NHS
Greater Glasgow and Clyde

Glasgow City
Acquired Brain Injury
Strategic Framework

2005 - 2014

VISION:
To provide a comprehensive network of accessible services which will maximise quality of life and independence for people with ABI. To promote a client centred approach, involving people with ABI and their carers in decision making and planning of services.

CONTENTS

CHAPTER 1 INTRODUCTION

1.1 INTRODUCTION

There are 3,500 people in Greater Glasgow each year that suffer from acquired brain injury (ABI) and more than half of these remain disabled 5 years after injury. People with ABI often differ from those associated with other common disabilities (eg physical disability, learning disability or mental health problems) because their problems tend to be cognitive and emotional, most are independent before injury, most do not have persisting physical disability and the onset is sudden and not predictable. The impact of the ABI on them, their carers, families and friends is often severe and proves a challenge for carers and service providers.

Most people with ABI;

- suffer from cognitive and emotional disabilities which are 'hidden' and unattributed to brain injury by the casual observer.
- are in the lowest social classes and from areas with a higher social deprivation index.
- do not continue in their employment
- become socially isolated with friends and family not understanding or correctly attributing changes in behaviour to the ABI.
- are often 'lost' to service providers after acute hospital treatment
- have difficulty in coping with life events
- do not access a range of proven therapies and treatments that can significantly reduce disability and can be preventative.

It is our aim in this our first strategy for people with ABI to outline how we intend to address these challenges. The strategy covers a ten year period and will be reviewed every three years. A series of three yearly detailed implementation plans will be developed – the first one following the outcome of the consultation on the strategy.

The strategy focuses on adults but recognises the need to consider the specific needs of children, adolescents and older people. The first review of the strategy and future implementation plans will cover these specific groups in more detail.

Traumatic Brain Injury (TBI) is by far the largest ABI sub group, (prevalence of disability in Teasdale's cohort of about 1400 at one year post-injury), has received most research interest and is a heterogeneous population in terms of needs. For these reasons the Strategic Framework is modelled on TBI. The Strategic Framework does however recognise that the needs of people with other acquired brain injuries may at times be met by some of the services described in the network. For example, disability arising from other conditions such as strokes, brain infections, brain tumours, cerebral anoxia and toxic damage. These other conditions might amount to a further 800-900 cases per

annum (mainly stroke), but the prevalence of those disabled and requiring rehabilitation is unclear (Langton-Hewer 1993). Further work is required to identify which groups may benefit from these services and which are better served by other specialist services.

1.2 BACKGROUND

1.2.1 For more than half a century we have been reminded about the severe shortcomings in service provision for acquired brain injury (Tomlinson 1943, Tunbridge 1972; Royal College of Physicians, 1986). More recently, the NIH Consensus Development Panel (National Institutes of Health 1999) noted shortcomings in rehabilitation in the US, which are relevant in the UK (Royal College of Surgeons, 1999; Royal College of Physicians, 2000).

These include the narrow focus of medical restoration approaches, the need to emphasise environmental modification to create enabling conditions, the needs of high risk groups are under-represented (e.g. infants, adolescents and the elderly), the need for rehabilitation over a lifetime, difficulties in accessing rehabilitation and the involvement of the brain injured person and their families in decision making. Although good practice exists in services for people with acquired brain injury (ABI) many academic papers attest to the shortfall in services for this group in the UK generally and explain ways in which people with ABI often fall through any “therapeutic net”. These people often return to the community with insufficient treatment and little or no support or follow-up (McMillan and Oddy 2001). Clearly there is considerable room for improvement.

1.2.2 This Strategic Framework takes a whole systems approach to the identification and assessment of needs of this population and to the delivery of services and support to meet those needs. This includes a range of specialist health, social care and voluntary sector services in addition to generic services that adults with ABI may use. It is the first Glasgow joint strategy for people with ABI and has been produced on behalf of the Glasgow City Acquired Brain Injury Planning and Implementation Group (ABI PIG), whose members include Glasgow City Social Work Services, NHS Greater Glasgow and Headway Glasgow

1.3 NATIONAL STRATEGIC CONTEXT

1.3.1 There is no National Strategic Framework for ABI. NHSQIS (formerly Scottish Health Advisory Service) highlighted in its review of services in Greater Glasgow in March 2003 the need to develop a strategic framework for ABI. In doing so we will take account of the following guidance produced by the Scottish Executive on the strategic framework within which services should be developed.

- **Disability Discrimination Act (1995)** strengthens the rights of disabled people and promotes access in its widest sense. It requires all agencies

/ services to address access issues, including making reasonable adjustments to the physical environment by October 2004.

- **Our National Health, an agenda for change (2001)** sets out a modernising agenda to achieve a patient centred approach to service delivery.

- **The Adults with Incapacity Act 2000** safeguards the rights of adults with incapacity, and aims to maximise their rights to make decisions and have personal autonomy over their lives, whilst protecting their financial and personal welfare. It has as its central principle 'minimum intervention', allowing the individual to make decisions for themselves but when they need help with decisions, ensuring that help is given in a way which respects them as people and listens to them.

- The **Joint Future Report 2001** aims to develop further partnership working between health and social care agencies for all community care groups (including ABI) through joint management and joint resourcing of services and single shared assessment of need.

- **Community Care and Health (Scotland) Act 2002** introduces direct payments for all adults with physical impairment from June 2003 and reinforces the importance of joint working by removing some of the obstacles.

- **Partnership for Care, Scotland's Health White Paper (2003) encourages** greater integration across the acute/primary care interface and with social care services and also promotes the health improvement agenda.

- **The Mental Health Care and Treatment Act 2003** changes the criteria, determining whether an individual's decision making is impaired, in relation to compulsory treatment. It also introduces a mandate to provide independent advocacy services to people who are detained for treatment and applies to people with ABI.

- **The Education (Additional Support for Learning) (Scotland) Act 2004** aims to improve planning and preparation for transition to post school life for children with identified special needs.

1.4 LOCAL CONTEXT

1.4.1 Strategic planning for community care across Greater Glasgow has developed over a number of years. A matrix of planning activity is in place now which sees some work focusing on particular age ranges (for example in older people's services), some planning activity focusing on particular care groups (for example learning disability and mental health) and others focusing on particular disease groups (for example Parkinson's Disease and Stroke). The planning activity takes place at both a strategic level across Glasgow City

and at a locality level (Local Health Care Co-operative and social work area team level).

1.4.2 It is therefore essential that service planning for individuals with ABI does not occur in isolation. The Acquired Brain Injury Planning and Implementation Group (ABI PIG) is one of three subgroups of the Disability Planning and Implementation Group (which is responsible for over-arching and cross cutting issues). The two other subgroups are the Physical Disability and Sensory Impairment Planning and Implementation Groups. The ABI PIG recognises the need to work closely with these and other strategic and locality planning groups particularly those that directly address the same population i.e. the joint planning groups for Mental Health, Addictions and Homelessness, the Managed Clinical Network (MCN) for Stroke and the planning process in relation to areas of transition from one service to another (e.g. children moving into adult services and adults moving into older peoples services). It also acknowledges the need to take account of the developments in Chronic Disease Management (including stroke and epilepsy).

1.4.3 The next twelve months or so will see significant change in the configuration of community health and social care in Glasgow with the introduction of Community Health and Social Care Partnerships (CHSCPs). The acute health sector is also in a period of significant change in Greater Glasgow (although over a longer time period). The needs of people with ABI require to be addressed appropriately throughout this change process.

1.4.4 Note; the health statistics used in this document relate to the whole of the Greater Glasgow NHS Board area. Glasgow City Council accounts for 67% of the GGNHSB population.

CHAPTER 2 PHILOSOPHY, PRINCIPLES AND OBJECTIVES

2.1 PHILOSOPHY

2.1.1 Whole Systems Approach: Our agreed philosophy in developing a comprehensive network of services for people with ABI is to take a whole systems approach. This will ensure an inclusive approach to service planning with all partners, whether statutory, voluntary or other stakeholders. This approach is underpinned by effective identification and needs assessment of people with ABI. It is, therefore, essential that there is a clear link and relationship between assessed need and service planning.

2.1.2 Maximise quality of life and independence: Many of the approaches for people with ABI are rehabilitative, that is they aim to improve quality of life and independence. The vast majority of people with ABI have led an independent life prior to their injury and given the correct treatment and support many can return to independent living. The aim is to empower people with acquired brain injury to maximise their potential within society.

2.1.3 User / Carer Views: Service development will take account of the views of people with ABI and their carers. It is important that service providers learn from the experience of those people who receive the services and that the service users and carers feel their input is welcomed and valued. People with ABI can find it difficult if asked to mix with other care groups who have not (eg learning difficulties), who do not have cognitive impairments (eg physical disability) or who they understand to be mentally ill. This is because they have usually led an independent lifestyle pre-injury, because their disabilities usually stem from cognitive and emotional rather than physical problems and they see themselves as having brain injury and not mental illness.

2.2 PRINCIPLES

2.2.1 Client Centred Approach

It is widely accepted that rehabilitation of ABI should be client centred, and adopt whenever possible a ‘partnership’ model between client and clinician / service provider. The importance of taking account of the views of close relatives has also been long recognised (Brooks et al 1987). Systems exist which incorporate this approach into the backbone of rehabilitation processes, such as client centred goal planning (McMillan and Sparkes 2001), needs led assessment and the care management framework. These approaches will embrace the principles of the Adults with Incapacity Act.

2.2.2 Locally Delivered Services

Most people with ABI return to the community within days or weeks of injury. A small number (but who are significant in terms of their needs) require longer periods of inpatient treatment. Some require treatment after return to the community. It is important that wherever possible, treatment and support

services are developed in areas of reasonable geographical proximity to the person's eventual destination. This allows flexibility in terms of gradual return to the community and allows relatives, carers and friends easier access during inpatient stay. Historically in the UK, there has tended to be a focus on hospital based rehabilitation services. These are needed but it has to be remembered that most people with ABI spend most of their lives in the community and there is a need to have a range of services in the community.

2.2.3 Access

Given that people with severe ABI are likely to have impairment and disability over the long term, it is important that services are accessible to them at times in their life when they are in need. It is not unusual for individuals to live in the community for some time even though their coping skills are reduced but then find they cannot manage following a life event (e.g. death of a carer) and require further help. Services must take account of the potential for intermittent need over a life-time. The role of assessment and care management is central to ensuring people get access to the right services at the right time.

2.2.4 Equality

People with ABI must not be discriminated against in gaining access to services and facilities across Glasgow, whether they are specialist or generic services (health, social care and the range of wider community services and facilities). Service providers require to consider the needs of people with ABI in developing their service. Some of the challenges will be of a physical or sensory nature, for example access to buildings, providing information in Braille or on audio tape. However, the majority of people with ABI will not have a physical or sensory disability. It is their cognitive functioning that is impaired and this presents more subtle difficulties. Changes in their personality or behaviour can make it difficult to maintain relationships, continue in employment and generally manage social circumstances. If service providers fail to recognise these issues then they can often result in the individual being socially isolated or excluding themselves from services and the community. Services require to adapt their ways of working to accommodate people with ABI.

2.2.5 Independent Living

Pursuit of the aim of encouraging people with ABI to live as independently in the community as possible will identify barriers that require targeting. This may require a specific intervention by health or social care professionals or more likely a package of treatment, therapy, care and support (short or long term) individually assessed for the person and reviewed as necessary.

2.2.6 Identification of cases

Many people with TBI are not coded as such in hospital and not referred for rehabilitation (Moss and Wade 1997). Indeed Thornhill et al (2000) found that 20% of their Greater Glasgow cohort was not identified as TBI in health service statistics. Clearly it is important to have a system which not only allows proper diagnostic labelling, but that allows this information to be easily transferred to services that offer post acute management, treatment, care and

support. Some people will not believe that they have problems early after injury and will not take up offers of help initially; however by making an early contact, they may be aware of how to access services at a later time.

