool was based on the standards for services as defined in the Royal College of Psychiatrist’s Faculty Report FR/RS/1 ***‘Enabling recovery for people with Complex Mental Health Needs -a Template for Rehabilitation Services’***.

Non-acute Hospital & Residential Services



It is very easy to see at a glance that services are patchy with very little in the way of designated rehab services. Some rehabilitation services are taking place 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. They tend to be open to mislabelling as 'old long stay' and are threatened with closure.

Both hospital and community based rehabilitation relies hugely on the services provided by the voluntary sector.

Voluntary sector services

These include vocational rehabilitation, low-key social activities and supported accommodation, education

and training, self-help and life skills. Voluntary organisations have been at the forefront of promoting service user and carer empowerment and have led the way in ensuring service users have an effective voice. They are strongly recovery orientated and have battled over many years to reduce stigma and ghettoization of people with mental health problems. These providers have considerable expertise in providing services for this particular service user group. In spite of their drive toward a recovery ethos, voluntary organisations express frustration at current models of funding and commissioning their services. They disagree with the emphasis on 'throughput' with 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. 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 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 orientated.

In fact there are major problems in trying to deliver true rehabilitation services within the restrictions of a *Supporting People* scheme.

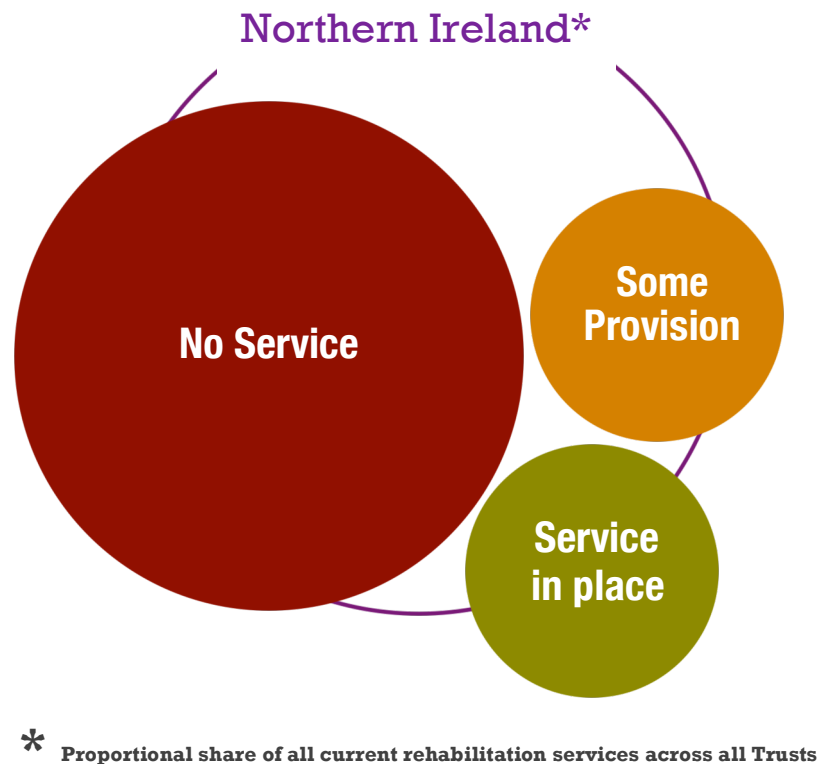
Community Services

	Belfast	S.Eastern	Southern	Northern	Western
Specialized community team for major mental illness	Some Provision	No Provision	Some Provision	Some Provision	Some Provision
Voluntary Sector Community Resources	Service provided	Service provided	Service provided	Service provided	Service provided
Designated Community Rehab team	Some Provision	Service provided	No Provision	No Provision	No Provision
Trust Day hospital	No Provision	Some Provision	Some Provision	Service provided	No Provision
Early Intervention Team	Service provided	No Provision	No Provision	No Provision	No Provision

 No Provision
  Some Provision
  Service provided

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 that puts the service users personal goals at the core of the recovery plan.



