Acquired Brain Injury Forum for London (ABIL)

http://www.abil.co.uk

Comments on the White Paper: Equity and excellence: Liberating the NHS

EXECUTIVE SUMMARY

1. Acquired Brain Injury Forum for London (ABIL)

ABIL is a group of front-line professionals, commissioners, survivors of acquired brain injury (ABI) and carers working to improve the lives of people who have had a brain injury, and their family and carers, across London.

2. The White Paper

We welcome many of the policy intentions expressed in the White Paper. In particular: ownership and decision-making being transferred to professional front-line staff and patients; the move towards integration of Health and Social Services; and an increased focus on clinical outcomes.

The GP commissioning role is welcomed, but its implementation requires careful planning for patient/client groups with complex needs, such as brain injury. It is critical that GP consortia draw upon the experience of commissioners, professionals and patients and carers with first-hand knowledge of services. This is where - for brain injury - organisations in London such as ABIL and Headway can play an important role.

3. Acquired Brain Injury (ABI)

An acquired brain injury is a non-degenerative injury to the brain that has occurred since birth. It includes traumatic brain injury (TBI) and brain injury from other causes, including stroke and other vascular events, tumours, infections, and hypoxic-ischaemic injury as a result of cardiac arrest.

4. Acquired Brain Injury - a neglected area

Brain injury is a neglected area as far as public and general clinical understanding and availability of appropriate services is concerned. This is despite two major reports in the last 10 years:

- **The Health Select Committee study 'HEAD INJURY: REHABILITATION' (2001)**
- **The National Service Framework for Long Term Neurological Conditions (NSF) (2005)** - which was the government's response in 2003 to the Health Select Committee inquiry.

Work carried out as part of the NSF estimated that there are 420,000 people of working age in England living with the long term effects of a traumatic brain injury. This takes no account of the other major causes of ABI.

The NSF represents a good basis for commissioning of ABI services, together with follow-on work such as that carried out by the British Society of Rehabilitation Medicine (BSRM).

5. The present position in London

NHS London and the PCTs in London have patently failed to recognise, and address, the need for appropriate local community rehabilitation and support services for ABI on an equitable basis across the whole of London. Such provision in the community is currently patchy, and continues to be a post-code lottery with services ranging from excellent through to non-existent.

For this to be rectified, GP commissioning arrangements have to take account of the expertise which already exists in London.

6. Effects of Brain Injury on the person and family - a hidden disability

A brain injury can happen to anyone at any time, and is frequently life-changing for the individual and their family.

The needs of brain injury survivors are in many ways different from those with other long term neurological conditions. After the initial acute and post-acute phases, they do not generally have a 'medical condition' as such, but rather are left with a range of challenges of a psychosocial kind - because of residual cognitive, behavioural and emotional problems - to which they are trying to adjust and with which they need help from people with knowledge and expertise in the area - and from society at large.

Without appropriate rehabilitation and support services, survivors will continue to 'fall through the gaps', and are at risk of social isolation, relationship breakdown, homelessness, alcohol and drug dependency, or criminality. The burden on their families is immense. All of this represents a significant cost to society, much of which could be avoided with appropriate and timely interventions.

7. The proposed new commissioning arrangements

The NSF provides a good basis for commissioning of ABI services, through its emphasis on person-centeredness and joined-up services and its quality requirements.

We recommend that new commissioning arrangements should:

- Primarily focus on community- and outpatient-based services, as there are already established mechanisms covering acute and specialised inpatient rehabilitation services.
- Recognise that services will need to be long-term - often life-long - for a significant proportion of ABI patients.
- Recognise that many patients with brain injuries initially felt to be 'minor', will go on to have persistent and disabling problems.

To be effective and cost efficient, new services in the community will need to:

- Involve teams that are sufficiently specialist and knowledgeable.
- Be interdisciplinary in nature, and include specialist physiotherapy, occupational therapy, speech & language therapy and neuropsychology; support from rehabilitation consultants; and input as necessary from neuropsychiatry, neurology, and endocrinology,
- Integrate closely with social services - with social workers and support workers in the community also having specific knowledge and experience of brain injury.

The key to successful commissioning of community services for brain injury (and other neurological conditions) is to ensure that the resources available are used to best effect - and will need to address such matters as the specialisms needed and the capacity of the services in terms of numbers of such staff in relation to the population they serve.