2.2.7 Safe and effective discharge from acute care

In most cases discharge planning should begin soon after admission. The principle is that individual needs for treatment, rehabilitation and support should be identified and assessed within a shared assessment framework. Care management services should be in place to ensure that people should be assisted to move on to the next stage in rehabilitation when they are capable of benefiting from it, including discharge home (with or without support as necessary), and / or to specialist community or residential rehabilitation. In 2005 work is progressing on two issues;

a) the development of a specialist assessment tool for disability (incorporating ABI). A pilot has been established in one Community Physical Disability Team to test the application of the tool.
b) the development of a GGNHSB wide joint discharge protocol due for completion in the autumn of 2005.

2.2.8 Liaison between Services

In the UK it is acknowledged that services which exist for ABI do not always communicate well with each other, or with other relevant services. The principle should be for provision of the appropriate service(s) at a time that the person needs it; systems need to be developed to allow closer interagency and within agency working. In particular those services include; Child and Adolescent, Mental Health, Forensic, Drug and Alcohol Abuse, Physical Disability, Older People and Homelessness.

2.2.9 Evaluation

A key focus of Health and Social Care Services in the new millennium is effectiveness of interventions. New services that are being created should at the outset have an inbuilt evaluation system and existing services need to develop such a system. This would include quantitative measures such as levels of activity (e.g. numbers and types of cases seen) but goes beyond this to other key result areas; e.g. for treatment services - objective indicators of change in disability; for other services that are not treatment focussed and by outcome in terms of maintaining or enhancing quality of life. A systematic evaluation process will inform decision making on current and future services.

2.3 VISION

2.3.1 Based on the philosophy and principles outlined above the vision for ABI services in Glasgow is;

To provide a comprehensive network of accessible services which will maximise quality of life and independence for people with ABI. To promote a client centred approach, involving people with ABI and their carers in decision making and planning of services.

Note: see Figures 1 and Figure 2 (pages 27/28) for a diagrammatic representation.

CHAPTER 3 NEEDS ASSESSMENT

3.1 EPIDEMIOLOGY STUDIES IN GLASGOW

3.1.1 An important study on a cohort of patients with traumatic brain injury (TBI) in Greater Glasgow was published by Thornhill, Teasdale, Roy et al (2000). The study presented data on admissions over the age of 13 to Greater Glasgow Hospitals with TBI in one year (including those with a history of drug and alcohol problems, psychiatric problems or previous head injury).

3.1.2 There were 3000 and of these 500 remained in hospital for 48 hours or longer (160 were transferred to neurosurgery). Of those admitted for more than 48 hours, more than half were discharged in a week or less and 16% (n = 84) were admitted for more than 4 weeks (Thornhill et al 2000, Kay et al 2001). Only a small proportion of cases admitted for more than 48 hours were aged over 70 (<10%, n = 45).

3.1.3 More than 40% of cases (estimated 1400 people) were disabled one year after injury. Despite the high and persisting incidence of disability only 47% of disabled survivors received hospital follow up and a minority had rehabilitation (28%) or contact from Social Services (15%). The representative sample from this cohort was followed up again 5-7 years after injury (Teasdale, McMillan, Murray et al 2003) and 53% were disabled (Glasgow Outcome Scale-extended).

3.1.4 Disability at the later follow-up was associated with depression, anxiety, lower self-esteem and stress. 25% of people with ‘good recovery’ at 1 year had deteriorated at 5 years. Improvement and deterioration were strongly associated with psychological factors. Few had rehabilitation at any time. The findings point to a potential for benefit from interventions directed towards psychological factors.

3.1.5 It is difficult to predict future epidemiological trends because these depend to an extent on governmental priorities and investments. We know that improved road safety and improving standards of hospital care have had a positive impact on the incidence of TBI. However, there has been a trend towards increasing crime (including assaults) and drug abuse, both of which are linked to TBI statistics. It is unlikely that there will be a further significant positive effect of medical care in the next 5 years, and probably not in terms of drug related crime, social deprivation and alcohol abuse. It is unlikely therefore that the incidence will decline over the next 5 years.

3.2 DEMOGRAPHIC AND SOCIO-ECONOMIC CIRCUMSTANCES

3.2.1 The largest incidence of TBI in the UK is among young (mean age 25) adult males, social classes III-V, whose injury is associated with a road traffic accident and alcohol or drugs. In Greater Glasgow the picture is similar,

except that assaults and falls, often associated with alcohol and drugs are the most common causes. There are two smaller peaks in terms of incidence for children and older adults (often falls). Teasdale's group considered all people over 13 (14-98); hence the mean age in his cohort was older (38), and cause was most commonly a fall or an assault.

3.2.2 **Table 1:** Incidence x age, Hospitalised Head Injury Study (Teasdale G, McMillan T personal communication)

	Incidence	Percent	Percent/decade
<20	412	14	07
21-40	1138	38	19
41-60	727	24	12
61-80	557	19	09
>81	154	05	03
total	2988		

3.2.3 **Social Deprivation:** It has long been recognised that disability in general is both a cause of poverty and an effect of poverty. The 1999 Scottish household survey found that 40% of all disabled people live in poverty, with half of all disabled people having an income in the bottom 25% for the general population. A recent study looking at admissions with TBI to accident and emergency throughout Scotland over a 3.5 year period (1996-2000), found that head trauma was more common in people living in areas of social deprivation. People living in a deprived area were more likely to sustain a TBI as a result of an assault, have co-morbid drug and alcohol problems and to have shorter hospital stays (Dunn, Henry and Beard 2003).

3.2.4 **Disability and Employment:** Disabled people in general make up between 12-16 % of the working age population. However just 40% of disabled people of working age are in employment compared with almost 80% of non-disabled people. Of those disabled people in employment, research shows they are disproportionately more likely to have lower average hourly earnings than their non-disabled peers. In addition one-third of disabled people who move into employment find themselves out of work again the following year, this compares to just one-fifth of non-disabled people. Studies on TBI in Glasgow show increases in numbers deemed unfit for work (eg 9% pre-injury and 34% six years post injury) and little formal vocational support (only 12/170 cases within 6 years after injury). Of 170 cases, 41% were unemployed / unfit for work 6 years after TBI.

3.2.5 **Disability and Housing:** The Housing Reference Group for Scotland statistics reveal 1% of Scotland's housing should be wheelchair accessible and 10% of housing should be for the 'ambulant disabled'. Approximately 60% of houses defined as wheelchair accessible are not actually occupied by wheelchair users.

3.2.6 **Disability and Ethnicity**: The Scottish household survey 1999 figures identify 5% of the physically disabled population being from a black or minority ethnic background. Recent studies have highlighted a number of issues faced

by ethnic minority communities in accessing services. Work is currently being undertaken with ethnic minority groups across Greater Glasgow to explore how services can better respond to their needs. There is no work specifically on needs of ethnic minorities or asylum seekers after ABI. Little is known about take up of services, outcome or follow-up and work is required here.

CHAPTER 4 PRIORITY AREAS

4.1 SUMMARY

4.1.1 In order to realise this vision for ABI services across Glasgow four key priority areas have been identified;

- Establish a comprehensive network of services
- Ensure services delivered are effective
- Encourage inclusiveness
- Promote preventative measures

These priority areas are not exclusive of one another indeed their ultimate success will depend upon each of them being delivered. A detailed implementation plan will be developed for each of these priority areas following consultation on the detail of the strategic framework.

4.2 ESTABLISH A COMPREHENSIVE NETWORK OF SERVICES

In developing a comprehensive service for people with ABI we need to cover the wide range of problems and the range of severity and outcome. Services for children, adolescents and older adults are referred to but will be developed as further work that will be integrated with existing and planned services. Figure 1 (page 27) shows a map of current services and Figure 2 (pages 28) the planned services and pathways for people with ABI.

4.2.1 Current Gaps in Service Provision

We have identified a number of areas where there are gaps in service provision. They include;

- Acute Management Unit (see Chapter 5 Service Glossary and Appendix 2)
- Specialist Care Home Service (see Chapter 5 Service Glossary and Appendix 3)
- Services for people with severely challenging behaviour (see Chapter 5 Service Glossary)
- Slow stream rehabilitation services (see Service Glossary chapter 5 and Appendix 3)
- Specialist support services, housing support and supported housing services for people with ABI.

4.2.2 Joint Working and Joint Future

It is known that service provision often breaks down when people cross into different age or care specific groupings, for example adolescent into adult, adult into older adult, addictions, mental health, homelessness etc. Multi-disciplinary and multi-agency working can prevent this. It is known that alcohol and drug addiction is associated with TBI in the majority of cases in Greater Glasgow (e.g. see Kay et al 2001). These cases may appear in TBI, addiction

or homelessness services and there is a need for improved joint working. In addition, there is probably a large number of cases that become involved with the Criminal Justice System, given the high incidence of assault as a cause of TBI in Greater Glasgow, and the association with drugs and alcohol (e.g. Thornhill et al 2000). Identification of TBI as a factor and provision of rehabilitation can lead to more positive outcomes. For some people with TBI they will have a pre-injury history of mental health problems and a small number of TBIs will develop severe mental illness after injury. Hence a need for links with mental health services.

The Scottish Executive focus on delivering a Joint Future for services across health and social care provides a number of key areas that need to be progressed. For most ABI services this work will be embedded in the integration work for Physical Disability services and reference should be made to the Physical Disability Strategy for further detail. An outline of the main areas is provided here.

4.2.2.1 Streamlining assessment and referral

Clear and simple referral systems between services, with agreed protocols in terms of criteria for acceptance are required. In addition to systematic referral within the TBI services, there is a need for simple, accessible referral mechanisms from the community, including self-referral (e.g. as found in the Community Treatment Centre for Brain Injury). The further development of a shared assessment approach will also require to address the management of care pathways between and within existing services.

4.2.2.2 Joint management

Arrangements will be developed over the coming months to support the improvement in joint working across services for people with ABI. The implementation of a single planning lead for disability services (incorporating physical disability, ABI and Sensory Impairment) and the re-organisation of the joint planning structure (as outlined at section 1.4 above) has started this process. We can demonstrate moves towards integration across a number of services including plans to provide a social care input to the multi-disciplinary team within the Community Treatment Centre for ABI, the development of the Joint Discharge Teams (health and social care staff, jointly managed) which incorporate the Throughcare Projects.

4.2.2.3 Joint Resourcing

The development of a shared financial framework is an essential element to understanding where resources are currently deployed and the potential for redesign. The first draft of a shared financial framework for Disability Services (incorporating Physical Disability, ABI and Sensory Impairment) between NHS Greater Glasgow and GCC Social Work Services can be found at Chapter 7.

4.2.2.4 Joint Performance Management

Our work on developing a Joint Performance Management Framework will see us develop our first set of Local Improvement Targets by April 2005. Also see section 4.3.4 below.

4.2.2.5 Development of Community Health and Social Care Partnerships

As noted above at paragraph 1.4.3 the establishment of Community Health and Social Care Partnerships (CHSCPs) will give a local focus to service delivery and planning. The relationship of ABI services to each CHSCP and the relationship the Local Authority will have with CHSCP will form a central element of work to progress integrated management of services.

4.2.3 Linkages

The linkages between services and service providers must be robust to ensure that people do not fall through the 'therapeutic net' as described earlier (see 'Background' on page 6). Monitoring systems are required that identify people with ABI when they present to services and ensure appropriate assessments and packages of treatment, therapy, care and support are designed and delivered to meet their needs.

In terms of planning services for people with ABI (at a strategic, local and operational level) it is vital that links with other planning groups and service providers are maintained and developed. In addition to the wide range of generic health and social care services that people with ABI may require to access links with addictions, homelessness, mental health, physical disability, sensory impairment, criminal justice, older people, child and adolescent and specialist ABI services will be central to the successful rehabilitation of the individual. Integrated ways of working are required that develop close relationships between service providers on a regular and routine basis. Further work is required here as the new structure (including CHSCPs and Rehabilitation and Assessment Directorate) is embedded.

