



**ACQUIRED
BRAIN INJURY**
IRELAND

Submission

Department of Health

**Improving Home Care
Services in Ireland**

September 2017



1. Introduction

Acquired Brain Injury Ireland (ABI Ireland) welcomes the opportunity to make a submission to the Department of Health on Improving Home Care Services in Ireland: Have Your Say! It also welcomes the opening up of the debate on the much needed legal entitlement to home care. This submission highlights the issues in relation to home care from the perspective of people with an acquired brain injury (ABI) and their families. It sets out some of the policy issues and then follows the format as outlined in the Department of Health's consultation document.

At the outset it is important to point out that home care services are as critical in terms of supporting people with disabilities to live at home as they are for older people. Therefore, any consideration of legislative developments in terms of home care policy must be cognisant of this. The age issue (under 65/over 65) is completely arbitrary and unhelpful and age should not be utilised as an inclusion/exclusion criteria to qualify for services either in terms of eligibility or entitlement.

2. Policy Context

The consistent thrust of stated Government policy over many decades and across a range of policy documents for people with disabilities and older people is to keep people at home for as long as possible. In particular, for people with disabilities, the most recent National Disability Inclusion Strategy emphasises the commitment to support people to live an independent life in a home of their own choosing in their community (NDIS, 2017: p.39). In terms of people with ABI the National Rehabilitation Strategy 2011-2015 is highly relevant. It articulates the need for a continuum of services on an ABI pathway to support the timely transition from hospital to home, maximise recovery and support participation in community life. At the macro level, the 10 year cross-party Slaintecare report (2017) recommends the re-orientation of the health care system from hospital to primary and community care. This radical shift is needed to make our health services effective, equitable and efficient. The provision of a home care service operates within this policy milieu and provides the context for the proposal to move home care services onto a statutory footing.

3. Demographic challenge – people surviving and living with long term 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 that goes beyond leaving people to 'exist'. People with ABI need to have a meaningful and seamless rehabilitation pathway from hospital to home. In order for this pathway to be effective, there must a range of rehabilitation and support services in the community to ensure their timely transition and long term sustainability in the community is guaranteed.

4. People with ABI and home care services

There is currently no data available on how many adults with ABI (18-65 years old) utilise home care services in the community. In addition, we have no data on the nature of the service they receive, the providers or funding arrangements in terms of the public/private mix.

As a community based neuro-rehabilitation service provider, we are aware of people with ABI across Ireland that avail of range of health and social care services. ABI Ireland case managers and clinicians also work directly with families and people with ABI who use home care services. This submission therefore is a synthesis of the views of families and people with ABI who use home care and our staff who have first-hand knowledge of how the service operates on the ground. The format for the submission follows the questions as laid out in **SECTION 4: Tell us what you think** of the Department's consultation document.

4.1 What are the good things about home care services in Ireland?

Many people with ABI and their families told us that one of the good things about the home care service they receive is the genuine warmth and kindness of the individual workers who provide the service. They reported that, despite the extremely defined duties, individual home care workers often go beyond their very restrictive role to support a particular person's circumstances. The service is valued by the people with ABI and their families and it is seen as vital to supporting people to make the transition from hospital to home and sustaining people to live in the community/at home in the long term. It was also reported by people with ABI and their families that where the same home care worker was involved, it allowed them to build a relationship get to know each other and establish a routine to provide consistent care.

4.2 What are the challenges in relation to the provision of home care services in Ireland?

There are many challenges reported in relation to the provision of home care services for people with ABI and their families:

- ✚ Home care services are increasingly provided to those with high level personal care needs only.
- ✚ The qualifying criteria for the service have become much stricter and now it is only those with extremely high needs (feeding and personal care only) who will be allocated hours. There are numerous examples of people with ABI being refused a home care service/package.
- ✚ The home care worker is on a very tight schedule and the allocation of hours (in some cases minutes) is usually the bare minimum and rarely enough to carry out the basic care needed. Families report that the care worker is constantly under pressure and "watching the clock".
- ✚ There is great variance in terms of assessment, decision making regarding hours allocated etc. across the country.
- ✚ The home care worker is assigned a time to the client and this is not always at a time that suits them – for example, the home care worker arrives mid-morning to get the person up out of bed and early evening to put the person to bed. The person with

ABI and their family are left with little to no choice in relation to the timing of the service rendering it neither adaptable nor flexible.

- ✚ Retaining home care staff is a challenge and leads to lack of continuity of service and difficulty in the building of trusting relationships in terms of having a home care worker in your home and supporting you with intimate personal care tasks. The low rates of pay are one of the contributory factors in the low retention rates.
- ✚ Overall, while there are individual stories where home care services work well, the experience of home care services in general point to the reality that they are ad hoc, piecemeal, fragmented, limited and lacking in flexibility to respond to the ABI population. The service is not needs led, the amount of financial resources in a particular CHO area determines the service, leading to delayed discharges and lengthy waiting times to gain access to the service.