There will need to be input from front-line professionals and survivors and family/carers. This will include professional bodies such as the BSRM and those representing Allied Health Professionals, neuropsychologists, specialist social workers, etc, and organisations such as ABIL and Headway groups in London.

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FULL RESPONSE

8. Acquired Brain Injury Forum for London (ABIL)
ABIL was established in 2007, and is a group of front-line professionals, commissioners, survivors of acquired brain injury (ABI) and carers working to improve the lives of people who have had a brain injury, and their family and carers, across London. It thus represents the views of a wide range of stakeholders. Its website is at http://www.abil.co.uk

9. The White Paper
We welcome many of the policy intentions expressed in the White Paper. In particular: ownership and decision-making being transferred to professional front-line staff and patients; the move towards more integrated working between Health and Social Services, and the increased focus on clinical outcomes.

10. Support in the commissioning role
The GP commissioning role is to be welcomed, but to be effective for patient/client groups with complex needs, such as brain injury, they will need to be able to draw upon the experience of commissioners, professionals and patients and carers with first-hand knowledge of such services. This is where - for brain injury - organisations in London such as ABIL and Headway can play an important role.

11. Acquired Brain Injury (ABI)
An acquired brain injury is a non-degenerative injury to the brain that has occurred since birth. It includes: traumatic brain injury (TBI) which can occur as a result of road traffic accidents, sport or leisure pursuits, assaults, falls or battle; and non-traumatic brain injury – which may be caused by: strokes and other vascular events, including subarachnoid haemorrhage; tumours; infections; and hypoxic-ischaemic injury as a result of cardiac arrest.

12. Acquired Brain Injury - a neglected area
Brain injury is a neglected area as far as public and general clinical understanding and availability of appropriate services is concerned. This is despite two major reports in the last 10 years:

- **The Health Select Committee study 'HEAD INJURY: REHABILITATION' (2001)** - (Ref 1). This stated:

"Head injury is the foremost cause of death and disability in young people. In an age of increased motorisation and violence, head injury is a healthcare problem which is not going to go away. There is a growing population of head-injured people in this country, as improved medical techniques have led to many head-injured people now surviving their accident and living into old age, with a normal life expectancy. However, a head-injured person is likely to require long term rehabilitation to live his or her life in society."

The Select Committee felt that the subject would have benefited from a wider inquiry by them, but time was not available for this.

- The government's response in 2003 to the Health Select Committee inquiry was the **National Service Framework for Long Term Neurological Conditions (NSF)**, which reported in April 2005 (Ref 2).

The NSF covered the whole spectrum of long-term neurological conditions - including acquired brain injury from all causes - but had no ring-fenced funding or targets associated with it, and matters were effectively left to local initiatives. We are over half-way through the 10-year implementation period.

Work carried out as part of the NSF estimated that there are 420,000 people of working age in England living with the long term effects of a traumatic brain injury. This takes no account of the other major causes of ABI.

There were at the same time and subsequently a whole raft of government initiatives in the Health and Social Care arena, which have tended to obscure the issue as far as long term neurological conditions (LTNC) are concerned.

The NSF represents a good basis for commissioning of ABI services, together with follow-on work such as that carried out by the British Society of Rehabilitation Medicine (BSRM) (Ref 3).

13. The present position in London

NHS London and the PCTs in London have patently failed to recognise, and address, the need for appropriate local community rehabilitation and support services for ABI (and other neurological conditions) on an equitable basis across the whole of London. Such provision in the community is currently patchy across London, and continues to be a post-code lottery, with services ranging from excellent through to non-existent.

For this to be rectified, GP commissioning arrangements have to take account of the front-line and other knowledge which already exists in London.

14. **Effects of Brain Injury on the person and family - a hidden disability**

A brain injury can happen to anyone at any time. A serious brain injury – from whatever cause – can be life-changing for the individual and their family.

TBI mainly affects young people, particularly in the age range 16 – 29 (and more men than women), whereas stroke affects in the main older people, although, importantly, about 25% will be under 65 and 10% under 50. After ABI, the main difficulties usually result from a complex mixture of physical, cognitive, emotional and behavioural problems, and typically a change in personality and a lack of awareness of how the brain injury has affected them.