4.2.4 Pathways

The pathway that someone follows when they acquire a brain injury needs to be mapped out and clear for all those concerned with their recovery and care. Most people with ABI are identified to services when they are admitted to hospital. This gives a focus for the capture of important information on the number and nature of cases presenting. The Brain Injury Database (BID) (see Appendix 1), which is now being piloted, will provide information on hospital admissions, specialist rehabilitation, care and support services and outcomes.

Discharge planning requires to be carried out in a systematic way for people with ABI especially since they may be discharged from a variety of hospital wards, some of which admit people with ABI relatively infrequently. The new Integrated Discharge Teams (within Glasgow City Council area) provide a joint focus across health and social care to facilitate these processes. Currently the Throughcare Projects in Glasgow Royal Infirmary and the Southern General Hospitals seek to identify and assess individual needs and provide and arrange support, ongoing care management services where necessary and facilitate a smooth discharge into the community. There are established links between the Throughcare projects and other specialist and generic services. There is also a dedicated specialist ABI nurse covering the hospitals in the North of GGNHSB who advises staff on care, management and discharge of people with ABI. This specialist nurse also has a central role

in the operation of the database. We need to explore the need for an equivalent service covering the hospitals in the South of GGNHSB.

Specialist services in the community provide ongoing therapy, care and support for people following discharge. The Community Treatment Centre for Acquired Brain Injury provides psychosocial and emotional treatment and advice. It has a multi-disciplinary team and offers a time limited treatment programme for people with moderate to severe injury with client centred goal planning at its core. A brief intervention service for those with minor brain injury who have been admitted to hospital for less than 48 hours is also offered. The team liaise with other services that deal with people who have sustained a brain injury, supporting the training of less specialist staff (e.g. in supported living accommodation). A focus of the service is to undertake clinical research that is relevant to this population and unique to the Scotland area. All people with ABI admitted to hospital should be referred to the Community Treatment Centre (they also accept referrals from the community, eg from GPs, social work staff and self referrals).

4.2.5 Regional Planning

Some components of the model may be more appropriately considered on a Regional basis. This may be the case where there are low frequencies of cases requiring specialist assessment, treatment or care and sometimes when it is difficult to recruit specialist staff. The ideal is for services to be available locally but this may not always be practical. The service components currently include residential treatment and long term care for people with severe challenging behaviour, assessment and rehabilitation of people in low awareness states and slow stream rehabilitation for people who are severely disabled, who cannot cope with intensive rehabilitation but nevertheless continue to benefit from residential rehabilitation inputs. Residential rehabilitation services for children and adolescents might also be appropriately considered in this way.

The Scottish Executive is considering a bid to establish a national Managed Clinical Network (MCN) for a range of specialist health services for people with ABI. It is likely that a decision will be made in early 2006.

4.2.6 What we will do:

- Design and deliver responses to meet these ‘gaps’ within the resources available, particularly required is work to:
    - develop plans to implement the proposed Acute Management Unit
    - implement the recommendations of the Review of Nursing Homes (see Appendix 3)
    - establish a financial framework for the small number of people with challenging behaviour (to develop services for them including integration and support in the community at the appropriate time)

    - assess the quality of existing services for people with ABI across admitting hospitals in Greater Glasgow against the strategy recommendations and SIGN guidelines
    - jointly develop plans for a slow stream rehabilitation service
    - review existing and develop additional specialist community based support services for people with ABI
- Implement the Database to capture information on people presenting with ABI across health and social care services.
- Improve the strategic planning links between generic and specialist services.
- Improve the operational links between generic and specialist services.
- Ensure consistent approaches to discharge planning and protocols for people with ABI across Glasgow, specifically to review the role of the Throughcare Projects and specialist nurse role.
- Identify any further gaps in service provision.
- Ensure the network is robust particularly in relation to transition issues (for example from child / adolescent services to adult and from adult to older peoples services).
- Ensure that the housing support needs of people with ABI are taken account of the Supporting People Review.

4.2.7 What we have already achieved:

- In the absence of the proposed Acute Management Unit and following on from the work of the Admissions Project Team (now ended) a sub group of the ABI PIG has been established to develop an interim plan for early management of people with ABI in acute hospitals and will complete some of the work around 'operational' issues (eg consistency of information, pathways and discharge protocols).
- An understanding of some of the gaps in service provision, for example locally provided specialist care for people with severe challenging behaviour.
- Establishment of the Community Treatment Centre for Acquired Brain Injury (a unique service in Scotland).
- Pilot sites in various hospital and community settings to test the operation of the database.
- Regular links with the Carers PIG and the Employment PIG.
- A strategy working group of the ABI PIG for child and adolescent services.

4.2.8 How we will demonstrate future progress:

- Develop the comprehensive network of services for people with ABI including those services that have been identified as gaps.
- Improved quality of information available to feed into planning processes (to consider needs, set targets and monitor performance across services and providers).

- Appropriate representation of issues affecting people with ABI in the other joint planning groups, particularly Homelessness, Addictions, Mental Health, Carers, Advocacy, Older People and Children's Services Groups.
- Increase in the number of people being followed up in the community.
- Have agreed and consistent discharge planning processes and protocols across Glasgow.
- Increase awareness, training opportunities and information available to generic service providers regarding the problems associated with ABI and how to manage them.
- Increase the range of services provided locally for people with ABI.
- Fewer people required to move outwith Glasgow for treatment, care or therapy.
- Have a clear strategic approach for children and adolescents with ABI and older people.

4.3 ENSURE SERVICES DELIVERED ARE EFFECTIVE

4.3.1 Demonstrating Effectiveness

Services must be able to demonstrate their effectiveness, this applies equally across the range of health and social care services. For some interventions there will be clear evidence to demonstrate the effectiveness of the intervention. Examples include inpatient rehabilitation (McMillan and Greenwood 2003), community-based rehabilitation for psychosocial problems (Powell et al 2002), residential treatment for challenging behaviour (Alderman 2001), specialist vocational re-entry programmes (Yasuda et al 2001). For others we may require to collect data and analyse information to demonstrate their effectiveness. The Brain Injury Database will be central to this work. It is designed to collect a wide range of data and provides the tool to monitor the information over time, detect trends and measure outcomes associated with particular interventions.

4.3.2 Audit and Effectiveness

There is a need for central monitoring of the numbers of people requiring services and its components to allow timely planning on the basis of need. To do this basic audit is required, both at the stage of initial hospital admission, and by the service components in terms of referrals to and utilisation of services.

Several components of the service are treatment based. Means of evaluating effectiveness in terms of reduction in disability are essential. Client Centred Goal Planning allows a simple measure of outcome and is now very widely used (McMillan and Sparkes 1999, McMillan and Ledder 2001, Wade and Enderby 2001). This should be combined with other measures appropriate to specific aspects of the service (e.g. Brain Injury Community Rehabilitation Outcome Scale, Barthel Index etc).

Currently the Greater Glasgow NHS Board monitors effectiveness of treatment provided by the independent sector. However this principle will be extended to all providers to give a complete picture. A project to establish a database system is underway. This can review specific providers, or services for sub-groups of clients overall (eg by age, sex, or level of disability) and enable ongoing review of activity and effectiveness of the brain injury rehabilitation service. The Brain Injury Database (BID) project is being piloted in various sites across Greater Glasgow (see Appendix 1).

4.3.3 Local Services

The provision of 'local' services is one factor known to affect outcomes and quality of care. For a small number of people with very severe brain injury it may not always be possible to provide services close to their home. However, for the majority of people, it is important that wherever possible services are provided close to their home. This ensures better continuity with community services that may provide treatment, care and support for the person after discharge, allows a graduated approach to discharge for more complex cases and ensures family, friends and carers can be more easily involved in the persons recovery. The social and long-term financial benefits should also be recognised.

4.3.4 Performance Management

Some preliminary work on performance management systems has been carried out but requires further development. The database will form a key role here in addition to other tools such as user / carer questionnaires and the joint performance information and assessment framework (JPIAF) outlined by the Scottish Executive Joint Future Unit and information collected locally by providers. A key component of the framework will be the development of the first set of Local Improvement Targets (LITs)(April 2005 – March 2006) and the monitoring, review and reporting of these targets.

4.3.5 What we will do:

- Implement the BID database across service providers to collect data on the number and nature of cases, the interventions provided and the outcomes achieved.
- Pilot questionnaires to sample user and carer views on services received (as part of the Brain Injury Database monitoring system).
- Ensure that any new services developed have an evidence base that demonstrates their effectiveness.
- Develop local services to meet the needs of people with ABI (in particular address the gap in service provision for people with ABI and challenging behaviour, including the financial package required support moves back into the community).

- Develop a performance management framework that will allow us to track progress and demonstrate effectiveness of services, including the development of Local Improvement Targets by April 2005.

4.3.6 What we have already achieved:

- Piloting the BID database at several hospital and community sites.
- The Community Treatment Centre for Brain Injury – a local service for treatment of psychosocial and emotional problems of people with ABI.
- Discussions with providers who have decided to implement a speculative development unit for people with ABI and challenging behaviour in or near Glasgow.
- Provided the Throughcare projects with financial support from MHSG, they are therefore subject to annual review as part of the funding agreement.

4.3.7 How we will demonstrate future progress:

- Implement the Brain Injury Database monitoring and evaluation system.
- Use analysis of service users information (via questionnaires) to inform planning of services.
- Cite published evidence for service developments under consideration in proposals and incorporate new services in the database system.
- Have more services for people with ABI within or near to Glasgow.
- Provision of annual reports to ABI PIG reporting on progress on agreed performance indicators.
- Implement a performance management framework for ABI (including relevant aspects of JPIAF for ABI and Local Improvement Targets – to set specific targets).
- Review current joint recording systems between health social care agencies.

4.4 ENCOURAGE INCLUSIVENESS

4.4.1 A key priority within the strategy is ensuring people with ABI are afforded the same opportunities to participate in the community as others and that they are treated as partners in decision making about their care and support. As previously mentioned this includes all people with ABI and we need to develop a strategic focus for older people, children and adolescents with ABI.

4.4.2 Employment Services

Some people with ABI are unable to return to work immediately after their injury whilst others may return but fail to maintain their employment and some cannot return to work or may not have been working pre-injury. Overall about 40% of people with ABI are not in work 5-7 years after injury. Employment Services should offer support and advice to people with ABI. Ways of

appropriately streaming people with ABI to specialist or generic services geared towards a return to work need to be developed and outcomes need to be monitored. For example, how many people successfully return to their employment, for how long and how does this compare with their pre-injury work status / employment? It is important that this takes into consideration the work being carried out under the Equal Access to Employment strategy.

4.4.3 Direct Payments

The Direct Payments Scheme was introduced in 2003 to allow users of a range of community care services greater choice in the delivery of their care and support. There are only a small number of people with ABI currently accessing direct payments (number = 4 at June 2004). We need to explore ways in which people with ABI can be supported to access direct payments if they so choose. The role of independent advocacy should be strengthened here.

4.4.4 User Perspective

The views and involvement of service users, carers and client representative groups are vital in influencing the way that services are delivered. Historically the involvement of users and carers in the planning ABI services has been limited by a number of factors;

1. lack of a local network of user / carer groups representing people with ABI.
2. difficulty in engaging people with ABI in planning services because of the nature of their injury.
3. large numbers of those with 'minor' brain injury will not come into contact with services on a regular basis; many make a good recovery and while it is important to facilitate the view that a good recovery is likely, for some there are persisting problems which the individual does not identify as ABI (ever or until the level of disability has become serious).

