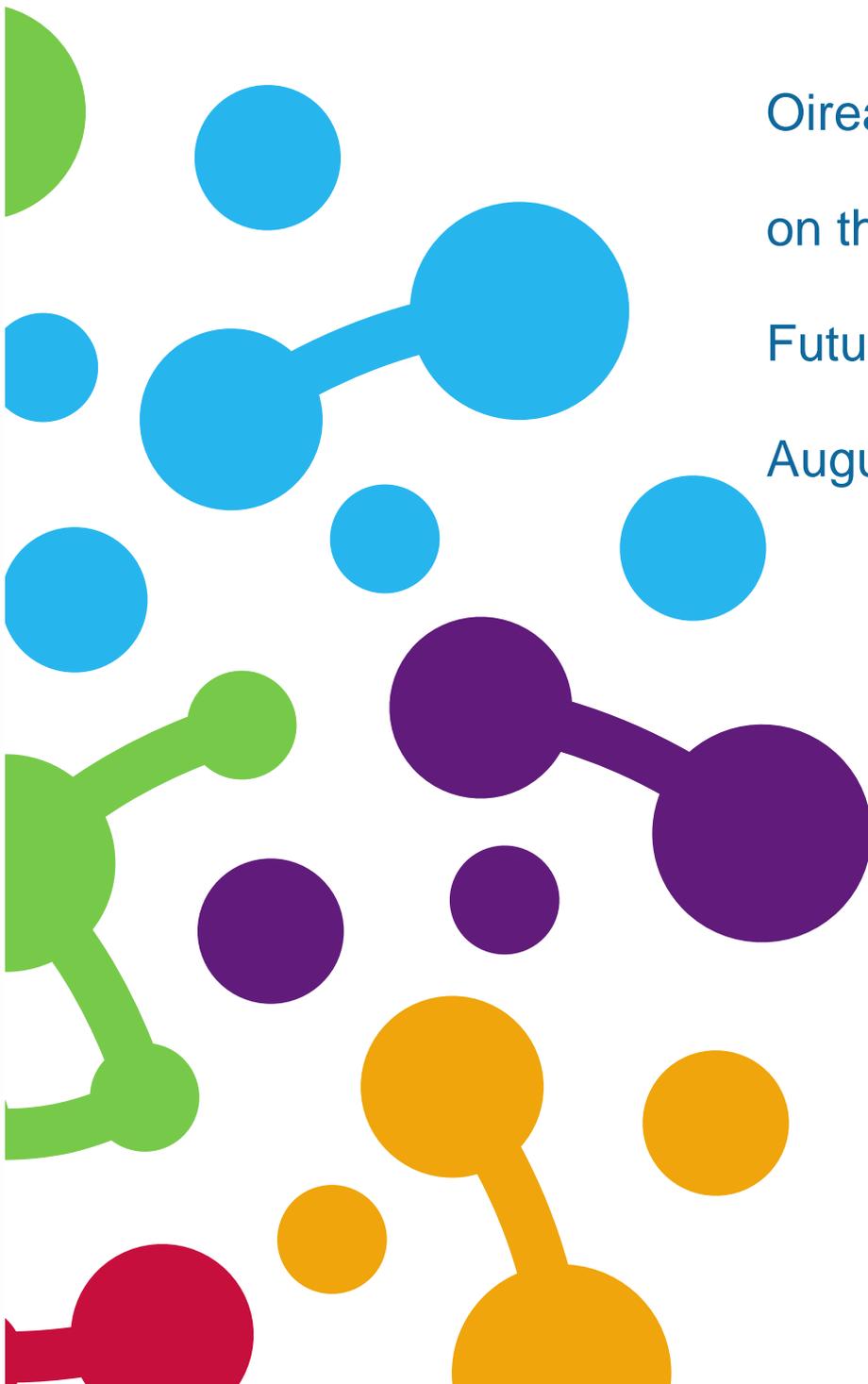


ACQUIRED
BRAIN INJURY
IRELAND

Oireachtas Committee
on the
Future of Healthcare
August 2016



Executive summary

A transformation of the health services in Ireland is critical in order to sustain ourselves as a healthy society and an economy. Health services need a radical re-orientation in order to be responsive to the needs of our population. Increasing number of people are surviving and living with complex conditions due to advances in medicine. However, the health services have not responded accordingly to this demographic. Those living with an acquired disability (s.a. an acquired brain injury) are not currently being prioritised in the health services, particularly in terms of their need for rehabilitation. They 'exist' rather than live full and meaningful lives.