In many cases after ABI, there is limited physical or sensory disability. The residual effects are largely "hidden", and thus less easy to observe. This results in misunderstandings, and thus loss of employment, relationship breakdown, low self-esteem, and social isolation for the person, as well as their family. The process of adjustment is very difficult for all. The affected person will in most cases have a normal life expectancy.

Even a 'mild' stroke or head injury can in some cases (up to 20%, for the latter) lead to long-term problems.

The needs of brain injury survivors are in many ways different from those with other long term neurological conditions. After the initial acute and post-acute phases, they do not generally have a 'medical condition' as such, but rather are left with a range of challenges of a psychosocial kind - because of residual cognitive, behavioural and emotional problems - to which they are trying to adjust and with which they need help from people with knowledge and expertise in the area - and from society at large.

Survivors of a brain injury largely go unrecognised by professionals and the public. Although it can have apparent similarities with a number of other conditions - physical disability, learning disabilities, mental health problems, and other long term neurological conditions - brain injury needs to be regarded as a condition in its own right. Otherwise it will continue to be marginalised and those with brain injury will continue to have difficulty in accessing the services they need.

Without appropriate rehabilitation and follow-up support services, brain injury survivors will continue to 'fall through the gaps' in service, and are at risk of social isolation, relationship breakdown, homelessness, alcohol and drug dependency, or finding themselves in the criminal justice system.

The burden on their families is immense. All of this represents a significant cost to society, much of which could be avoided with appropriate and timely interventions.

15. **Extent of ABI (and some economic implications)**

According to the NSF for Long Term Neurological Conditions and the National Stroke Strategy (2007):

- Around 10,000 people of working age are hospitalised in London with a TBI each year
- a much larger number (ca. 130,000 in London) attend A & E each year, with post-concussion syndrome (very short or no period of unconsciousness) – so-called 'mild TBI'
- about 3000-3500 people under 65 (approx 1000 under 50) suffer a stroke each year in London
- there are approx 55,000 people of working age living with the long-term effects of a TBI in London (there are no comparable estimates for stroke or other forms of ABI)

Not only the personal but also the economic consequences of ABI are enormous. In the UK the annual costs of direct and informal care and lost productivity after stroke have recently been estimated at £7 billion. Similar data describing the overall economic burden of TBI in the UK are not available, but the cost must be of similar magnitude as that of stroke as it has been estimated to be about $60 billion annually in the USA (Refs 4, 5, 6).

There is evidence that providing the right rehabilitation and support at the right time can result in substantial cost savings – but this often means spending money in one area to provide greater savings in another. Two obvious examples are:

- if people who have had a mild-to-moderate brain injury (the former can lead to long-term problems for up to 20% of people) can be helped to retain their existing job or return to paid work in some other way, the savings to the exchequer will by far outweigh the cost of the interventions.
- If people who would otherwise find themselves in the criminal justice system can be supported to live in the community, the cost savings will be substantial.

Other situations are, of course, more complex, and thus less easy to demonstrate cost savings, but there is a strong evidence base that if the right interventions are made at the right time, then the cost savings can be substantial and the quality of life optimised for survivors and their family and carers. However, this needs joined-up thinking and working to achieve the necessary outcomes as outlined in the NSF.

16. **Rehabilitation and support needs after ABI**

To achieve the best level of recovery, people will need specialist rehabilitation and support services across the whole care pathway – both as an inpatient and in the community.

With the right interventions – and, importantly, long-term follow-up support and encouragement – the person can be helped to be as independent as possible, and to have a good quality of life. Currently there are shortages of provision – in terms of expertise and capacity – in brain injury rehabilitation at all levels, and a lack of recognition that impairments following brain injury often require long-term support.

17. The proposed new commissioning arrangements

We suggest that the NSF provides a good basis for commissioning of ABI services, through its emphasis on person-centeredness and its quality requirements, which address all aspects of the care pathway for people with ABI. This is represented diagrammatically in **Figure 1** for the whole range of long term neurological conditions covered by the NSF. Integrated working between Health and Social Services is absolutely essential in implementing the recommendations of the NSF.

Figure 2 illustrates the range and kind of services needed for rehabilitation after brain injury.