This strategy aims to actively promote the participation of service users / carers in the planning, design and development of health and social care services.

4.4.5 What we will do:

- Develop this Strategic Framework to incorporate services for older people, children and adolescents.
- Review the role and outcomes achieved by employment services and vocational re-entry programmes accessed by people with ABI.
- Monitor the uptake of direct payments by people with ABI.
- Assess how to improve the awareness and knowledge of direct payments for people with ABI and how best to support them in accessing direct payments when they decide to do so.
- Develop and support the role of user / carer groups to participate in the planning of ABI services.
- Canvas the nine carers centres / projects that cover Glasgow City for any issues relating to services for people with ABI or their carers.

- Schedule annual 'stakeholder events' for users, carers and the public to inform and debate issues around service planning for ABI.
- Encourage people with ABI to use independent advocacy services where they feel there is a need or desire to do so.

4.4.6 What we have already achieved:

- Support for Headway (Glasgow) to allow them to continue to provide a service while developing a strategy and financial plan for the organisation.
- Offer a seat at the ABI PIG to the Headway Development Officer, to act as a voice for service users.
- Enable the Headway Development Officer to provide a user perspective at the ABI PIG meetings by;
    - ensuring agenda and papers are circulated in advance of the meeting so that time is given to allow consultation and feedback from users and carers within Headway.
    - protecting a regular slot on the agenda for user / carer issues.
- Enhance links with the Carers and Employment PIGs to increase the profile of ABI. (Members of the ABI PIG now sit on these PIGs).

4.4.7 How we will demonstrate future progress:

- Develop this Strategic Framework and a series of detailed implementation plans covering all people with ABI (i.e. including the specific needs of children, adolescents and older people).
- Action the recommendations from the review of employment and vocational re-entry services for people with ABI.
- Better informed staff, users and carers about direct payments.
- User / carer representation on the ABI PIG.
- Annual stakeholder events taking place – where users, carers, providers and other interested partners review the progress of the strategic framework and implementation plans and inform future plans.
- Monitor the update of independent advocacy services for people with ABI.

4.5 PROMOTING PREVENTATIVE MEASURES

4.5.1 The challenge of preventing ABI can be viewed on two levels;

- Preventing the occurrence of brain injury

and

- Preventing development of secondary problems and deterioration.

4.5.2 Primary Prevention

To prevent brain injury in the first instance we must understand causes. Within Glasgow for TBI these are mainly falls (46%), assaults (28%) and road

traffic accidents (11%) with alcohol involved / suspected in 69% of cases (Thornhill et al, 2000). Prevention of these injuries requires responses across a broad range of service providers in the community. We need to develop thinking further in this area.

4.5.3 Secondary Prevention

Changes in behaviour or in symptoms such as irritability often resolve within a few months of minor brain injury. However during recovery these problems can create significant difficulties for the person with ABI. For example, someone may be advised that an immediate return to work might not be appropriate because of problems with concentration, and irritability. Family, friends and employers may not understand the reasons for the changes in behaviour and become intolerant of them. Research suggests that information, advice and support can greatly reduce the impact of early symptoms at one year follow-up.

4.5.4 The Community Treatment Centre for Acquired Brain Injury follows up people with less severe ABI to ensure they have the appropriate information and advice about their condition and the potential for deterioration.

4.5.5 After more severe ABI there is more often persisting disability. This can be reduced by treatment. Secondary consequences of disability including anxiety and depression can result in further dependency and are common complaints in people with ABI. The Community Treatment Centre for ABI offers treatment to this group of people, on an individual or group basis to prevent the condition worsening, to treat psychological problems and to equip the person with techniques that facilitate coping and independence in the Community.

4.5.6 An information leaflet has been developed. It is distributed to people with less severe ABI when they are in hospital. The leaflet contains specific information about ABI and offers advice on how to recognise potential problems early and where to seek help and support from.

4.5.7 The recommendations from the *Report of the Caleb Ness Inquiry* need to be taken account of by all professionals providing services to individuals with ABI, particularly in relation to information sharing and awareness raising. There are two specific recommendations in relation to services for adults. Firstly, it recommends the “streamlining and supporting” of housing applications by people suffering from brain injury”. Secondly it recommends the “registration with General Practitioners of brain injury patients, with a view to providing them with appropriate care outside of hospital”. This appears to echo the recognition within the current strategy of the need for care pathways and for effective identification and assessment mechanisms for post acute care.

4.5.8 What we will do:

- Improve links with other planning groups, in particular addictions, child and adolescent and older people, to develop clear preventative strategies (eg falls prevention, advice regarding addictions).
- Feed into the Community Planning agenda the need to share information and advice with various agencies including the police and education.
- Consider a public information campaign on the causes and effects of ABI.
- Monitor the referral pathways into the Community Treatment Centre to ensure all those who could benefit from the services and support offered there are being referred.
- Consider the results from the pilot on the impact of the information leaflets distributed in hospitals.
- Maintain links with the Scottish Head Injury Forum (particularly in terms of issues around standards and campaigns they may be running).
- Establish links with user organisations to ensure that awareness of national campaigns is disseminated.
- Promote awareness of ABI within health and social care agencies and facilitate in provision of information to the public.
- Identify opportunities for disseminating information through public service publications.
- Explore initiatives within health promotion and public health that may have a link to prevention of ABI (eg accident prevention work, advice on addictions).
- Promote awareness of the particular issues highlighted by the Caleb Ness Enquiry within specialist services to adults with ABI and within generic services accessed by individuals with ABI.

4.5.9 What we have already achieved:

- Links with the Carers and Employment PIGs and establishment of a working group to develop the strategic framework to incorporate child and adolescent services.
- Article on Throughcare projects in Glasgow “City Insider” publication in 2002.
- Information leaflet for people with ABI, giving details of signs and symptoms to look out for and advice on how to deal with concerns people may have following discharge from hospital.
- Establishment of the Community Treatment Centre for ABI offering early advice to people with ABI, including coping strategies, one to one therapy, treatment, information and advice.

4.5.10 How we will demonstrate future progress:

- ABI links to all relevant planning groups.
- Better informed community planning partners on the causes and effects of ABI and the need to address preventative measures.
- Deliver a public information campaign on the causes and effects of ABI, increasing public awareness and knowledge.

- Increased level of (appropriate) referrals to the Community Treatment Centre for ABI.
- Delivering the comprehensive network of services for ABI will help prevent deterioration (where it can be avoided) in a number of people with ABI.
- Involvement of user and carer organisations in developing preventative strategies and awareness campaigns.

4.6 FIGURE 1 – CURRENT SERVICE MAP (July 2004)

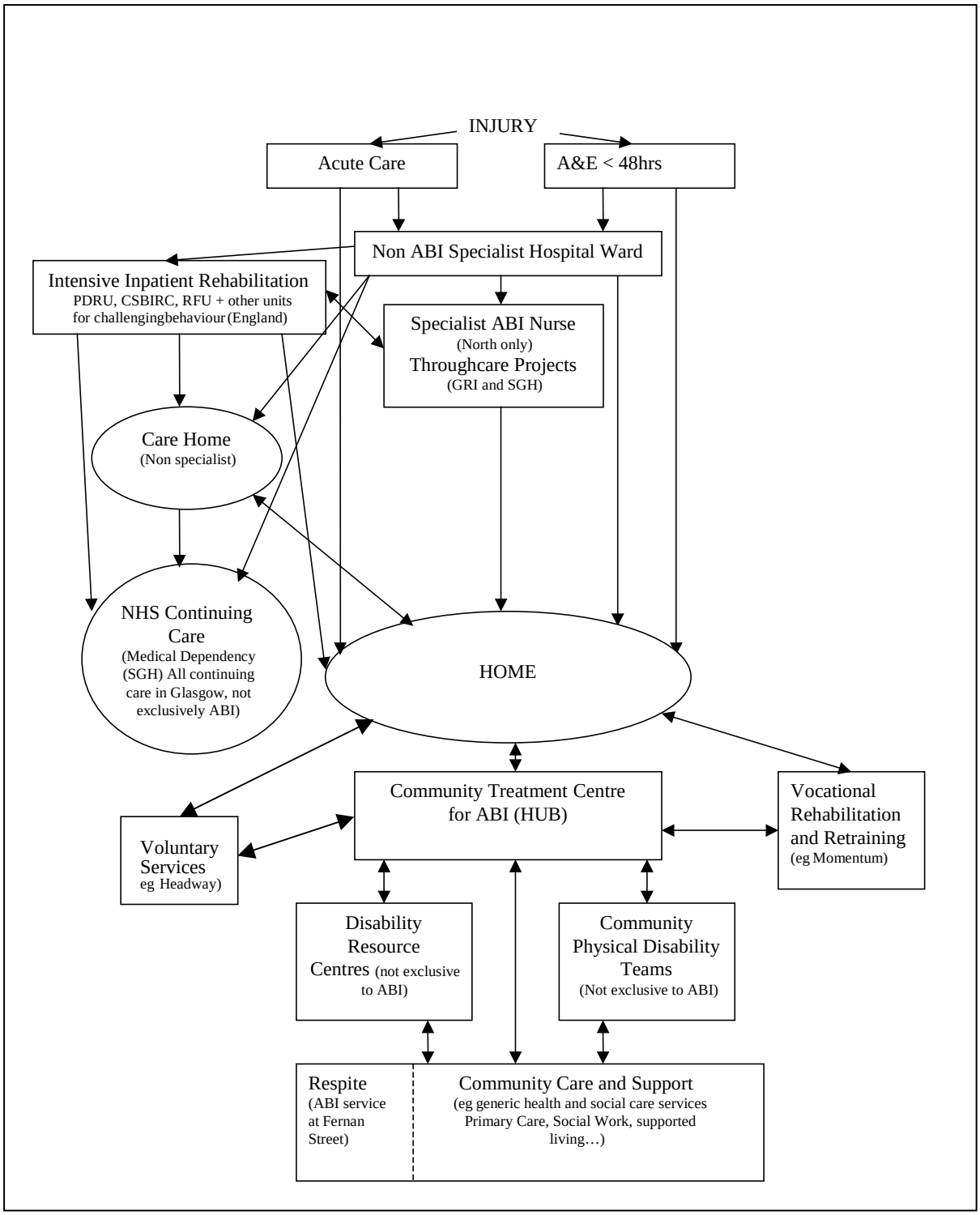
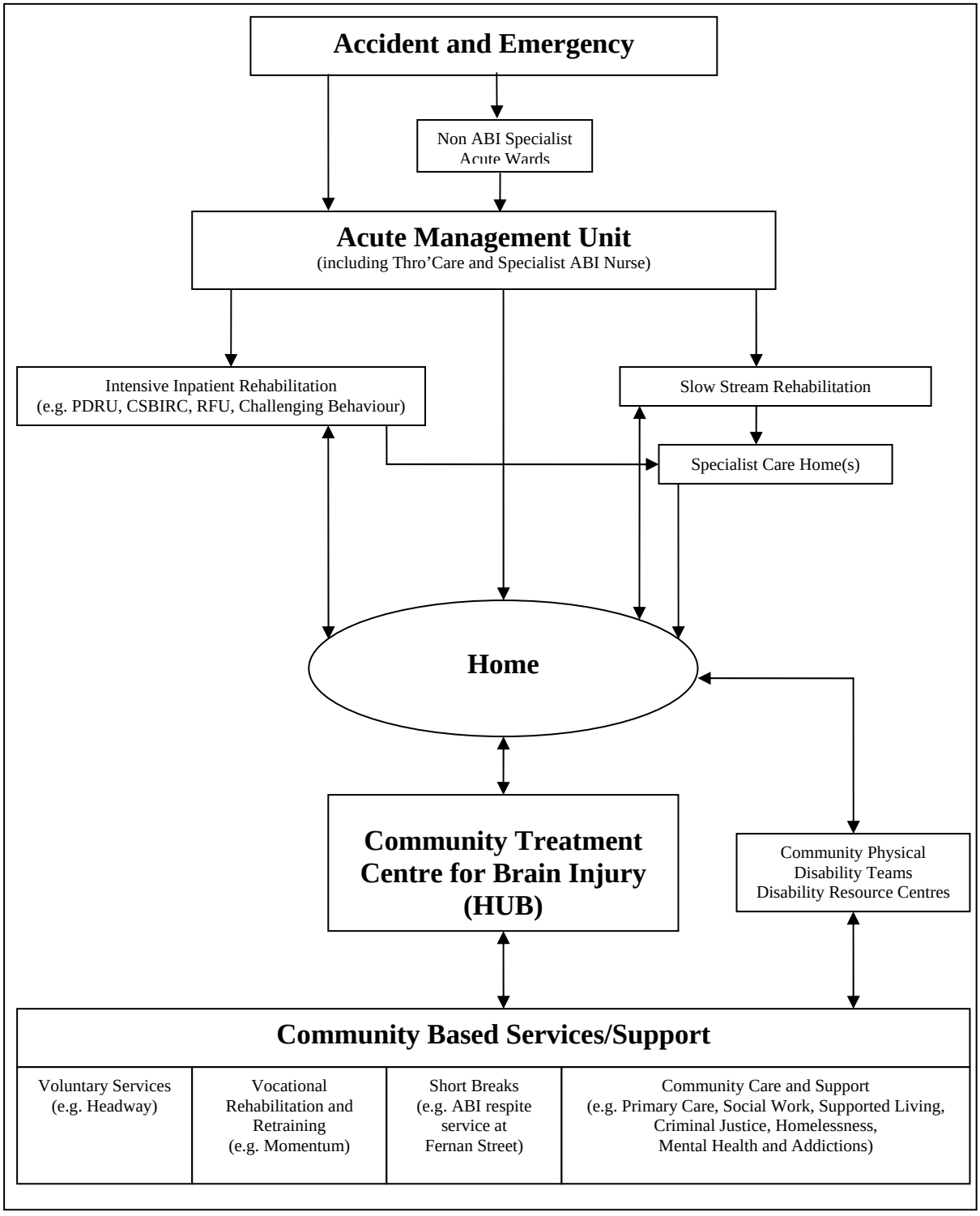