List of recommendations

- It is essential that **neuro-rehabilitation is recognised as playing a critical role in healthcare policy in Ireland** and an **integral part** of our health services. With survival rates as they are, the healthcare services must embed rehabilitation as an essential part of the response for both patients and families.
- The Irish health services must be **re-orientated in terms of priorities** in order to **develop neuro-rehabilitation services** and a **seamless pathway** for patients from hospital to home.
- The **role of the NGO sector** in terms of services development and delivery must be recognised and a fully resourced NGO sector is a vital element of a fully integrated health system. NGOs are essential to elevate **the voice of the patient/family** in the milieu of stakeholder voices in healthcare discourse.
- There is a need for a **systemic approach** to **collecting comprehensive** data. It must be a **resourced function** across the health services.
- **Case management** for complex cases that require **interdisciplinary, cross-agency** working must become an embedded feature of our health service.
- Prevention of disease and injury and taking a **comprehensive and meaningful public health approach** is essential for the long term sustainability of the health service in Ireland.

1. Introduction

Acquired Brain Injury Ireland (ABI Ireland) welcomes the opportunity to make a submission to the Oireachtas Committee on the Future of Healthcare. Our submission focuses on the key strategic issues that our healthcare system from the perspective of people with an acquired brain injury (ABI).

2. People with brain injury in the health system

When a person experiences a brain injury, as a result of a fall, assault, accident, stroke or tumour, they will need to re-learn the skills of life again. Many required specialist services with skilled multi-disciplinary teams support them on their rehabilitation pathway. Depending on what part of the brain is injured and the extent of the injury, the person will have to live with different consequences, many hidden, others not and may range from physical, sensory, cognitive, psychological and emotional.

2.1 Key roadblocks

There is limited recognition of people with ABI as a group with who require specialised rehabilitation within current health policy. Rehabilitation services are **under-developed** and **under-resourced**. Their experience of the health system can be summed up as:

- ✚ **Lack of availability** of timely neuro-rehab services and therefore forced to remain in hospital or go to live in a nursing home
- ✚ There are massive **inequities** in terms of the *access to the neuro-rehabilitation* services that do exist and getting a service is largely based on luck and a post-code lottery.
- ✚ **Waiting long periods** of time to access both in-patient and community neuro-rehabilitation services that are there
- ✚ Lack of a **meaningful pathway** from hospital to home
- ✚ Lack of **co-ordination** and **integration** of services and providers
- ✚ Major challenge with '**navigating the system**'
- ✚ Lack of **support** and **training** for **family members** who are propelled into role of carer
- ✚ Lack of **availability of skilled (neuro) rehabilitation healthcare professionals** across the service providers
- ✚ A vacuum in terms of **leadership** and **vision** in the Department of Health and the HSE to drive the necessary change in relation to growth and development of neuro-rehabilitation services within the Irish health service.

3. Key issues

3.1 Demographic challenge – people surviving and living with conditions

We often hear of the ageing demographic challenge but another significant demographic challenge for our health service is the ever increasing numbers of people who are surviving and living with a complex injury or condition due to advances in medicine, technology and science. How the health service responds to these continually increased demands on a finite resource is a massive challenge.

Our health services, (emergency services, emergency medicine, intensive care, neuro-surgery) have improved enormously in Ireland in terms of saving people who experience an injury whether traumatic or vascular but once the person is kept alive what next? If we continue to 'save' people then we must develop a response to that goes beyond leave people to 'exist'. To date, the health services have not responded and are failing these people due to the lack of a pathway for rehabilitation and enabling the person to maximise their recovery and lead a meaningful life again.

