



ACQUIRED BRAIN INJURY IRELAND



REBUILDING LIVES AFTER BRAIN INJURY

**Strategic Plan
2020-2024**

www.abiireland.ie



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ACQUIRED
BRAIN INJURY
IRELAND



Foreword by CEO

Acquired brain injuries can happen to anyone, at any time with life-changing consequences to individuals and their families.

Today in Ireland, around 19,000 people will acquire a brain injury. In fact, brain injury is set to surpass other diseases as the major cause of death and disability worldwide.

There is hardly a family in the country that hasn't been touched by brain injuries caused by stroke, road traffic accidents, falls, tumours and assault. Yet it remains a hidden phenomenon in Irish society.

Nobody ever thinks a brain injury will happen to them. But it happens to 52 people in this country every day, often leaving them with a chronic, ongoing condition that can affect their lives and those of their family, for months, years and even decades after the initial injury.

When we first opened our doors in 2000, there were little or no dedicated services for people who acquired a brain injury in Ireland. Twenty years later we have demonstrated an innovative, effective and efficient model of specialised neuro-rehabilitation in the community. While our service has grown and continues to grow from strength to strength, there are still a lot of gaps and challenges facing families in Ireland affected by brain injury.

We've come a long way but we still have a long way to go. Right now brain injury survivors face a lottery to access to the rehabilitation they need to support their recovery. This is not good enough. Some people are discharged home to their families without any supports. Families are pushed to breaking point because of severe under-resourcing of neuro-rehabilitation.

Others are stuck indefinitely in a hospital bed because there is no rehabilitation place for them. There are also those who are placed in an inappropriate setting like a nursing home merely left to exist, when they don't need to be there.

That's exactly what happened to my brother Peter at the age of 42. To see him misplaced in a nursing home at such a young age was devastating and this drove me, along with my husband and the support of my family, to establish this organisation.

Only a small few are lucky enough to experience a good pathway through our health system from hospital to home with access to neuro-rehabilitation and support along the way.

This country cannot continue to save a life on the one hand but rob quality of life on the other hand by not investing in community rehabilitation.

This document describes our strategy for the next five years. Our ambition is to ensure that every brain injury survivor can access personalised rehabilitation and support in their community to maximise their potential and independence for a meaningful life. There's a long way to go and this strategy expresses our commitment as a leading voice for change on behalf of brain injury survivors and their families.

Barbara O'Connell
Co-founder and Chief Executive
Acquired Brain Injury Ireland



Message from the Chairman:

Our strategic planning process first started in spring 2019. After months of thought-provoking sessions and workshops, we completed a thorough assessment of strategic factors affecting the organisation now and for the next 5 years. The result is a strategic plan that provides a framework to guide the organisation through challenges and help identify opportunities to strengthen our capacity and support access to community rehabilitation nationwide.

Acquired Brain Injury Ireland is a person-centred organisation with an inherent sense of advocacy at its core. Every day, our rehabilitation teams go the extra mile to relentlessly advocate on behalf of clients and their families so they can get access to vital services. This passion and drive underpins

our Strategic Plan 2020-2024 and this is reflected in our newly articulated mission statement. My sincere thanks to my colleagues on the Board, the CEO and the Executive Management Team, the strategic planning committee and to all the staff in Acquired Brain Injury Ireland who have embraced this project providing vital insights on our journey to identify our strengths and goals for the future.

Denis Buckley
Chairman
Acquired Brain Injury Ireland

WHAT ARE THE MAIN CAUSES OF BRAIN INJURY?



Stroke (39%)



RTA's (14%)



Falls (14%)



Tumour (7%)



Assault (5%)



Our Vision, Mission and Values

Our Vision

A society where brain injury is understood and all those impacted receive world-class, personalised rehabilitation and support, as and when they need it.

Our Mission

We will passionately serve and relentlessly advocate to empower and support people impacted by brain injury to rebuild their lives.