FIGURE 2 – PROPOSED SERVICE MAP *[1]



***[1] Note:** This diagram details the main and most common pathways through services for people with ABI. It is not intended to detail every possible pathway or all non-ABI specialist services that people with ABI may access. It is also not a linear one-way pathway

CHAPTER 5 GLOSSARY OF SERVICES

5.1 OVERVIEW

5.1.1 This chapter acts as a reference point for the strategy. It outlines the current and proposed range of services with a brief descriptor.

5.1.2 Generic Services

People with acquired brain injury should have access to general mainstream services, appropriate to their needs. These services form an important part of the comprehensive network of services for people with ABI. The following is not an exhaustive list but represents the range of services available from statutory providers;

GP services, practice nurses, community nurses, physiotherapy, podiatry, community dietetics, defined range of equipment provision, advice and information services, acute sector care.

These services should be directly accessed by the service user through the usual routes and not dependent upon assessment from any single or joint agency.

Services to maintain or sustain optimum community living and inclusion will be subject to a community care assessment. This assessment should fully engage with the user as an equal partner and should be a single shared assessment involving the user (carer where involved) and all relevant care agencies (most usually health and social care). This should result in a single agreed statement of need, identification of resource to meet need and plan to put required responses in place. The kinds of service which should be accessible during or following this assessment include; home care, housing support, day opportunities, income maximisation, access to employment, community alarms, sheltered housing and short breaks.

The needs of individuals will change over time or through altered circumstances. Approaches to assessment therefore include processes for review and provide a continuing link for the management of care. Assessment and care management approaches must take account of both changes in need in the community and where the early involvement of specialist services can limit the impact of impairment, or further development of disability.

Assessment and care management constitutes one integrated process for identifying and addressing the needs of individuals while recognising that these needs are unique to the individual concerned, and involves the nomination of a dedicated person with responsibility for co-ordinating and sustaining a network of formal and informal supports and activities designed to optimise functioning, well being and control. Improved long term monitoring and review of rehabilitation needs as suggested elsewhere (e.g. 5.3.5) would enhance an holistic assessment and care management approach.

5.1.3 Specialist Services

For service users with needs for more comprehensive or specialist support, a much more detailed assessment of need is required and may need to be complemented by specialist assessment.

Following this access should be arranged to the services listed here if appropriate; the Physically Disabled Rehabilitation Unit, Robert Fergusson Unit, local services for challenging behaviour, the Central Scotland Brain Injury Rehabilitation Centre (Murdostoun), the Community Treatment Centre for Acquired Brain Injury, Community Physical Disability Teams, 'Pathways' vocational re-entry programme (Momentum), 'Access' programme (Momentum), the Disability Resource Centres (also provide advice, information and income maximisation), major housing adaptations, short breaks, respite, supported living care packages, residential services, specialist equipment, enhanced home care, overnight care, supported employment including Equal Access to Employment Teams.

5.2 Early Management and Rehabilitation

5.2.1 A&E Services

About 2,500 people per annum with less severe TBI are admitted to Accident & Emergency for up to 48 hours (Royal College of Surgeons 1999, Thornhill et al 2000). During this time they are often confused and disorientated and it is often unclear whether this is an effect of brain injury or of alcohol or drugs consumed. A period of recovery is required with monitoring to discount the possibility that they have sustained a more severe brain injury. If the injury is more severe then they will be passed to the appropriate acute service (currently a non-specialist hospital ward) and in future to the planned Acute Management and Rehabilitation Unit with capacity to serve all Greater Glasgow Hospitals.

5.2.2 Proposed Acute Management and Rehabilitation Unit

This would serve people soon after brain injury once medically stable even if still having medical treatment needs. This includes people who remain confused and disorientated, agitated, tend to wander, require drug or alcohol detoxification or are in prolonged coma. Often these people require a period in hospital during which they recover rapidly. They can be disruptive and difficult to manage in non-specialist wards where agitation can lead to prolonged difficult behaviour. All are likely to require rehabilitation subsequently. There needs to be assessment of their needs and referral to the next stage in rehabilitation. Some will benefit from intensive rehabilitation at this next stage and others will fatigue rapidly, or may have very severe cognitive impairment and may need an interim phase of 'slow stream' rehabilitation. About 500 cases per annum might be admitted for a maximum of 6 weeks.

The principle is that they should be moved on when they have sufficiently recovered and are capable of benefiting from rehabilitation, or can be discharged to home with follow-up from the Community Treatment Centre, or require specialist inpatient rehabilitation. There is a separate document which outlines the proposal for the Acute Management Unit (see appendix 2).

5.2.3 The Throughcare Project for ABI

The Project serves SGH and GRI. Their purpose is to assess needs as people move into the community, to facilitate discharge, offer support and help to develop care packages. They also offer an information and advice to users, carers and staff. Their "throughcare" remit allows ongoing follow up post discharge and where necessary co-ordination and care management of complex packages of health and social care. The remit of the Throughcare Project and the specialist liaison nurse needs to be reviewed in light of the recent establishment of Joint Discharge Teams the work of the Admissions Project Team and the Community Treatment Centre for ABI. The current staffing establishment for the Throughcare service consists of two FTE qualified posts and two para-professional posts. Line management of these posts is provided by two Practice Team Leaders on each of the acute sites.

5.3 Residential Rehabilitation after acute hospital admission

5.3.1 Inpatient Physical Rehabilitation Services

The Physically Disabled Rehabilitation Unit at the Southern General Hospital currently offers this service. It can take 6-8 patients with traumatic brain injury at any time and in addition will take young people with stroke. The emphasis is on physical rehabilitation. It will not take patients who do not require intensive physical rehabilitation or have a challenging behaviour problem that is likely to impact on their rehabilitation. It is likely that this number of beds is sufficient for the Greater Glasgow population (McMillan and Greenwood 2003; Pentland and Barnes 1988). Length of admission will vary, but for most cases will be between 6 and 12 weeks. Admission to the PDRU for people with ABI is usually from hospital following their injury although some are admitted from the community.

5.3.2 Inpatient Psychosocial Rehabilitation Services

A subgroup of those who have had severe brain injury, require help in adjusting to psychological (i.e. cognitive or emotional) effects and may have difficulty with day to day living tasks (e.g. dressing, cooking and so on). They may require some physical rehabilitation but this is not their main need. These patients are usually referred to the Central Scotland Brain Injury Rehabilitation Centre near Wishaw; this unit is in the independent sector. The rehabilitation needs of these cases are first assessed by GGNHSB who also monitor progress and outcome. The average number of admissions per year in the

past three years is 19. This is a stepping-stone between hospital and home, but some are admitted if struggling in the community.

5.3.3 Services for people with Challenging Behaviour

This can range from provocative outbursts, embarrassing behaviour and verbal tantrums to threatening behaviour and actual violence. Some units (such as the Central Scotland Brain Injury Rehabilitation Centre) will manage challenging behaviour if it is not severe (i.e. not violence requiring physical restraint and not high levels of disruption to other patients). The only specialised unit for dealing with severe challenging behaviour in Scotland is the Robert Fergusson Unit in Edinburgh. The median bed use over the past 5 years by Greater Glasgow residents has been 3. The expected duration of stay in units of this kind is 6 to 12 months, but some cases stay for more than 1 year.

The nature of these cases often requires urgent admission and this is not always possible. To avoid waiting list delays Glasgow has sent people to treatment units in England This is not ideal in terms of discharge, including graduated discharge to reduce risk. The number of such specialist beds required by Greater Glasgow for treatment after traumatic brain injury is likely to be around 3 per annum (Greenwood and McMillan 1993).

Following development of the Acute Management Unit, some people admitted there (or currently to acute wards) will exhibit challenging behaviour for more than 6 weeks but may not be sufficiently severe to transfer to Edinburgh. There is also a need for the services of such a unit for people with brain injury from other causes (alcohol related, brain infection, cerebral anoxia). It is also likely that further cases will be identified within homeless services . Altogether there may be a need for six beds for people with acquired brain injury per annum who are Greater Glasgow residents.

For a very small minority of people, despite treatment, their behaviour causes them to be a significant risk to themselves or others and they cannot be discharged to the community. In the past these cases would often be given major tranquillisers and placed in long-term beds in psychiatric units. Currently these cases tend to block beds in the RFU. Some are released or self-discharge from hospital after acute care and their fate is unknown. However some are likely to be found in criminal custody, become homeless, some may die and some are found in nursing homes.

A survey of Greater Glasgow Nursing Homes in 2001 (McMillan and Laurie 2004) found 14 residents with disruptive challenging behaviour, although all may not need a specialist facility. It is the environment and operation of behaviour management principles in the facility that would make the clients manageable. The skill required to do this should not be underestimated, nor the need for ongoing professional advice to such a facility including from psychiatry and clinical psychology in order to maintain community placement (Alderman 2001).

Options are to continue to refer people to Edinburgh and at times to units in England (it is inappropriate to put them on a waiting list). The disadvantage of continuing with this model is that patients are placed in a setting geographically distant from their relatives and it makes a flexible / experimental and a graduated approach to community re-entry difficult. A second option would be to develop a unit for the West of Scotland, which might be based near to or in Greater Glasgow. A third option would be to attempt treatment of these people in the community; however, there is no evidence that this is effective for brain injury in the UK or elsewhere and there is reason to believe that it would not be. Another option is to develop a unit for NHSGG in partnership with another care group i.e. Alcohol related Brain injury.