3.2 The data challenge – evidence based policy making and planning

The paucity of data to inform evidence based policy making is a massive challenge in the Irish healthcare system. Collecting robust and reliable health service data is an essential cornerstone of policy making and service planning. This must be a priority to ensure a sustainable future for our health service. Again, there are pockets of good practice in our healthcare services, such as the Irish Cancer Registry <http://www.ncri.ie/> but there is a need for a systemic approach to collecting comprehensive data. It must be resourced function across the health services.

3.3 Re-orientation and re-prioritisation of the health services

- There is a need to have a radical shift in healthcare priorities in order to develop services to ensure that there is a meaningful rehabilitation pathway for those who experience brain injury. This requires systemic change in terms of the way our health services are provided and funded. Addressing the currently 'silos' in terms of funding for our health services must be a priority in any reform of healthcare in Ireland.
- It is essential that neuro-rehabilitation is recognised as playing a critical role in healthcare policy in Ireland and an integral part of our health services. With survival rates as they are, the healthcare services must embed rehabilitation as an essential part of the response for both patients and families.
- For rehabilitation to be successful in terms of outcomes, it should be timely and part of a seamless pathway that extends from the acute hospital phase right through to the community. Success of one element in the pathway (for e.g. acute rehab) is predicated on the successful implementation of the other (e.g. the availability of community based neuro-rehab services). Timely intervention is a key determinant of the optimal outcomes for the person with a brain injury. In addition, rehabilitation must begin at the earliest possible time for the patient.

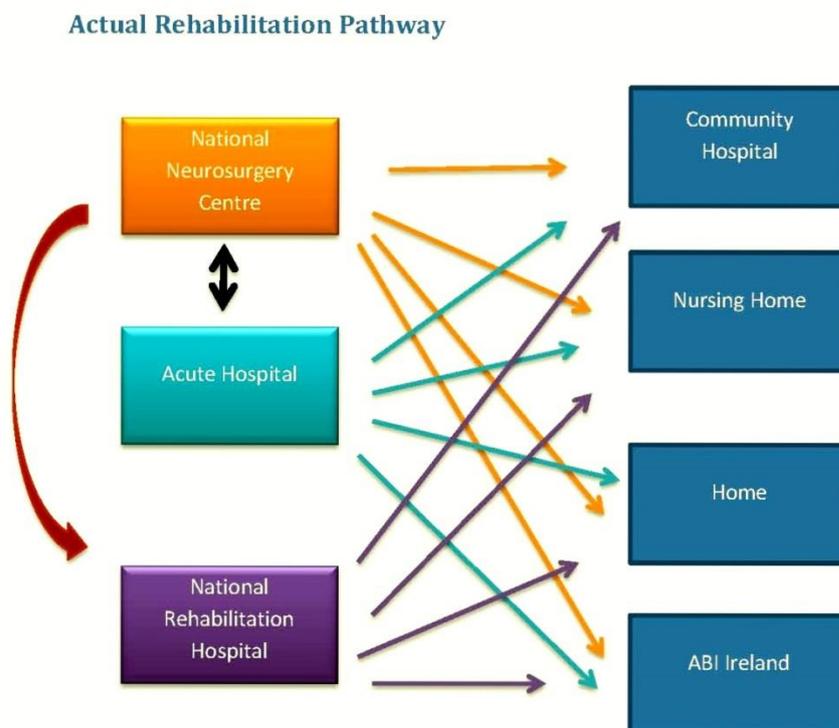
4. ABI Pathway – addressing deficits in services and fragmentation

The current ABI pathway is extremely fragmented and there are massive limitations due to the lack of availability of services across the span of the pathway from hospital to home. Addressing the gaps in services and the lack of a meaningful and seamless pathway for the person with brain injury is essential to any reforms in the health within the health service. Investment must be driven by the principles espoused in the Neuro-rehabilitation Strategy¹ (2011). Diagrams 1 and 2 illustrate the contrast in the current and ideal ABI pathways.