We envisage that, for brain injury in London, new commissioning arrangements should primarily focus on community- and outpatient-based services. In addition, the established mechanisms covering acute and specialised inpatient rehabilitation services (see below) will need to adjust to the demands of London's new stroke and major trauma networks.

A key consideration is to ensure that services across the whole care pathway are sufficiently specialist & knowledgeable, and dovetail as seamlessly as possible, if they are to be effective and cost-efficient in the longer term.

a. The acute situation

The situation regarding acute services for people sustaining a serious head injury should be covered appropriately by the new Major Trauma system for London - which should lead to reduced mortality and better initial outcomes for survivors of TBI (either isolated brain injury or as part of polytrauma), who constitute about 60% of major trauma patients. It is however still early days, and one can foresee problems with 'navigation' to other, follow-on services and in particular to the community part of the care pathway.

Also, as we stated in our response to the Major Trauma consultation process, unless the necessary follow-on rehabilitation and support is provided, the benefits from the excellent rapid response and acute treatment would be severely compromised, both as regards long-term cost-effectiveness and the quality of life of the survivors, their families and carers.

A key issue in improving patient outcomes is ensuring that intervention is appropriate and timely. Patient care pathways are often fragmented, leading to delayed and inappropriate treatments. This can be greatly improved, for example, by:

- Expansion of the number of brain injury specialist nurses who provide a critical role co-ordinating patient care and interfacing between primary and secondary care providers.

- Early brain injury follow-up clinics. These provide assessment of patients shortly after discharge from acute care. Ideally these clinics are multi-disciplinary. Particularly in the case of mild to moderate traumatic brain injury, they provide a mechanism for efficiently managing the early diagnosis and treatment of patients who are at high risk of long-term disability.

b. Specialised inpatient rehabilitation

This is already covered by the pan-London specialised neuro-rehabilitation consortium, which commissions services across London via nine specialist providers. Since its inception in 2007, the operation of the Consortium has led to:

- better co-ordination and more timely delivery of services to patients;
- equality of access across London to the most-appropriate services; and
- increased cost-effectiveness.

It is responding to the demands of London's new stroke and major trauma networks.

It is a model of good practice, and should be supported to improve its operations even further.

c. Community rehabilitation and support services

Our main concern relates to rehabilitation and support services in the community, which will need to be long-term - often life-long - for a significant proportion of those sustaining a brain injury.

As already stated, there is effectively a 'post code lottery' in relation to such services - which is unacceptable, and has not been addressed by current commissioning arrangements. The number of GP consortia across London is likely significantly to exceed the current number of PCTs, and we have some concern that, if suitable mechanisms such as collaborative commissioning are not put in place, this could lead to even greater disparity, and inequality of access, to appropriate community brain injury services across London.

Such rehabilitation services need to be specialist and interdisciplinary in nature - they would need to include:

- specialist physiotherapy, occupational therapy (OT), speech & language therapy (S & LT) and neuropsychology;
- support from rehabilitation consultants; and
- input as necessary from neuropsychiatry, neurology and endocrinology

They should ideally be part of an integrated system with social services. Such services could be specific brain injury rehabilitation services or within broader neurorehabilitation services (with a specific brain injury element).

Another area that would require attention and resources would be the support of the family members/carers providing ongoing care and support to the survivor. They will need initial and follow up education and training, as well as respite, and ongoing support from the relevant healthcare specialists involved in community rehabilitation.

The key to successful commissioning of community services is to ensure that the resources available are used to the best effect on behalf of the people with brain injury, and will need to address such matters as the specialisms needed and the capacity of the services in terms of number of staff in relation to the population they serve.

It is most likely that a collaborative commissioning approach would be helpful, but it is important to keep in mind the need for specialist services close to where people live. Effective commissioning can only be achieved with input from the whole range of stakeholders (including front-line professionals and people with brain injury, their families and carers). Therefore, structures will need to be put in place to enable consultation with professional bodies such as the BSRM and those representing Allied Health Professionals, neuropsychologists, specialist social workers, etc, and organisations such as ABIL and Headway groups in London.

d. **Vocational rehabilitation services**

Returning to work is very important for people after a brain injury, either to their previous employment or, if this is not possible, in some other form of productive activity, It provides opportunities to rebuild self esteem and re-integrate into society, as well as the more obvious potential financial benefits. The need is for knowledgeable brain injury services to provide such rehabilitation, since the more-general, mainstream providers do not have sufficient expertise and understanding of the effects of ABI to work effectively with this client group.