Our Values

DIGNITY & RESPECT

We treat each other with the utmost dignity and respect in our interactions

CHOICES

We empower each other through choices to manage and direct our lives within our capabilities

RELATIONSHIPS

We engage meaningfully with each with honesty, integrity and kindness

CONTRIBUTION

We encourage everyone to play their part no matter how small

SHARING EVERYDAY PLACES

We value inclusion for all in our communities and sharing everyday experiences

The scale of Brain Injury in Ireland

Brain injuries can happen suddenly and are often traumatic. Acquired brain injury (ABI) refers to an injury to the brain that has occurred after birth and the most common causes we see in our services are from stroke, road traffic accidents, assaults, falls and brain tumours. Brain injuries differ from other neurological conditions because they are non-progressive. As a result, individuals can make significant gains when they have access to the appropriate and timely neuro-rehabilitation services. Unlike other conditions, our focus is not on prevention or delaying disability – our focus is recovery and maximising potential through neuro-rehabilitation.

We estimate more than 19,000 brain injuries are acquired in Ireland every year. This is based on a minimum of 18,800 brain injuries occurring annually as confirmed by 8,500 strokes a year (National Stroke Audit), 300 brain tumour cases (National Cancer Registry) and 10,000 people hospitalised with traumatic brain injuries (National Neuro Rehabilitation Strategy). A further, 120,000 people in Ireland are estimated to be living with moderate or severe disability caused by brain injuries. We believe these figures are only scratching the surface of the scale of brain injury in this country, the true extent of which is difficult to quantify accurately due to the lack of data available.

People with an acquired brain injury can have hidden problems that can often mean they cannot resume their previous lives. Damage to the brain from an acquired brain injury can result in a change in the behavioural and physical aspects of a person. It can affect individuals in different ways including physically, cognitively, emotionally, behaviourally, socially, financially and the impact on family relationships.

Too often people who acquire brain injuries are young and due to lack of services available at the time of their injury, these young people are often left in inappropriate settings such as nursing homes, community hospitals or at home where families are unable to cope.

This highlights a greater need for awareness around brain injury. If more people understand about brain injury at political level, in the health system and widely in the public, the easier it will be to achieve support for investment in the services needed to support individuals and their families.

Currently there is little Irish epidemiological research to show the actual incidence or prevalence of acquired brain injury. Without this research it is difficult to secure additional financial resources required to ensure people have access to vital, specialist neuro-rehabilitation services like ours.

In Ireland, here is what we know:

1 19,000 new brain injuries happen annually

2 10,000 people are hospitalised with traumatic brain injuries annually

3 8000-8,500 new strokes happen every year

4 300 new brain tumours per annum

5 120,000 people living with disabilities after brain injury



In Acquired Brain Injury Ireland, here is what we know:

1 Stroke is the **no.1 cause of brain injury** in our services

2 **69%** of the brain injury survivors we help are male

3 **1 in 5 brain injuries** are caused by road traffic accidents and assault

4 **6.5% increase** in referrals to our service

5 **1,161 clients** benefited from our services in 2018



A challenging landscape

An appalling lack of neuro-rehabilitation services is devastating thousands of brain injury survivors and their families across the country who are left merely to exist. Persistent service gaps mean that brain injury survivors face an uphill battle to access neuro-rehabilitation services in Ireland. A severe lack of statutory investment in home, community and residential rehabilitation services has resulted in:

- significant waiting lists for brain injury survivors across the country
- delayed discharges from both acute hospitals and the National Rehabilitation Hospital (NRH)
- inappropriate placement of young brain injury survivors in nursing homes

As we embark on a new strategy, our major overarching goal is to expand our services to ensure that everyone has access to neuro-rehabilitation services nationwide. Currently in Ireland, there is a significant gap between

the complex and specialised rehabilitation delivered by the NRH and the generalist rehabilitation system that is often provided in the primary care network. While Acquired Brain Injury Ireland has grown year on year to become the leading national service provider of community neuro-rehabilitation in the country, our specialist services are not consistently available across the country.