Best practice guidelines published in the UK in 2005² recommends that people with ABI have access to specialist neuro-rehabilitation services provided by co-ordinated inter-disciplinary teams. In addition there is a need for a clear rehabilitation pathway, where services are co-ordinated and integrated. People with ABI may require different services at different times and may need multiple services. Specialist support for the family is an essential component of rehabilitation and people with ABI should have access to lifelong support if needed.

In particular for those with a brain injury, the lack of timely and appropriate rehabilitation services means that valuable recovery time is lost and the outcomes for the individual are not optimal. The lack of a pathway, means that people who despite surviving the major trauma, end up living in highly inappropriate settings including nursing homes, community hospitals or at home where families are unable to cope.

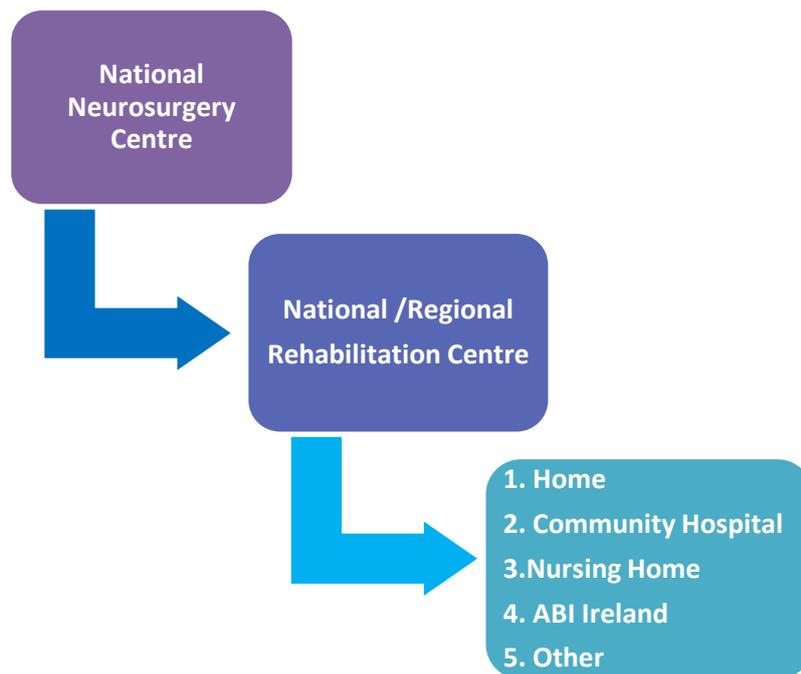
Diagram 1: Actual ABI Pathway



¹ Department of Health and HSE (2011) National Policy and Strategy for the Provision of Neuro-rehabilitation Services in Ireland 2011-2015

² British Society of Rehabilitation Medicine (2005) NSF for Long Term Conditions, UK

Diagram 2: Ideal ABI Pathway



In addition, the role of the NGO sector in terms of services development and delivery must be recognised and a fully resourced NGO sector is a vital element of a fully integrated health system. NGOs also elevate the voice of the patient/family in the milieu of stakeholder voices in healthcare discourse.

5. Case Management – addressing integration and a seamless path

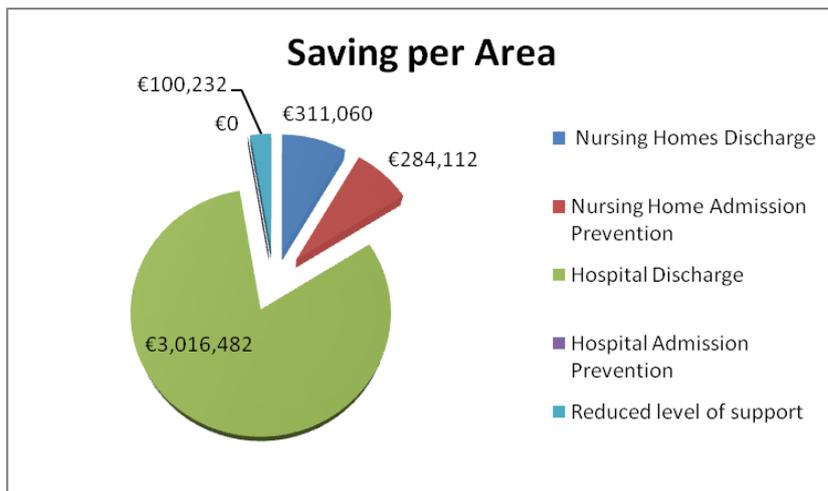
There is compelling evidence that case management is a key way to enable service integration across the range of specialists and service providers. Research from the UK indicates that case management for complex cases that require interdisciplinary working is both person centred and serves to maximise the person’s independence and quality of life. It also leads to significant benefits to society including the reduction in the burden of care with avoidable, expensive and long or frequent hospital admissions being significantly reduced.³