There remains no coherent plan for how to meet the needs of people whose mental health problems are of the more severe and complex type and who need recovery with specialist treatment over longer time periods.

What would a good Mental Health Rehabilitation Service look like?

Complex living skills

Psychosocial Interventions:

These may include Specialist cognitive behavioural therapy for psychosis pCBT. Help for families, cognitive remediation, help with substance misuse problems, help with challenging or socially stigmatising behaviours. Interventions to help with co morbid symptoms such as anxiety & depression.

Self Care

Pharmacological Management:

Clients of a rehabilitation service will by definition have complex needs often with difficult to treat symptoms and complex medication regimes. Specialist expertise of a psychiatrist with interest and training in this area can help to optimise pharmacological treatment.

What are the key tasks for a mental health rehabilitation service?

These are the key components identified by practitioners and service users. Providing all of it requires the expertise of a multidisciplinary team with a specific set of skills.

Making and retaining social contacts and relationships.

Therapeutic living environments:

Rehabilitation services will have links to a variety of supported and independent living options. All of these should provide a safe and homely place which fosters stability and security, avoids institutionalisation and provides the experience for service users of positive relationships.

Satisfying and fulfilling work and leisure activity

**Service user
involvement and
empowerment:**

Rehabilitation services have traditionally had at their core a focus on strengths rather than problems and on positive risk taking

Social inclusion:

A socially inclusive society is defined as one where all people feel valued, their differences are respected, and their basic needs are met so they can live in dignity.

**What are the core
values of a mental
health rehabilitation
service?**

Therapeutic optimism:

A core component of a recovery ethos. Rehabilitation teams work to maintain this optimism often in the face of what seem like intractable problems. Recovery for this group of patients can take time but means everything.

These values require a team who not only have the skills to carry out the tasks of the service but also the personal qualities necessary for this work. These include patience, flexibility and an ability to work comfortably in an environment that doesn't adhere as traditionally to the 'patient- staff boundary'

Where should mental health rehabilitation take place?

Rehabilitation services form part of a pathway to recovery for people with schizophrenia and related psychoses. Rehabilitation services should be provided in a variety of settings, accepting referrals from acute wards and low secure wards through inpatient rehabilitation, 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 in the community that is hard to address through traditional community mental health teams.

1. Inpatient services

Inpatient rehabilitation is an essential part of the pathway for service users whose mental health needs are severe and complex.

Service users whose needs are not well met in acute inpatient 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. It should be able to manage complex physical and mental health needs with intensive interventions as previously described.

In Northern Ireland legislative restrictions mean that this part of the pathway will need to be hospital based. While having a hospital designation there should be a clear understanding that admissions may be several months and can be around a year and the environment and ethos must reflect this. For example: the environment should be comfortable welcoming and homely, there should be a high specification with appropriate facilities to enable privacy and dignity. Institutionalisation should be avoided. Service users should have access to proactive Primary Healthcare (a GP)

There may be more than one type of inpatient rehabilitation unit depending on local need.

2. Community based residential rehabilitation unit.

There is more than one model of provision for a community residential rehabilitation service. Some Trusts provide these services and in some areas they are provided by voluntary agencies. There may be more than one type of residential facility, with some providing for service users with comparatively higher

functioning. A facility such as this may provide a very intensive and active programme and link in strongly with local vocational services. Often this type of service will take referrals directly from acute wards or the community as well as from inpatient rehabilitation. Other units may be more suited to those service users with on going severe and complex needs who will benefit from a slower and less pressurised recovery process.

It is vital to understand the difference between community based rehabilitation and supported living. Rehabilitation includes support, as one of its elements but it is considerably more than that.

3. Community Rehabilitation Teams

Community rehabilitation teams work often as extensions of inpatient or community rehab units. They provide continuity of care over time and further the work of functional and quality of life improvement for service users. Social inclusion is an important part of their role, often achieving life-changing reductions in social isolation. These teams have higher staff to patient ratios, which are justified economically by reduced need for acute admissions.