Development of our services nationwide will:

- Free up acute beds
- Save time and money
- Reduce delays for discharge
- Improve health outcomes
- Reduce caregiver burden

A major gap is the lack of a regional step-down facility from the NRH where rehabilitation could be advanced at an intensive level in preparation for receiving services at a community level. Further gaps relate to the lack of services for brain injury survivors under 18 years and over 65 years. Even in locations where we are funded to deliver rehabilitation services, these situations are often not optimally resourced and experience significant waiting lists. We are particularly focused on the persistent gaps in the West and parts of the eastern seaboard between now and 2024.

The Policy Context

There is no shortage of policy papers and programmes to support our argument around the need to expand our community neuro-rehabilitation services but what is lacking is the political will to make it happen. It is nine years since the launch of the National Neuro-Rehabilitation Strategy (2011) and a year into the subsequent implementation plan (2019) with little/no

action to benefit people after brain injury. At Acquired Brain Injury Ireland we remain steadfast in our conviction and will continue to raise the voice of brain injury as we advocate the need for development of clear pathways for brain injury survivors accessing services from hospital to home.

Slaintecare

This marks the first time there has been political consensus on a health reform plan with cross-party support to deliver a universal health system in Ireland. It emphasises that care should be provided at the lowest level of complexity, often outside of hospital and in an integrated way.

National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland (Implementation Framework 2019-2021)

This framework recognises that neuro-rehabilitation services are under-developed across the pathway and acknowledges the need for new investment and new resources.

Key health policy milestones

Neuro-rehabilitation and brain injury



Burke et al (2019) The 2019 neuro-rehabilitation implementation framework in Ireland: Challenges for implementation and the implications for people with brain injuries, Health Policy (2020)



Our Vision

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Our Mission

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Dignity and respect – we treat each other with the utmost dignity and respect in our interactions

Choices – we empower each other through choices to manage and direct our lives within our capabilities

Relationships – we engage meaningfully with each other with honesty, integrity and kindness

Contribution – we encourage everyone to play their part no matter how small

Sharing everyday places – we value inclusion for all in our communities and sharing everyday experiences

Strategic priorities

Equal Access

Create equal access to neuro-rehabilitation



- Drive the development of specialist, community-based, neuro-rehabilitation services to ensure consistent access nationwide

Public Policy

Influence change and raise the voice of brain injury survivors



- Build research evidence to influence public policy and drive neuro-rehab services provision
- Grow the voice of brain injury survivors to drive their needs higher on public agenda

Strategic priorities

Educate

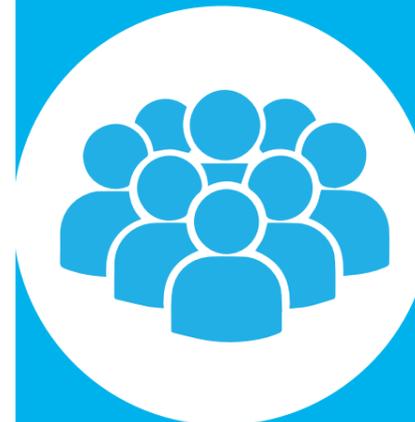
Develop specialist training in brain injury rehab



- Be the leader in quality training for professionals in brain injury rehabilitation

Support Network

Reduce caregiver burden for families affected by brain injury



- Initiate a national network to support families and caregivers of those with brain injury

The Capacity

Build and optimise organisational capacity



- Deliver on the mission by building sustainable funding and driving strong governance



Our Strategic Priorities

PRIORITY ONE: EQUAL ACCESS

Creating equal access to neuro-rehabilitation services nationwide

We believe a consistency of service must be available to those who suffer acquired brain injury regardless of geographic location. Currently many parts of Ireland only have access to the acute hospital setting and it is our key priority to close the gaps along the pathway for brain injury survivors from hospital to home. While we will continue to deliver current brain injury specific, community rehabilitation services overseen by a clinical team, we will prioritise blackspot areas such as the west of Ireland for the provision of rehabilitation services. We will work with the new proposed community networks and collaborate at all levels. Our neuro-rehabilitation services are delivered in the community through various settings comprising residential, community, clubhouse and transitional living. We are driven to see these services available to all who need them regardless of address.