There are attractions in the development of a 10 bedded facility in Glasgow which might serve the West of Scotland, which would have a flexible and graduated approach to discharge, which might offer a 'step down' transitional function and which links with housing agencies and social services to optimise the probability of community discharge. It is not appropriate to have waiting lists for people who are a risk to themselves or others. The intention would not be to supplant the service provided by the RFU (who might take extremely severe or medically complex cases from Glasgow) but to enhance the service to this client group by provision of a local service.

Historically the difficulties encountered in assisting individuals to move on from specialist treatment resources such as the Robert Fergusson unit have been attributable in a large part to the absence of a joint financial framework between health and social care agencies. The success of any future strategic plan in relation to the provision of services for individuals with complex needs, including specialised behaviour management would require such an agreed financial framework in addition to identified appropriate providers.

5.3.4 Services for people who are Minimally Conscious or in a Vegetative State

This refers to patients who are in a vegetative state (no evidence of cognitive functioning), who are in a minimally conscious state or where cognitive ability is unknown because of severe physical impairment. These cases are also small in number. Many die within the first 12 months, but some survive for many years (Jennett 2002). They may be in acute beds in general wards for many months and are then discharged to care homes where they receive no rehabilitation.

There is an absence of expert advice with regard to whether the person is progressing and is moving (or has moved) out of the vegetative state, whether they would be able to communicate if the appropriate response medium was found and the person was trained to use it or whether they are not recovering. Clearly there are very different social and care implications for someone who is "locked in" with relatively intact cognitive functioning and an inability to express this, someone who is 'minimally conscious' with limited (but unknown) cognitive capacity and someone who is in a vegetative state with absence of

cognitive function. The Adults with Incapacity Act (Scotland) 2002 states that cases such as these require specialist assessment.

The Central Scotland Brain Injury Rehabilitation Centre near Wishaw has developed 6 beds for these cases. In 2003, 5 Greater Glasgow residents were admitted (average waiting list time 8 weeks). Length of stay has averaged 9 months. The unit have been considering increasing their capacity, but a difficulty is the random frequency of occurrence in any calendar year with implications of planning to run with empty beds at times if waiting lists have to be kept short.

5.3.5 Slowstream Rehabilitation Services

A small number of people remain severely physically disabled for more than six months post injury. Although they show signs of recovery this is slow, continuing over a year or more. Where disability is severe these cases are often discharged home with extensive care packages requiring extensive care from relatives or are placed in care homes. Community Physical Disability Teams may see them for a period of time. With longer term, low intensity residential or community team rehabilitation, these people may achieve a higher level of independence and would consequently need a less intensive care package and care from relatives / friends. What is needed is the option of low intensity rehabilitation that can take place over a longer period of time and with ongoing Consultant monitoring.

In addition, there is a small group of people with severe disability who require long term residential care and who currently reside in care homes. A recent review of care homes in Greater Glasgow has made recommendations in relation to this group of people (see 5.4.6) suggesting that regular review by Consultants in Rehabilitation Medicine and opportunity for ongoing rehabilitation is required (similar to a US Rehabilitation Care Home model).

It may be that two or more specialist care homes could be developed to provide appropriate services for both of these groups; those with slow stream rehabilitation needs and also those with long-term care needs. Further work is required within the overall commissioning strategy in relation to institutional care within Glasgow and GGNHSB.

5.4 Community Based Services

5.4.1 Community Physical Disability Teams

Where physical disability persists beyond the inpatient phase there are 3 community physical disability teams who can offer treatment in the person's home. The caseload of these teams is largely multiple sclerosis and stroke and a relatively small proportion is traumatic brain injury (perhaps 5%). Nevertheless, this is an important aspect of the treatment service available for people with ABI and persisting physical disability.

5.4.2 Services for people with Psychosocial and Emotional Problems

Hitherto there has been no specific service to deal with the large proportion of people with ABI who make a near perfect recovery from physical disability. It is widely recognised that a significant number of these people have persisting changes in personality and ongoing cognitive and emotional problems. These changes can be severely debilitating, can result in marital break up, loss of employment and social isolation. This in turn results in further demands being made on health and social services such as acute hospital admissions, community mental health, forensic, drug and alcohol and housing.

5.4.2.1 The Community Treatment Centre for Acquired Brain Injury

The CTC for ABI opened in February 2003 in the Gorbals redevelopment area. It specifically deals with this group of patients. It does not provide physical therapy but provides group and individual based treatment packages for the "walking wounded". It has a team comprising clinical neuropsychologists, speech and language therapists, occupational therapists and rehabilitation assistants. It has been designed to admit around 100 new cases of severe acquired brain injury each year and will offer a time limited programme with client centred goal planning at its core.

It will also offer a brief intervention service for about 200 people with minor brain injury per annum who were admitted to hospital. Previously rehabilitation of minor brain injury has largely been neglected. It is thought that most will recover within a period of three months post injury although some will remain disabled for longer. There is evidence to suggest that education and advice at an early stage can prevent the development of later disability. All cases admitted with ABI to Glasgow Hospitals should be referred to this unit (many, especially those with less severe TBI will not take up the offer of follow-up).

The Community Treatment Centre will also offer liaison with other services who deal with brain injured people, training of less specialist staff (e.g. in Care Homes) and clinical research. Clinical research forms an integral part of the work undertaken at the centre. This ensures clinical effectiveness within the service and adds to the body of knowledge regarding brain injury from both a local and international perspective. The centre provides a clinical setting for the training of health professionals wanting to specialise in neuroassessment and neurorehabilitation. In addition the team liaise with other services who deal with people who have sustained a brain injury, supporting the training of less specialist staff (e.g. in supported living accommodation).

5.4.2.2 'Access' Programme at Momentum

In addition to the services offered at the Community Treatment Centre a small number of people have accessed the 'Access' Programme at Momentum (Rehab Scotland). They offer group and individual based programmes to help people who have returned to the community following a brain injury. It is based in central Glasgow. Over the past 4 years an average of 9 people have received rehabilitation per annum (range 5-12). This programme is currently

refocusing, possibly as an outreach programme working with people in their homes and as a prevocational programme.

5.4.3 Services to support Vocational Re-entry

A range of programmes is required. In addition to assessment and advice, these include adult education, retraining and re-employment schemes and specific vocational re-entry schemes for people with ABI (eg the Momentum 'Pathways' programme). Some work is required to map out the range of available services that are suitable for ABI. It will be important to liaise with the soon to be developed Equal Access Teams regarding this. A joint review of vocational programmes by Social Services and Health is required, with a remit to obtain an overview of available services and to identify gaps. It is known that supported employment (rehabilitation) schemes, can return people with TBI to sustained employment even when they have previously failed. These schemes are systematic and often require intensive input (Yasuda et al 2001).

5.4.4 Disability Resource Centres

Two Centres operate a centralised referral system serving the City of Glasgow (Fernan St in the East End; Pollok in the South). The remit of the Centres is to provide information, encourage social inclusion and facilitate the development of independent living skills. They provide a wide range of support and information to disabled people in the community, opportunities to increase independent living skills, improve knowledge, facilitate employment and recreation. They are each staffed by multidisciplinary teams.

The Centres will work closely with other specialist services for ABI to facilitate smooth transition between hospital and home and to maintain and enhance quality of life in the community. The focus of work within the Resource Centres is on assisting individuals to achieve community re-integration including employment opportunities according to their individuals needs and aspirations. This may include aspects of physical and cognitive rehabilitation and / or joint work with other specialist health rehabilitation services. Support for carers is also provided by these services.

5.4.5 Self Help Groups

The National Head Injuries Association (Headway) has a branch in Greater Glasgow which is currently redeveloping. It offers a "drop in" centre one half day per week and the participants organise social events. Expansion of this type of service is required particularly since the demise of the Head Injury Trust for Scotland in 2000. Greater Glasgow Headway has suffered from an absence of core funding in the past. In 2001 there were 90 members and the service closed temporarily for around 6 months because of this funding issue. Support from health and social work will be provided to allow Headway Glasgow to continue operating as it develops a robust comprehensive plan for the future of the organisation.

5.4.6 Care Homes

The 2001 review of Greater Glasgow care homes gives detail about the 92 young adults with ABI who were residents; only a minority had rehabilitation pre-admission or specialist review since admission, documentation was poor, making rationale for admission, medication and so on difficult to understand (see McMillan and Laurie 2004 and appendix 3). The recommendations of this report are as follows;

1. Proactive, regular review of medical, rehabilitation and medication needs of young adults (<65yrs) with acquired brain injury in nursing homes, at least twice yearly.
2. Provision of formal rehabilitation as required.
3. Development of 'specialist' care homes for young adults (<65yrs) with acquired brain injury. Staff should have access to regular education and training events to maximise the service that they give and to allow continuation of therapy / management strategies.
4. Care homes should have copies of hospital discharge reports to inform regarding immediate history preadmission including prescription rationale.

Further work is required to progress these recommendations within the context of the Institutional Care Commissioning Strategy and contract management framework within Glasgow City and GGNHSB.

5.4.7 Supported Living Services and Group Homes

There are accommodation needs for people who do not wish to, or cannot live with their family and are capable of living in the community. It has long been recognised that people with acquired brain injury often prefer not to live with people who have chronic mental health problems or congenital learning disabilities usually with the argument that up to the point of their injury their history was different.

5.4.8 Homecare services

Home care services provide an essential element of support within the home. Enhanced Home Care provides an extended level of personal care support; currently this service is available to those over 65. Work is underway to assess the demand from younger adults.

5.4.9 Short Breaks (Respite Care)

This is a scarce and potentially under-utilised resource. Residential short breaks for ABI are offered within the Fernan Street complex in East Glasgow, in addition to resources in the independent sector. Current work will identify the volume of use and scope the need of short breaks services for people with ABI.

CHAPTER 6 ACTION POINTS (To be revised into detailed implementation plan)

	Action Point	Lead Agency	Target Date	Resource Required
1.	Develop and agree comprehensive care and / or care packages for people with complex needs including persisting severe challenging behaviour.	Health and Social Work	Apr 2005	Staff time to develop care packages. Redirect some resource from RFU and estimated additional finance required £650k (still to identify social care costs)
2	Review the role of community based services geared towards community integration (including DRCs).	Social Work	April 2005	Staff time initially
3.	Jointly review discharge planning for people with acquired brain injury, including the roles of the Throughcare Projects and the Specialist ABI Nurse post in North Glasgow Division.	Health and Social Work	Aug 2005	Staff time to carry out review.
4.	Develop plans for an Acute Management Unit	Health	April 2005	Estimated £1.2m
5.	Ensure provision of comprehensive screening, assessment and care in A+E for up to 48 hrs after injury throughout Greater Glasgow.	Health and Social Work	Apr 2005	Staff time to develop, agree and roll out improved protocols
6.	Pilot and establish audit and evaluation database for overall (adult) service.	Health and Social Work	Apr 2005	No additional resource required
7.	Develop plans for a slow stream rehabilitation facility	Health and Social Work	Dec 2005	Staff time to develop plan
8.	Action recommendations re nursing homes (linking with ongoing work on commissioning strategy and contract management of institutional care	Health and Social Work	Dec 2005	Costs to be identified during consultation period as implementation plan is

	services).			finalised
9.	Develop a plan for vocational re-entry for people with ABI with different levels of disability (including rehabilitation and retraining services) in conjunction with the work of the Employment PIG.	Social Work	July 2005	Staff time initially
10	Review and support role of user / carer groups in the planning and delivery of services.	Health and Social Work	April 2005	Staff time initially
11	Review accommodation needs (housing and supported living) in conjunction with Physical Disability PIG and Housing agencies.	Social Work	Dec 2005	Staff time initially
12	Review of short breaks (respite care) (in conjunction with Physical Disability PIG).	Social Work	Dec 2005	Staff time initially
13	Develop the Strategic Framework to include children, adolescents and older people in conjunction with representatives from Children's Services / Planning and Older Peoples Services (Acute and Community).	Health lead Children and Adolescents, Social Work lead for Older People.	Child and Adol draft for consultation (July 2005), Older People (December 2005)	Staff time initially

CHAPTER 7 FINANCIAL PLAN

Work will continue throughout the consultation period for this Strategy to develop a financial plan that covers ABI services. Currently some of these are included within the Financial Framework for Physical Disability.