A geographically based ABI-specific case manager acts as a single point of contact and provides a clear pathway to support the person’s transition from acute settings through post-acute and into community rehabilitation services. The case manager is the link person and helps to reduce the number of people with an ABI who fall through the net and provides on-going support to ensure that the person receives the necessary services. Research carried out in 2009 in the North East HSE region on ABI-specific case management services proved that they were cost effective. The study showed that case management facilitated discharge from nursing homes and hospitals, prevented admission to nursing homes and hospitals and lead to a reduced level

³ Department of Health (UK) (2005) Supporting People with Long Term Conditions: An NHS and Social Care Model to support local innovation and integration, London, Department of Health

of support (post case management intervention). In the year in question, the research showed that a net savings of €3.5m occurred. The following graph (Fig 1) represents the savings in monetary terms across the whole of the North East HSE area⁴. Therefore, a comprehensive ABI case management service with national coverage and linkages to the CRTs is needed.

Fig 1:



6. Final Comments

The Irish healthcare system is facing major challenges in the future. Our changing demographics are a massive factor that influences decision making with regard to resource allocation.

Finite resources require evidence based decision making. Research and good evidence for policy decision making and service planning must become an integral feature of our health policy discourse. Limited resources and their allocation also require strong policy and clinical leadership.

Prevention of disease and injury and adopting a comprehensive public health approach is essential to the long term sustainability of the health service in Ireland.

⁴ Whelan, D. (2010) An evaluation of the cost effectiveness of acquired brain Injury Ireland case management in the North East Area (Meath, Cavan/Monaghan and Louth). Unpublished MA thesis, Institute for Public Administration

Supporting Information

About ABI Ireland

ABI Ireland is a dedicated provider of community-based neuro-rehabilitation services for people with an acquired brain injury (ABI) and their families. As a brain injury can affect a person's ability to manage their own life, ABI Ireland works in communities across Ireland to support and empower people to rebuild their lives. ABI Ireland also campaigns, educates and advocates for the rights and needs of this hidden group in society.

ABI Ireland Services

ABI Ireland provides a diverse range of accredited neuro-rehabilitation services. The core services include:

- Clinical neuro-rehabilitation team
- Residential rehabilitation
- Transitional living
- Day resource/clubhouse
- Home and community rehabilitation
- Case management

Additional support services are also provided and include ABI information, family support and carer training.

Key Facts on ABI

- There are many ways in which a person can acquire a brain injury. These include, among others, a fall, assault, accident, infection, stroke or tumour.
- Depending on what part of the brain is injured, and the extent of the injury, the person will have to live with different consequences.
- Many of the consequences of brain injury may be hidden, others not. They range from physical and sensory to cognitive and psychological affecting how a person feels, thinks, acts and relates to others.
- Each year it is estimated that 13,000 people in Ireland acquire a brain injury. However, there are no official statistics on ABI in Ireland.
- ABI is one of the leading causes of disability and can have life-long consequences
- Neuro-rehabilitation is a clinical and social process to aid recovery after a brain injury. It is about relearning, compensating and regrowth so the person lives a life of their own choosing. It supports the person to live a meaningful everyday life.

Contact Details

Grainne McGettrick, Policy and Research Manager T: 01 280 4164 E: gmcgettrick@abiireland.ie



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