Objectives

We are driven to close significant gaps around the country by:

1. Having specialist community-based rehabilitation services consistently available across the country.
2. To provide a regional neuro-rehabilitation centre in the community as outlined in the National Neuro-Rehabilitation Strategy.

PRIORITY TWO: PUBLIC POLICY

Influencing change and raising the voice of brain injury survivors

Quantifying the problem of brain injury in Ireland is extremely difficult due to the lack of data available. Establishing a base of reliable evidence is essential to support our advocacy for greater investment in brain injury supports and solutions. Such data provides a vital basis for health service planning. We will engage in research that supports our mission to relentlessly advocate on behalf of brain injury survivors. By increasing awareness of our organisation and the impact of what we do, we can drive greater support for our cause at policy, political, professional and donor levels.

Objectives

We will collaborate with our partners and supporters to:

1. Engage in policy analysis and advocacy to ensure inclusion of brain injury survivors and their families so their voice is heard in the policy making process.
2. Engage in research to generate evidence to influence policy and services provision. In particular, health economic evidence that will support the organisation's policy and advocacy work.
3. Provide a platform for researchers to grow and enhance collaboration among the community of brain injury researchers.



4. Build relationships with stakeholders including clinicians, allied health care professionals, carers, families and people with brain injury, academics and researchers, political representatives, policy makers and government officials to create awareness of policy issues and work collectively where possible to advocate for change.
5. Increase the profile of the organisation by sharing the impact of what we do through survivor stories and leveraging multimedia channels.
6. In 2021, Acquired Brain Injury Ireland will host the International World Brain Injury Congress on Brain Injury. We will use this opportunity to build relationships, generate awareness, boost the perceived image of Acquired Brain Injury Ireland, and gain media experience.

PRIORITY THREE: EDUCATE

Developing specialist training in brain injury rehabilitation

Acquired Brain Injury Ireland is the national certified training location for the international Academy of Certified Brain Injury Specialists (ACBIS) programme. We are the 'go to' expert organisation in Ireland for quality training in brain injury rehabilitation. Currently we deliver this ongoing best practice professional training for staff only. We believe specialist training is essential for all healthcare professionals working with brain injury survivors.

Objectives

We will expand our specialist brain injury programme outside the organisation by:

1. Establishing a project team and project expansion plan 2020-2024 to include external organisations.
2. Maximising our current 'Learning and Development Programme' infrastructure and expertise.



Where we work

Current map of where our neuro-rehabilitation services are available across the country and a clear picture of the gaps we face:

PRIORITY FOUR: SUPPORT NETWORK

Reducing caregiver burden for families affected by brain injury

Brain injury is life altering not just for the person involved, but for their family and friends. Many family members and friends are thrust into the role of carer without warning and with no support or training. Reduction of caregiver burden is vital to the long-term support and recovery of brain injury survivors. It is imperative to the success of our neuro-rehabilitation model that this group has access to brain injury specific supports including clinical guidance, information and training.

Objectives

We will respond to the burden of family, friends and carers of those with brain injury by:

1. Providing access to a national support structure dedicated to families and caregivers of those with brain injury.
2. Providing access to clinical guidance, therapy and specialist brain injury training. These supports will deliver practical strategies to families to reduce the burden of coping with brain injury.
3. Facilitating national peer support for caregivers to manage their own health and wellbeing nationwide.

PRIORITY FIVE: CAPACITY

Building and optimising organisational capacity

Ensuring sustainability of funding and investment for growth is critical to our ability to deliver brain injury rehabilitation services consistently nationwide. Arising from Sláintecare, and other forces in the healthcare environment, we anticipate the need for responsive shifts in service delivery in the coming years. Adherence to good governance practise remains a key focus for the organisation to maintain trust with our funders, donors, clients and supporters.