In addition to the small number of specialist brain injury vocational rehabilitation service providers, there is scope for brain injury community teams, and Headway centres in London, to provide such rehabilitation and support to a greater extent.

e. Follow-on support in the community

This should be as specialist and informed as rehabilitative care to enable maintenance and consolidation of gains made through rehabilitation. It will in particular involve support through local Social Services, and provision of support workers, as well as from Headway and other voluntary sector organisations in London.

Headway provides important social rehabilitation and long-term peer support to survivors and carers and family members. There is however a significant lack of capacity in terms of Headway support services in London – with only two major Headway centres, two other groups providing some daytime services, and two others providing monthly evening support services (including carer support). For links to Headway in London see http://www.headway.org.uk/Regions/London.aspx

There is also for some people a need for supported accommodation, with knowledgeable support onsite or otherwise readily available; this would be a partnership between Local Authority Housing

and Social Services. For others, who are unable to be supported in their own homes, there is a need for local specialist residential accommodation; provision currently is often inappropriate or a long distance from close family members.

18. **Prevention & contributory factors**

The wearing of helmets when cycling and undertaking physical sporting activities is known to reduce the extent of brain damage and, in some cases, can save lives.

Alcohol is a major contributor to the occurrence of brain injury. Of equal concern is the high proportion (over 50%) of adolescents and adults hospitalised for traumatic brain injuries who have had pre-injury substance use disorders.

Studies have shown that a significant majority of the prison population have had at least one prior head injury - and often as a child or adolescent.

Work in New York has demonstrated ways in which young people with ABI who were in restrictive settings, including the criminal justice system, could be supported to live in the community - with significant savings to society (Ref 7).

5th October 2010

References

1. The Health Select Committee study 'HEAD INJURY: REHABILITATION' (2001) - which related to TBI
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2. The National Service Framework for Long Term Neurological Conditions (NSF), which reported in April 2005 http://www.dh.gov.uk/en/Healthcare/Longtermconditions/Long-TermNeurologicalConditionsNSF/index.htm

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4. Department of Health. Reducing Brain Damage: faster access to better stroke care'. National Audit Office, London, 2005.