In addition to specialist ABI services, people with ABI access a range of other services, some specialist, for example Community Physical Disability Teams, Disability Resource Centres and some generic, for example the range of primary care services (including GPs, community nursing) and social care services (including homecare, social work area teams).

Below are the main specific elements of service for people with ABI with their costings. The figures relate to the financial year 2003/04. These represent constituent parts of a financial framework. A full financial framework for all physical disability services is shown at Appendix 4. At this stage it is only provisional and during the consultation period further work will be undertaken to make the financial framework more comprehensive and consistent with those with those for other care groups.

2004	GGNHSB	GCC	Total
Throughcare Projects		133,000	133,000
Inpatient Physical Rehabilitation	200,000		200,000
Inpatient Neuro Rehabilitation	701,000		701,000
Challenging Behaviour (RFU + other units in England)	500,000		500,000
Community Treatment Centre for Brain Injury	430,000		430,000
MISG grant – support to rehabilitation		117,000	117,000
Vocational Re-entry	31,000	281,000	312,000
Disability Resource Centres			
Nursing Homes		1,900,000	1,900,000
Total	**1,862,000**	**2,431,000**	**4,293,000**

References

Alderman (2001) Managing Challenging Behaviour. In RLI Wood, TM McMillan, Neurobehavioural Disability and Social Handicap. Psychology Press, Hove, pp175-208

Brooks DN, Campsie L, Symington C et al (1987) The effects of severe head injury on patient and relative within seven years of injury. J Head Trauma Rehabilitation,

Dunn L, Henry J, Beard D (2003) Social Deprivation and Adult Head Injury, A National Study. J Neurol, Neurosurg and Psychiatry 74, 1060-1064

Greenwood RJ, McMillan TM (1993) Models of rehabilitation programmes for the brain-injured adult I: Current service provision. Clin Rehabil 7, 248-255

Jennett B (2002) Vegetative States. Cambridge University Press, Cambridge

Kay AD, Thornhill S, Teasdale GM (2001) The head injured adult-who cares? B J Neurosurgery, 15, 508-510

Langton-Hewer R (1993) The epidemiology of disabling neurological disorders. In : RG Greenwood et al Neurological Rehabilitation, Psychology Press, Hove, pp 3-12.

McMillan TM, Oddy M (2001) Service provision for social disability and handicap after acquired brain injury. In: RLl Wood, TM McMillan, Neurobehavioural Disability and Social Handicap. Psychology Press, Hove, pp 257-274.

McMillan TM, Sparkes C (2001) Goal planning and neurorehabilitation: The Wolfson Neuro-Rehabilitation Centre approach. Neuropsychological Rehabilitation.

McMillan TM, Greenwood RJ (2003) Head Injury. In RJ Greenwood et al Handbook of Neurological Rehabilitation. Psychology Press, Hove, pp 465-487.

McMillan TM, Laurie M (2004) Young adults with brain injuries in nursing homes in Greater Glasgow. Clinical Rehabilitation, 18, 132-138

Moss NE, Wade DT (1997) Admission after head injury; how many occur and how many are recorded? Injury, 27, 159-161

National Institutes of Health (1999). Rehabilitation of persons with traumatic brain injury. J American Medical Association, 282, 974-983

Royal College of Physicians (1986). Physical disability in 1986 and beyond. J Roy Coll Phys Lond 20, 30-37.

Pentland B, Barnes MP (1988) Staffing provision for early head injury rehabilitation. Clin Rehabilitation 2, 309-313.

Powel J, et al (2002) Community Based Rehabilitation after Severe TBI: A randomised control trial. J Neurol, Neurosurg, Psychiatry, 72 193-202

Royal College of Physicians (2000). Medical rehabilitation for people with physical and complex disabilities. Royal College of Physicians, London.

Royal College of Surgeons(1999) Report of the Working Party on the Management of Head Injuries. Royal College of Surgeons of England, London

Teasdale G, McMillan TM, Murray G et al (2003) Further follow up of the hospitalised Head Injury Study (5-7 years after injury). Final report to the Chief Scientist Office (Scotland)

Thornhill S, Teasdale G, Murray G, McEwen J, Roy CW, Kay P (2001) Disability in young people and adults one year after head injury: prospective cohort study. B Med. J 320, 1631-1635.

Tomlinson Report (1943). Report of the Inter-departmental Committee on the Rehabilitation and Resettlement of Disabled Persons. Cmmd. 64115. London, HMSO.

Tunbridge Report (1972). Rehabilitation report of a sub-committee of the standing medical advisory committee. London, HMSO.

Yasuda S, et al (2001) Return to Work for Persons with TBI. American Journal Physical Medicine and Rehabilitation, 80, 852-864

APPENDIX 1 Brain Injury Database (BID)

GREATER GLASGOW - ACQUIRED BRAIN INJURY SERVICE - AUDIT AND EVALUATION

Purpose: An audit and evaluation process that allows monitoring and informed development/modification of the multi-component rehabilitation and care services for ABI; (Brain Injury Database-BID)

The database will answer questions about subgroups of the ABI population or about component services. For example, what proportion of young adult males who are admitted with ABI are offered rehabilitation- how many receive it and what is the outcome in terms of change in disability or handicap. What is the flow (numbers) and rate of flow (time) through the service? Alternatively, information at the level of individual provider units; for example, is the efficiency of unit A altered following a service development at time B, how long are waiting times for admission and discharge, is planned capacity being reached, how long are people admitted for, does duration of admission have impact on change in disability and so on. From this some notion of cost and effectiveness could be gleaned.

It is possible that this database could serve as a referral route for specific services, and this will be considered. It is likely that there will be a need to trace the progress of individuals in order to determine how the system is used and at what points it is accessed and reaccessed for example and to prevent 'double counting'. Data Protection Act issues may complicate this (but see below).

The database applies to neurorehabilitation and care provided by the Health, Social Services and Independent sector components of the ABI Service, but not to acute care or local authority care.

Background and Concept: When fully developed the ABI Service offers management, treatment and support for the range of ABI presentations, at any stage after injury, and deal with the heterogeneity in terms of presenting problems and severity of disability and handicap.

The database is centrally held and run by GGNHSB, and will be contributed to by all component services to allow a perception of the 'complete picture'. It should include data on all hospital admissions relevant to the ABI Service and admissions from the community to component services. It is intended that the Database will be extended to all age groups but currently includes only adults (16-65years).The database will allow extraction of data according to key variables such as age, severity of injury, service usage waiting times (see separate audit document) and also effectiveness of any interventions. Evaluation of outcome will use a battery of validated and devised measures in addition to the GGNHSB Goal Evaluation and Rehabilitation Monitoring (GERM) form or a modification thereof (outcome in terms of rehabilitation goals x change in disability or handicap). The providers will have to use these measures and will themselves collect the data-clearly not all measures will be used by all providers, although some will be the same for all.

Method: Providers will electronically record their monitoring and outcome data and this will be transferred on a monthly basis to the main database. Data will be transferred electronically (eg by e-mail) from listed service providers to the central database at GGNHSB. There will essentially be 2 databases. The first will simply hold the patients name, date of birth, postcode and identifier (probably Community Health Index Number). The second will contain the CHIN and data re ABI rehabilitation services received. Some service providers may have the CHIN database and their own local database of cases they have seen/are seeing. If the provider does not have access to the CHIN, they can contact the BID co-ordinator to obtain the CHIN for individual cases. Each month the provider would electronically mail data on new patients and discharges. If not received there will be an automatic reminder sent to the provider and copied to the BID administrator.

Other than A+E most sites have relatively small numbers of cases to report monthly (less than 25; most less than 10). For A+E the dataset that is required is smaller (as they are not providing rehabilitation) and will only pertain to those admitted for observation or referred to another provider in the ABI service. This information might largely be extracted from existing data that they collect electronically-or alternatively by routine copying of a modified discharged report.

The set-up of the database needs to be maintained in association with uniform development of audit and outcome data collection by providers.

Appendix 1.1
Audit

1. Client code no.
2. Health Board
3. Unit code
4. Referral source
5. Diagnostic Grouping (primary- i.e. leading to admission)
6. Other current diagnoses
7. GCS score on admission
8. Previous destination
9. Consultant/team leader/clinical director in charge
10. Client's age
11. Client's sex
12. Time between diagnosis and admission
13. Dependency rating (initial on admission)
14. Referral reason (assess/review/treat/care support/respite)
15. Global problem area leading to admission (i.e. physical, emotional, behavioural, social, cognitive)
16. Waiting time referral to admission (wks)
17. MDT involvement (i.e. which disciplines)
18. Length of admission (wks-includes code for ongoing or complete)
19. Intensity of treatment (hours/week)
20. Supervised care (hours/day)
21. Next destination
22. Referrals to other services
23. Bed block time (i.e. between decision to discharge and discharge)
24. Bed block reason

25. Dependency rating (final at discharge)
26. Discharge date

Evaluation of Treatment Effectiveness
Normally completed at beginning and end of treatment, or every three months and at follow-up.

1. GERM document
2. Barthel Index
3. Inpatient Outcome Scale
4. Glasgow Outcome Scale (Outpatients)
5. Client/relative feedback form (completed after discharge/sent to Health Board)
6. (Specific measures relevant to service component)

SERVICE PROVIDERS INCLUDED IN THE SYSTEM

- A+E departments (limited data set)
- (Early management unit)*
- PDRU
- Scotcare (Wishaw)
- Robert Fergusson Unit (Edinburgh)
- Community Treatment Centre
- Physical Disability Community Teams
- Momentum
- (Slow stream rehab unit)
- (Local Unit for persisting challenging behaviour)
- (Specialist care homes)
- DRCs (2 in Glasgow)
- Throughcare Projects
- Capacity to add other vocational rehab providers
- Respite care (Fernan St)
- Day services (Headway, Fernan Street etc; limited data set)

*(units in brackets are at planning phase-the database will have capacity to include when they come on stream)

APPENDIX 2 – ACUTE MANAGEMENT UNIT PROPOSAL

This draft document outlines the need and function of a unit for the acute management and rehabilitation (AMR) of people with acquired brain injury (ABI) in Greater Glasgow, as noted in the Planning and Implementation Group Strategy for ABI, discussions and follows from a visit to London by representatives of the ABIPIG on 23rd July 2002. The visit was to a specialist Unit of this type that is under the direction of Dr Richard Greenwood at the National Hospital, Queen's Square London (see notes in Appendix 2.1). This document also takes into account documentation provided by Dr Greenwood and a proposal from the North Trust from 2001.

Readers who are not acquainted with the overall ABI Strategy, should note that this describes a comprehensive service for the rehabilitation, care and support of people with ABI of which the AMR Unit is a *component* of the overall service.

An audit of service need due to begin in the autumn of 2005 will further define staffing and resources required (including costs).

The Client Group: People with ABI can be admitted to this unit if they require admission for more than 48 hours (otherwise the Accident and Emergency Service), they will be medically stable and will have completed specialist medical treatments (eg orthopaedic).

They will often lack insight into their difficulties, be confused, disorientated and have severe impairment of new learning. Their behaviour may be difficult, related to the last; for example may try to return home, be at risk of wandering, at times may be aggressive, may mis-recognise people including other patients and personal items. Many will be or will become independently mobile during their admission. Some will have ongoing medical treatment and nursing needs for detoxification, treatment of infections and so on. Some will have significant physical disability and will require daily physical therapy from physiotherapists and nurses to promote recovery and reduce the likelihood of contractures. Some will be in coma, vegetative or minimally responsive states and will require ongoing assessment and appropriate stimulation.