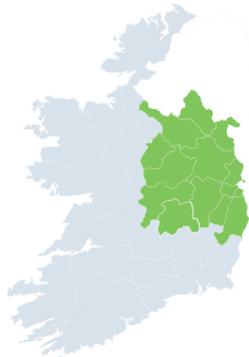
Objectives

We will optimise and build organisational capacity by:

1. Developing flexible staffing systems that can respond to organisational needs as they evolve.
2. Developing a sustainable funding model in collaboration with our public funders externally, with our fundraising department internally and in alignment with public policy. Ensuring appropriate resourcing of core funding in the organisation to support the building of strong strategic functions and operational systems including finance, human resources, IT and compliance.
3. Ensuring appropriate systems are in place to support fully informed decision making and effective quality management.
4. Driving effective governance and continuous quality improvement through best practise standards including HIQA, SORP, Triple Lock and CARF accreditations.

Case Management

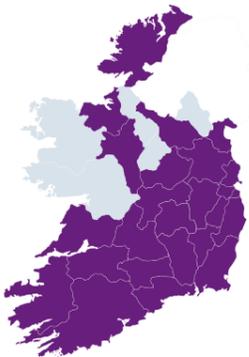
Number of clients: 588



Our Case Managers are brain injury experts who act as a single point of contact providing a clear pathway and linkages to the variety of services to support a person's transition from hospital to home.

Home and Community Rehabilitation

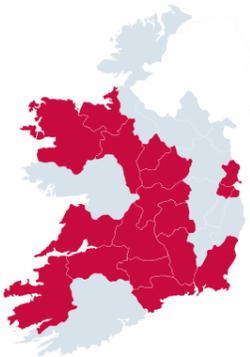
Number of clients: 282



Our Rehabilitation Assistants deliver one-to-one neuro-rehabilitation to support individuals with their rehabilitation goals at home and integrate back into their community and family life.

Day Resource/ Clubhouse Service

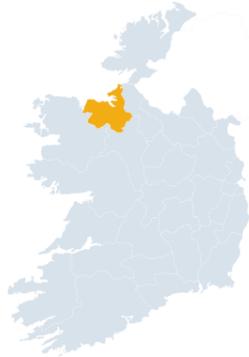
Number of clients: 212



Our clubhouse day services provide vital peer support, group rehabilitation and cognitive rehabilitation to enhance independence and encourage learning new skills.

Transitional Living Services

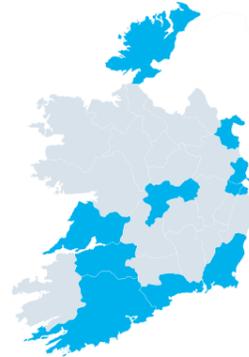
Number of beds: 4



Our transitional living service is a bridge for brain injury survivors to prepare to return to independent living. It provides intensive rehabilitation and support in a residential setting Monday to Friday from 6 weeks up to 6 months.

Residential Services

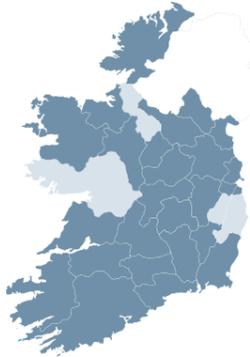
Number of beds: 79



Our unique neuro-rehabilitation residential homes provide long-term tailored rehabilitation and support to 4-5 residents in a house to maximise their independence in a safe and homely place on a 24/7 basis.

Family Services

Nationwide



Our family services deliver support nationally through case management, family therapy, parenting skills training, carer training and peer support groups.

What We Do

Acquired Brain Injury Ireland is the leading national provider of community-based neuro-rehabilitation services for adults with brain injury and their families. A brain injury can affect a person's ability to manage their own life which is why we work in communities across Ireland to empower people with practical strategies to rebuild their lives. We deliver a biopsychosocial model of service which combines a medical, practice and social model. Our services cater for different stages of an acquired brain injury as individuals make progress with rehabilitation goals. We also campaign, educate and advocate for the rights and needs of this hidden group in society.

Why we exist

We exist because after a life is saved, that's just the beginning. Despite the scale of acquired brain injury in Ireland, a severe lack of access to neuro rehabilitation services persists. We exist because we have the experts who can help fill that gap. Two decades ago, Acquired Brain Injury Ireland was founded with one residential rehabilitation unit in Dublin borne from one family's desperation to find suitable services that would maximise their loved one's potential and quality of life after a brain injury. This service has since grown into a

national service commissioned by the Health Services Executive (HSE) to deliver community rehabilitation across Ireland.