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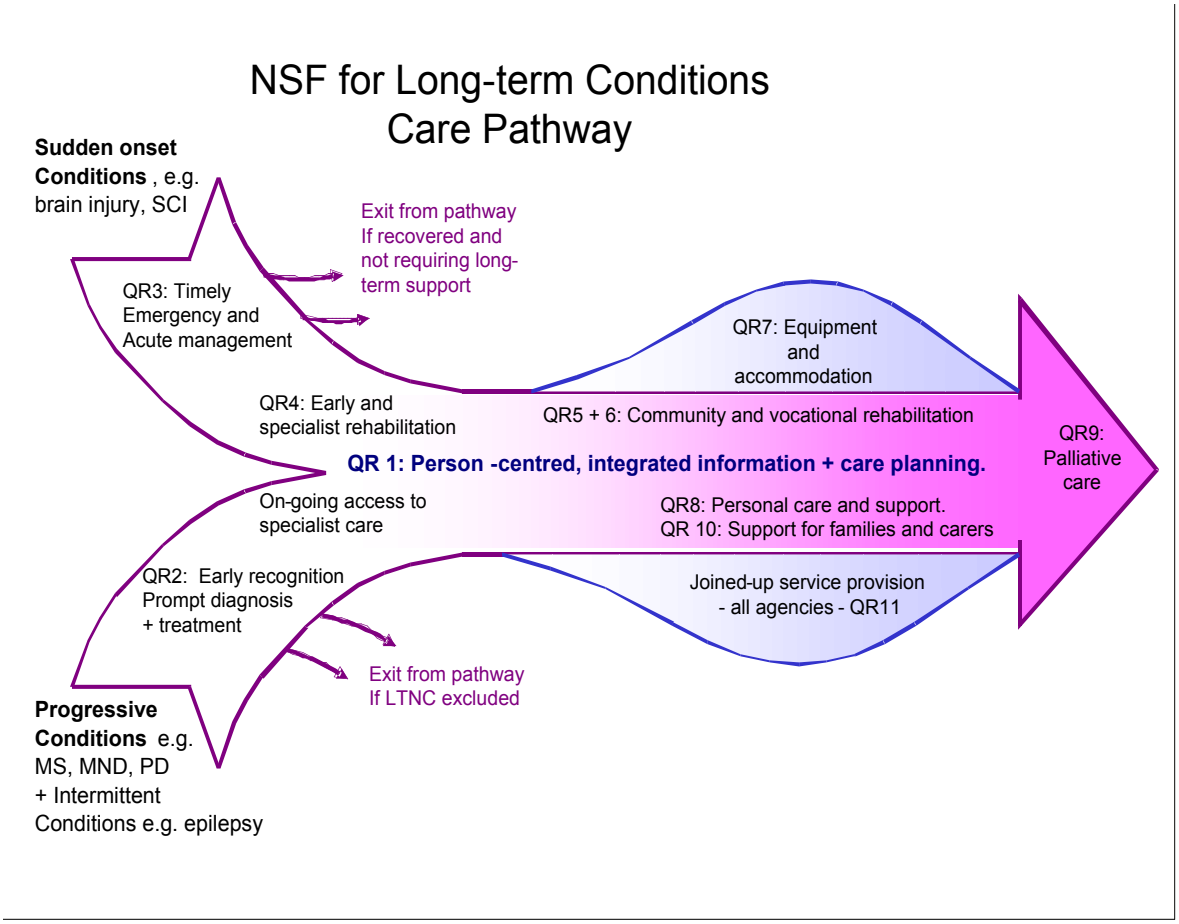
8. Mapping rehabilitation resources for head injury. J D Pickard, H M Seeley, S Kirker, C Maimaris, K McGlashan, E Roels, R Greenwood, C Steward, P J Hutchinson, G Carroll, J R Soc Med. 2004; 97: 384–389.

Fig 1 (provided by Professor Lynne Turner-Stokes - who was Deputy Chair of the NSF External Reference Group)

The fish diagram illustrates the 11 Quality requirements of the NSF, and the cross section shows the type of services that need to be coordinated during integrated care planning