Rationale: The rationale for having a Unit of this kind in Greater Glasgow is as follows:-

To concentrate people with ABI who are medically stable but unfit for discharge in one geographical location. This will allow:-

- staff to develop skills in managing and treating these cases
- efficient referral for further rehabilitation.
- prevention of bed blocking on other (eg surgical) wards.
- Improve appropriate use of surgical/other wards and perhaps reduce existing waiting times.
- reduce the likelihood of behaviour problems developing via assessment and consistent behaviour management.
- reduce the likelihood of contractures developing in the severely disabled
- reduce the likelihood of inappropriate discharge and no follow-up behaviour problems via assessment, and knowledge of available services.

Roles of the Unit:

- acute management and rehabilitation
- assessment
- treatment of medical complications
- timely and appropriate discharge
- rapid throughput of cases
- liaison with other parts of the ABI service

Key Issues:

- operational principles of neural protection and restoration
- critical staff mass and concentration of expertise
- staff ownership and responsibility for this phase of recovery and rehabilitation of ABI (as opposed to surgical/other wards perhaps thinking it is not quite their job to deal with brain injury)
- marketing would be important, ideally via personal contact with senior or lead clinicians in general/surgical wards, emergency receiving units, neurosurgery and for non-TBI also stroke and neurology.

Length of Stay and Discharge:

It is anticipated that the average length of stay will be around 3 weeks on the basis of the experience of the London Unit. Given that there is not an option to discharge to neurology beds, the maximum length of stay would be 8 weeks.

A frequent criticism of the concept of units of this kind is that they are unable to discharge their patients, and quickly develop a waiting list, which can defeat the purpose of the unit. This should not be the case in Greater Glasgow. Discharge may be to a range of services. For example-intensive inpatient (PDRU and Scotcare), slow stream residential (yet to be implemented-current alternative is community or nursing home with follow-up review by the Board), community treatment (Community Treatment Service for ABI or Physical Disability CRTs), in the case of prolonged coma-for further assessment and treatment (Scotcare currently), if severe challenging behaviour (Robert Fergusson Unit or Specialist Units in England) for vocational rehabilitation (eg Rehab Scotland) or to the community with social services support as needed. Discharges requiring social services input would be facilitated by review of the Head Injury Throughcare Project and relocation in part or whole to the AMRU and Community Treatment 'Hub'.

Follow-Up:

This would not be required generally, because all cases discharged to the community directly or via inpatient rehabilitation would be routinely referred to the Community Treatment 'Hub' and this process will be monitored via the GGNHSB database for ABI (BID – see appendix 1 of ABI Strategic Framework).

Location and Size of Unit:

- Given that the patients may require medical treatments and possibly continuing consultation with orthopaedic neurosurgical and other specialists it should be on a hospital site. As Clinical Neurosciences, including

Neurosurgery is based at the Southern General, that this would be the optimal site for the Unit.

- According to the Queen's Square figures, their demand is 15-25/100,000 for TBI, which would be i.e. 135-225 cases per annum for Greater Glasgow and an additional twice this number for stroke. The incidence of TBI admissions greater than 48hr in Greater Glasgow is about 57/100,000. Some strokes are dealt with by existing services. The Unit would accept referrals from other causes of ABI including brain infections that otherwise fulfil criteria for admission; the numbers here are likely to be small. In Greater Glasgow we benefit from the comprehensive study by Kay, Thornhill and Teasdale (2001). Of the total number of TBI admissions to Glasgow hospitals in one calendar year, 515 were admitted for more than 48 hours and 145 for more than 2 weeks (of which 84 were admitted for more than a month). It is unlikely that all cases will access the Early Management and Rehabilitation unit. Some will self-discharge after acute medical care and refuse this help, some will be deemed sufficiently recovered not to require admission to the Unit by the end of medical care and will be referred to other parts of the rehabilitation system. We must assume that the maximum length of stay will need to be longer than for the London unit because Glasgow cannot discharge to neurology beds (i.e. 8 weeks rather than 6 weeks). Some further work needs to be done to establish the size of the unit, but an initial 'guesstimate' **for TBI and other non-stroke ABI** (data on young strokes needs to be considered specifically). If assuming that the average length of stay of up to 10% of cases is 8 weeks rather than 6 (as in London) because of the difference in use on neurology beds, then a 12 bedded unit would admit about 195 cases per year (also consistent with the estimated admissions of severe ABI to the Community Treatment 'Hub'). Clearly this estimate assumes that a significant proportion of cases who are admitted for less than two weeks would not be admitted to this unit, for reasons as given above.

  This estimate is generally in keeping with the estimate from the North Trust, which is for 7 beds and given that they admit around 60% of TBIs in Greater Glasgow. A single unit is likely to be more effective, given issues of size, the disruptive nature of the patients (less ideal as part of another ward) and the need to recruit specialist staff.

Leadership and Staffing

- Given the need for medical treatment sat this time, there needs to be medical leadership. The experience of the London unit is that day-to-day management can be effectively led by an SpR and SHO plus a senior nurse acquainted with medical and psychological issues in management, backed by input from a clinical psychologist for the latter. The source of medical leadership is an issue; this would be a part-time post, requiring input from junior staff, with experience in dealing with the management issue outlined above and an understanding of how this component fits with the rest of the ABI service.
- The staff mix at the London Unit should be a guideline, to be modified in the specification document when the size of the unit is agreed.
- A draft proposal for staffing is given in Appendix 2.2.

Audit/Outcomes/Documentation:

The Unit would be included in the BID database being developed by GGNHSB for the ABI service overall. This will allow audit of this component and of the overall ABI rehabilitation and care service. Of note is the reduction of deaths in the London unit as an additional measure. If a unit of this kind is established in Glasgow, it should collaborate with the London Unit including in terms of the development of outcome measures and we have access to their assessment/monitoring/documentation tools.

Implications for Social services:

- A benefit would be the location of these patients on a single site, making them easy to find and enabling good relations to be established because of regular contact between NHS and SW specialists.
- The Throughcare Project (eg at the Southern General) could be redefined to have a main purpose of working closely with this Unit.
- There may be some resource implications simply because many of these cases have social or care needs and fewer will 'fall through the net'.

Financial Implications:

Most cases admitted for more than 48hr are placed in an orthopaedic bed. A few are found in cardiothoracic or general surgery beds. The weekly cost of an orthopaedic bed is £2200. The cost of the AMRU (£1840 per bed per week), should therefore be seen in the context of reducing existing costs and maximising efficient use of the more expensive surgery beds (eg reducing waiting times for elective admissions).

It may be unlikely that costs can be reduced by transfer of exiting staff. My understanding is that Ward 29 staff at GRI have been absorbed elsewhere for example, it is unlikely that fewer surgical beds are needed. If considering a physical site for the Unit, this has not been discussed as yet with the South Trust.

-

APPENDIX 2.1

The London Unit, Queen's Square July 02: (representatives from North and South Trusts, GGNHSB)

- Launched in February 2000, a ward at The National Hospital, Queens Square
- 8 SITU beds feed into the 12 bedded Unit; these are adjacent to 12 neurosurgery recovery beds
- Admissions are 15-20 TBIs/100k population; the rest (a further 2/3) are stroke
- TBI/SAH come from neurosurgery (who have broader remit cf GLA); stroke from A+E.
- Average length of stay for TBI = 21d; max is 6 weeks
- The unit will manage medical problems eg detoxification; they do not cherry-pick!
- Discharge: 32% to further rehab, 32% to community services+Community Rehab Teams or 28% community but a few are discharged temporarily to neurology beds.

- Staffing 2 physio; 1.5 OT; 0.5 SLT; 1 neuropsychology, 0.5 dietician; 33 nurses (12+beds); medical staff part/time of 3 neurologists, 1 SpR, 1 SHO
- Nurse specialist has a day to day leadership role and runs a follow-up clinic
- Therapy typically per patient OTx3/wk; Physio daily; SLT weekly, others as required.
- Would like further staff-0.5 neuropsychologist; dedicated junior med cover.
- Audit measures: Rankin, Barthel, GOAT, GOS, HADS.

APPENDIX 2.2 (to be revised following 2005-2006 audit of service need)

Proposed Staffing and Costs: (assuming 12 beds; based on London Unit and North Trust figures) Salary figures need to be updated; therapist grades to be added; all needs to be cross-checked x Dr Greenwood).

	Number	wte	Cost 1.0 wte	Actual cost
Lead Consultant	01	0.4	83,104	33,242
Consultant cover	01	?0.6	83,104	49,862[1]
SpR	01	1.0	31,435	31,435[2]
SHO	01	1.0	26,300	26,300[3]
G nurse	01	1.0	29,308	29,308
F nurse	03	1.0	28,870	86,610
E nurse	11	1.0	25,414	279,554
D nurse	13	1.0	21,892	284,596
Auxiliary nurse	05	1.0	14,768	73,840[4]
Clin neuropsychol grade B*	01	0.5	53,333	26,666
OT snr 1	01	1.0	27,068	27,068
OT snr 11	01	0.5	27,068 ? lower salary	13,534
Physiotherapy snr 1	01	1.0	22,670	22,670
Physiotherapy snr 11	01	1.0	22,670 ? lower salary	22,670
Speech Language Therapist snr 11	01	0.5	38,969	19,485
Dietician	01	0.5	27,068	13,534
Capital upgrade				150,000
TOTALS	--	--	--	1,190,374[5]

1 or experience grade A with supervision x grade B.
2 add extra for on-call duties
3 ?should be on-call costs and not proportion wte
4 London Unit has 2xHCA11 and 3xHCA1 which are cheaper
5 These costs assume transfer of Throughcare social workers to this unit under existing costs.

APPENDIX 3 – NURSING HOME STUDY – GREATER GLASGOW

Young Adults with Acquired Brain Injury in Nursing Homes in Glasgow

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ABSTRACT

Objective: To survey characteristics, level of disability and services received by young adults with acquired brain injury (ABI) resident in nursing homes in Greater Glasgow.

Design: Telephone survey of 75 nursing homes followed by a questionnaire survey and review of medication cardexes. Included were all people under 65 years with ABI resident in nursing homes in Greater Glasgow between 1st February 2000 and 31st January 2001.

Setting: 28 nursing homes in Greater Glasgow, Scotland (population 0.9 million).

Subjects: Young adults (16-64) with ABI.

Main outcome measures: Structured questionnaire, Barthel Index, Office of Population Census Survey Disability Form, review of medication cardexes.

Results: Information was obtained on all cases identified in 75 nursing homes. There were 92 people with ABI in 28 nursing homes; 43/92 were in 3 homes. Only 42 had inpatient rehabilitation preadmission. Severe disability (OPCS categories 7-10) was found in 54 cases and minimal/minor disability (OPCS categories 1-2) in 18. Thirty-two exhibited challenging behaviour, 9 of these were physically violent. Homes were staffed by unqualified assistants, supervised by nurses. No home itself offered rehabilitation, but some had accessed an NHS physical disability community team (28/92 cases) or other community teams (5/92). Proactive medical review was uncommon. Medication had been reviewed since admission in a minority (21/92). Most had regular visits from relatives.

Conclusions: There is a wide range of disability in nursing home residents in Greater Glasgow. Proactive, routine review of medical, rehabilitation and medication needs is rare as is rehabilitation pre and post discharge. This is serious given the likelihood of reduced intellectual and/or physical capacity in this population. Nursing homes should have hospital discharge reports that inform about immediate preadmission history, rationale for medication and placement. There is a need for regular and ongoing health service review of nursing home residents including potential for rehabilitation and return to community living.

APPENDIX 4 Glasgow City and Greater Glasgow NHS Financial Framework for Disability Services

To view this appendix please double click on the link below.

http://www.nhsgg.org.uk/content/mediaassets/excel/Financial_Framework_for_ABI_Strat_Nov_4.xls