At the end of 2019, Acquired Brain Injury Ireland's national service comprised:

- 16 HIQA registered residential rehabilitation services (a home from home for brain injury survivors) including one dedicated transitional living unit
- 16 community rehabilitation services supporting brain injury survivors at home and helping them re-engage in life in their communities
- 7 case management services providing a vital point of contact to brain injury survivors and their families to help them navigate the health system and access services
- 7 clubhouse and day resource centres providing peer to peer support, practical goal setting and group cognitive rehabilitation
- National family support service providing training, therapy and peer support as needed



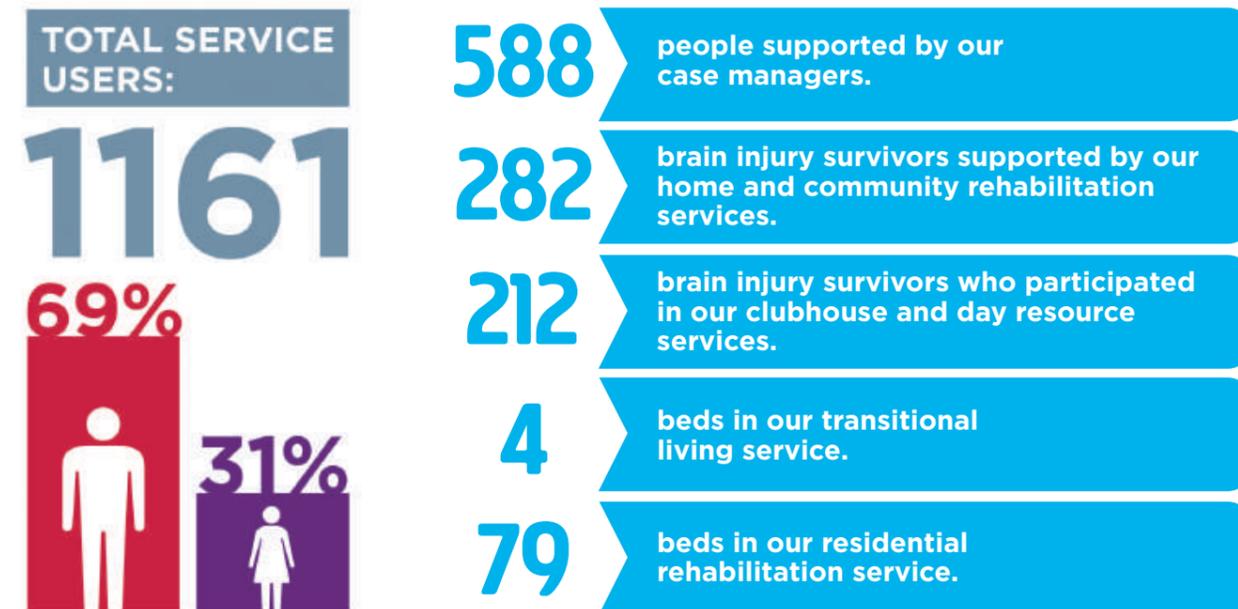
Clinically-led services

Our neuro-rehabilitation services are clinically-led which includes expertise from neuro-psychologists, social workers, occupational therapists, speech and language therapists as well as on the ground support from case managers, local services managers and rehabilitation assistants.

Person-centred

We understand that every brain is different and every brain injury is unique to each individual affected. Having a brain injury may mean you can no longer do things the way

you did them before. But it doesn't mean you can't do them differently. When we work with brain injury survivors, we look at the whole person, their likes and dislikes, their ability and support needs and we look at the life they had before their brain injury. We understand that people need to feel supported in an environment that allows them to do things for themselves. For that reason, we champion the Individual Rehabilitation Plan (IRP) which is developed with the individual, their family and our clinical neuro-rehab teams. Building positive relationships between our clients and rehab teams is essential to achieving personalised goals. These relationships are what makes our service and culture so unique.



Our clinical neuro-rehabilitation teams:



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