Planning a Mental Health Rehabilitation Service for Northern Ireland

“Guidance for Commissioners of Rehabilitation Services for People with Complex Mental Health Needs”

<http://www.rcpsych.ac.uk/pdf/rehab%20guide.pdf>

has been published by an expert multi-disciplinary panel including the Royal College of Psychiatrists in London, service users and carers.

In England nearly all Trusts have a rehabilitation inpatient unit and about half of all Trusts have a community rehabilitation team. The document explains that a region equivalent to Northern Ireland should have not just one tier but also a range of local inpatient rehabilitation services that manage differing levels of complexity for different durations. Only a planned, regional approach could achieve this.

1. Inpatient Rehabilitation Unit.

The recommendation is that there should be one unit 300,000 population-therefore one per HSC Trust.

In England differences in mental health legislation mean that an inpatient unit of this type can be located away from a hospital site. Whether situated in a hospital or standing separately an inpatient facility will have multi-disciplinary staff and usually admit patients for 1-2 years. They are able to take detained patients and usually have a mix of detained and voluntary patients. Patients become voluntary during their inpatient stay.

2. Regional and sub regional services

High-dependency and longer-term units are recommended per 600k -1 million population and take patients for up to 3 and 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.

3. 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 inpatient services and supporting them to maximise independence and social inclusion.

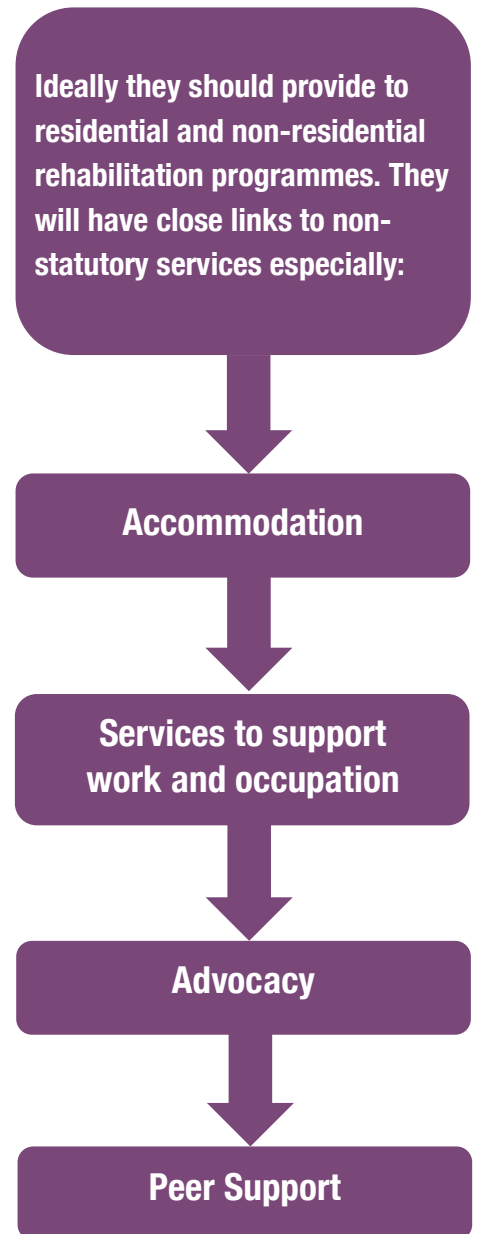
Ideally they should provide to residential and non-residential rehabilitation programmes. They will have close links to non-statutory services especially:

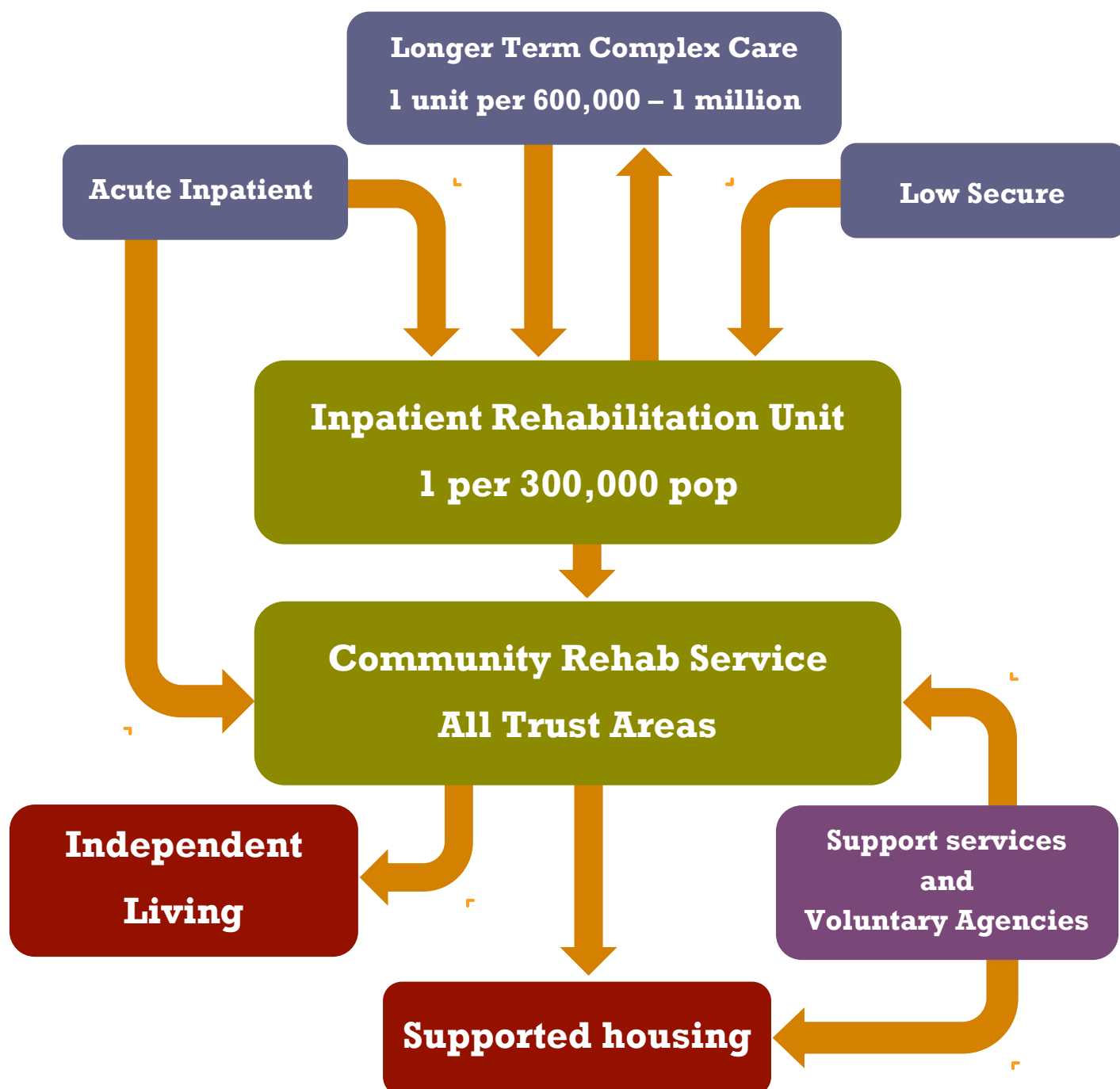
Accommodation

Services to support work and occupation

Advocacy

Peer Support





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 reprioritised under on-going Bamford review and TYC implementation.

Only then will Trusts be incentivised to value, retain and develop these services. Trusts must be held to account for how they plan to develop a pathway to recovery for people with severe and complex mental health problems beyond the implementation of TYC.

If this does not happen we will not succeed in ending institutional care by 2015 but will only create a new generation of people at risk of poor outcomes and “virtual institutionalization”.

The time-scale of the TYC goals creates an urgency but also an opportunity.

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