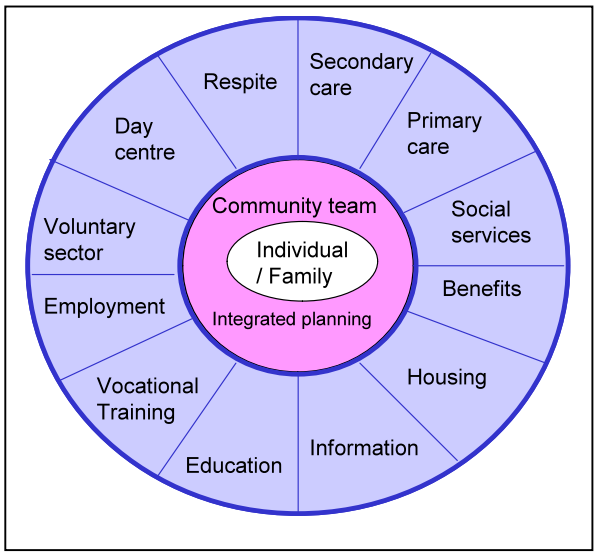
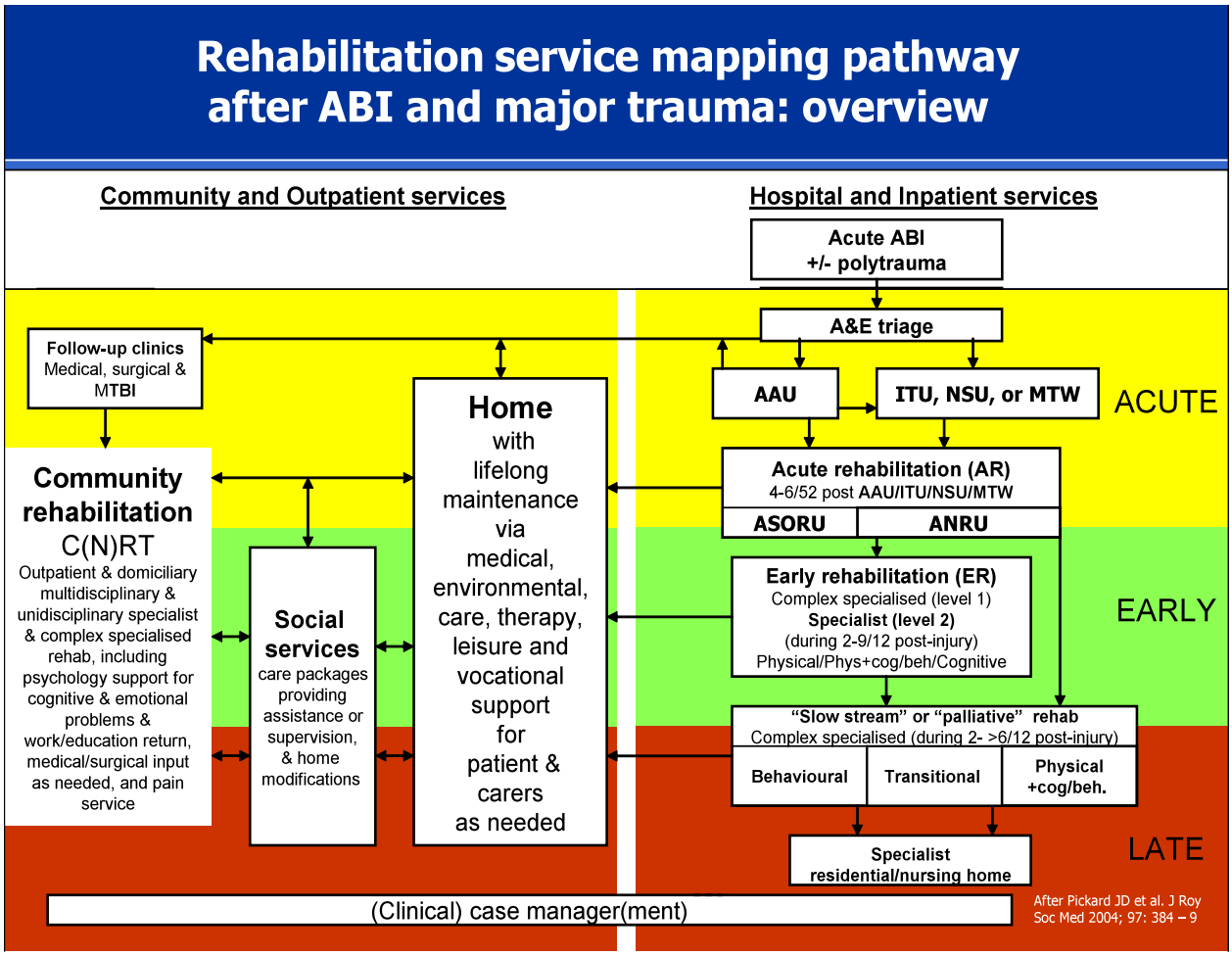


Fig 2: Rehabilitation service mapping pathway after brain injury and major trauma

An overview of the "menu" of the different rehabilitation programmes needed long term to establish a care pathway after acquired brain injury (ABI) and major polytrauma. Many of the later elements of this care pathway are most appropriately provided in the community by PCTs and Social Services. (This is based on a service classification originally derived in the Eastern Region by Professor John Pickard and others (Ref 8) and work subsequently carried out by Dr Richard Greenwood.)



Acute hospital provider Trusts should focus on the provision of organised goal-focused acute (AR) and early (ER) inpatient rehabilitation services that enable timely discharge of patients with neurological disorders from acute beds.

Patients in acute beds in (i) the surgical or medical intensive care unit (ITU), (ii) acute admission unit (AAU), (iii) neurosurgical unit (NSU), and a major trauma ward (MTW), should initially be discharged to: (a) an acute neurological rehabilitation unit (ANRU); or (b) an acute surgical and orthopaedic rehabilitation unit (ASORU) for patients admitted after polytrauma without significant neurological injury.

Many (for example, about 70%) of these patients can be discharged home, with community rehabilitation (C(N)RT) and carer support, while some patients need longer periods of inpatient rehabilitation in complex specialised (level 1) or specialist (level 2) early inpatient units.