



ACQUIRED
BRAIN INJURY
IRELAND

SAGE

Support and Advocacy
Service for Older People

Forum on Long Term
Care

February 2016



1. Introduction

Acquired Brain Injury Ireland (ABI Ireland) welcomes the opportunity to make a submission to the SAGE Forum on Long-Term Care. We support the need for a meaningful policy discourse on long term care in Ireland and appreciate that there is a need to advocate for change.

ABI Ireland is particularly concerned with the reality that many younger people are living in long term care facilities designed for older people. Therefore, any discourse on long term care must include this cohort of people. **Rather than labelling long-term care as an older people's issue exclusively, we would argue that the discourse should open up to be inclusive of all people who are living in long term care settings across the country and their families.** This is an issue that many people are currently living with and many more in the future will have to face.

ABI Ireland's obvious concern are those people with an acquired brain injury living in nursing homes, how they are funded and how there is a complete lack of any alternative living arrangements.

2. People with an Acquired Brain Injury (ABI) and Residential Care – Current Policy Context

2.1 Lack of appropriate community services

Because of the lack of appropriate services in the community and residential rehabilitation services, many people with an ABI live in nursing homes designed for older people. There are no numbers available in relation to people with an ABI living in nursing homes. A small-scale geographically based study (Bray Area Partnership, 2012) on people under disability 65 living in nursing homes found that over 10% residents were less than 65 years of age. Out of a total of 42 residents under 65 in the study, 13 people had a diagnosis of an ABI. Anecdotally, ABI Ireland is aware of several individuals with an ABI living in institutional care designed for older people. Their admission usually follows a lengthy stay in a hospital. They are the "bed blockers".

2.2 Human rights and disability

ABI Ireland believes the practice of placing younger people in residential care services that are designed and created to respond to the needs of older people is fundamentally wrong, unethical and denies people their basic human rights. It contravenes the United Nations Convention on the Rights of Persons with Disabilities. It is also contrary to stated government policy in relation to enabling people with disabilities to lead independent and empower lives. (National Disability Strategy, 2005). It also runs contrary to the government's policy in relation to reducing the number of people with disabilities living in congregated settings and supporting their inclusion in the mainstream community life. (Nolan, 2011)

2.3 Policy disconnect

Despite the policy rhetoric, the practice still continues of placing younger people with particular care needs in highly unsuitable settings such as nursing homes for older people, with little hope of that person ever moving on. The evidence indicates that the lives lived in these homes for this particular cohort is one of isolation, loneliness and exclusion from community life, peers and families. One

small scale study concluded that younger people with disabilities are “socially isolated, disengaged from the community, spending a lot of time in their bedroom and not engaged in the life of the home”. (Farrell, 2012, p.21) Australian research on people with an ABI under 65 living in aged care facilities (i.e. equivalent of our nursing homes) concluded that the social, cognitive and rehabilitation aspects of client care were found to be inadequate in facilities where staffing levels, training and funding resources were limited. Over 40% of the facilities surveyed indicated they did not adequately meet the specific and complex needs of these clients. Aged care facilities were the least favoured model of care for this client group with the majority favouring a model of small group homes. It concluded that the current use of aged care facilities for housing younger people with high level care needs resulting from ABI is inappropriate and does not meet client needs.

2.4 Funding and developing appropriate services

In reality, without any meaningful policy response to support discharge, younger people with an ABI and others may spend several decades in a nursing home. There has been a consistent failure by policy makers to look at growing and developing suitably designed services that are responsive, age appropriate and able to meet the range of cognitive and rehabilitation needs of people with an ABI. ABI Ireland is challenging the fact that an allocation of funding through Fair Deal can only be spent on nursing home care. Ironically, our healthcare system is moving increasingly towards the principle of the “money follows the person”. Specifically, the focus of disability policy is on individualisation and person-centeredness, community based supports with an explicit moving away from congregated settings. (DoH, 2012, DoH, 2012 (a))

3. Recommendations/Points for SAGE to Consider for the Forum on Long Term Care

There are a number of issues that ABI Ireland believes that SAGE should consider in developing a Forum on Long Term Care. These include:

Nature of the dialogue

Ensuring that it is an **inclusive dialogue**; this is not an exclusively an older people’s issue. It affects a much wider community of people and their families. Dialogue should be driven by the principles of **solidarity** and **human rights**.

Need for research and evidence base

We need significantly more evidence of long term care provision in Ireland including demographic data, health economic analysis, legal considerations, best practice, funding models and the lived experience from a range of perspectives.

All actors and stakeholders - priority

The long term care sector in Ireland is significant with a wide range of actors and stakeholders needing to interact. It traverses the public and private arenas and the sector is a profit making industry and employer. Relationships are complex and interdependent. Clearly, the Forum needs to engage with all the actors but given the nature of the engagement, should prioritise the end service user; those who live in nursing homes and their families and give voice to them.

Legal expertise

The Forum needs access to legal expertise especially in terms of advising on new proposals for legislation that enshrine the right to community services and care in the community. The current legalisation (Fair Deal) is the only piece of legislation that people have access to in terms of having their care needs met so a new legislative framework needs to be explored.

Collective advocacy

Collective advocacy is a powerful tool and needed in order to change the landscape in relation to the long term care needs of people living in communities across Ireland. Collective advocacy requires leadership and resources to be effective. It requires multiple voices to reflect the diversity of the population and the range of issues that need to be addressed. Such advocacy is needed in a wide range of social policy domains and governmental departments and agencies.

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 to support people and rebuild lives. ABI Ireland also campaigns, educates and advocates for the rights and needs of this hidden group in society.

Key Facts and Figures on ABI in Ireland

- Each year it is estimated that 13,000 people in Ireland acquire a brain injury
- There are no accurate statistics on the numbers of people with ABI but, based on international prevalence rates, there are approximately 130,000 people with an ABI in Ireland today
- ABI is one of the leading causes of disability and can have life-long consequences for people with the condition, their carers and families
- ABI can vary in its severity and impact on the person personality and behaviour
- ABI can be caused by among others assaults, accidents, brain haemorrhage, strokes and tumours
- Neuro-rehabilitation is an essential part of the person's recovery at every stage, (acute, specialist and community) and critical to maximising independence and quality of life
- ABI has significant personal, societal and economic implications.

What is an 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. People's lives can change suddenly and significantly following an ABI. Having a serious brain injury is totally life altering for both the person and their family due the effects of brain injury. The brain is a complex organ. 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 these consequences may be hidden, others not. They range from physical and sensory to cognitive and psychological.

Effects of an ABI

Brain injury can affect how a person feels, thinks, acts and relates to others. ABI can cause a wide range of changes that effect thinking (memory and reasoning), sensation (touch, taste and smell), language (communication, expression and understanding), emotions (personality changes, anxiety, acting out and coping skills) These impairments have consequences for the individual with the brain injury and their family and they may experience loss of income and unemployment, social and economic isolation and changes in relationships family dynamics.

What is neuro-rehabilitation?

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. Each individual is assessed and a plan is put in place. The person is gradually supported by the (neuro-rehabilitation) team to regain skills, adapt to the environment and learn new ways to cope with day-to-day life.

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