4.3 Do the home care services work well alongside primary care/hospital/informal carers to meet people's needs?

People with brain injury require a broad range of community based services to maximise their recovery and participation in community life. The ABI pathway includes community based specialist rehabilitation as well as continuing care services. (HSE Draft Rehab Medicine Model of Care, 2015:57) The primary care teams are responsible for condition management and the social care/disability services to support the person to live in the community. (IBID) In addition to the need for a seamless pathway from hospital to home, there are other services s.a. housing that is an essential part of the mix. The experience reported by people with ABI, their families and ABI Ireland case managers of primary care, specialist services and community support services is that they are fragmented, disjointed and in some cases, not existent. The lack of a comprehensive case management service across the country further compounds the experience of service fragmentation and significant delays. International best practice guidelines (British Society of Rehabilitation Medicine 2009 Standards for Rehabilitation Services, 2009:9) recommends that people living in the community (with ABI) should have timely and on-going access to a case manager/team to take responsibility for their rehabilitation and for their continuing care and support, who has knowledge of the various specialist and local services available and who works across the range of statutory, voluntary and other independent services to meet the person's needs.

The urgent need to move people out of acute care and to address the delayed discharges to free up bed capacity is the main driver in terms increased demand on services in the community. However, despite the policy rhetoric, services in the community have not developed at the pace that is necessary to respond, so very often 'care in the community' is often left to the family alone. Families struggle to provide the necessary support and are not able to cope with demands. The experiences reported to us indicate that there is huge variance in how the supports in the community are put in place with no consistency in how they are operated and work alongside primary care/hospitals and informal carers. The presence of a case manager (ABI specific) in an area is reported to bring many benefits to the families – in particular, timely information, liaison with the necessary service providers, advocacy for services and access to consistent and professional expertise in one location.

The other issue that arises is that when the necessary supports are not available in the community, the person with ABI and their family are faced with no choice but take up a place in a nursing home. Nursing homes in Ireland are largely designed for older people and are not readily suitable to support a rehabilitation programme or for a younger person with an ABI to live long term. Recent research in Ireland on the ABI population in nursing homes talks about young adults with ABI can experience aged care as an “existential prison in which their lives feels at a standstill”. People describe the experience of “confinement, disempowerment and emptiness”. (Dwyer, 2017: 1)

4.4 Should people who use them have more of a say in the range of services and a choice of who provides the care?

The involvement of people with ABI and their families in the services they avail of is crucial to maximising the person’s recovery and ensuring their opportunities to participate in family and community life are optimised.

This is also reflected in BSRM standards (2009, p.9) for rehabilitation services. In particular, the quality requirement on community rehabilitation and support services states that “families and carers should be involved in the assessment and subsequent decisions about the help that is required and offered assessment to establish their own needs and to increase the sustainability of the caring role”.

At a basic level, people with ABI and their families want to input into the ‘who, what, where, when and how’ of the service which is currently not the case.

4.5 Could home care services in Ireland be improved?

There are a wide range of recommendations in terms of improving home care services for people with ABI:

1. Set out **qualifying criteria** and a **standardised assessment process**, that is both clear and transparent for all.
2. Increase the **flexibility** of what the home care worker can do and for what duration. (For e.g. people with ABI may have significant cognitive impairment as a result of their brain injury and need home supports to help them with a range of activities and not just personal care tasks).
3. Need to enhance the focus of home care services on **cognitive** and **communication functioning** and **impairment** as well as physical impairment and the almost exclusive current focus on personal care tasks and ‘feeding’. (See the World Health Organisation International Classification of Functioning, Disability and Health, 2002)
4. The **level of investment** in home care services has to **increase** in line with the demand. A **sustainable funding model** is needed.
5. **Timely assessment** and provision of home care services is essential to avoid people having to remain in hospital for longer than is necessary.
6. Home care **standards** are needed to ensure a **quality** driven service.
7. The issues of **recruiting** and **retaining staff** in the sector must be addressed.

8. **Training** for home care workers is essential as is recognition of this training in terms of remuneration and career plan.
9. Home care services need to part of an **integrated package** of support for people with ABI moving from hospital to home. **Case management** for complex cases of brain injury needs to part of the integrated package of support.
10. Develop clear and accessible **information** for people with ABI and their families on the services that are available in the community.
11. **Development of intensive home care packages at a national level.** There are a number of people with ABI with complex needs who require intensive home care packages (as currently exist for people with dementia) where there is a comprehensive package of support put in place to enable the person to live at home. The provision of such intensive home care packages needs a national framework and should be streamlined and centralised, with its own separate budget. One assessment process should apply which should be open and transparent. The involvement of an ABI case manager to co-ordinate the care package across the range of service providers is required.

4.6 How do people who need home care access information about the service?

Families tell us that following a brain injury that they have great difficulty in navigating the services and service providers. The information on services is not readily available in a 'one-stop-shop' type scenario and families report that it is very often a process of luck/chance encounters. The social workers in the hospital setting were identified as key providers of information on services and in the community where there is a case manager, families identified their invaluable contribution to not only providing information but also offering real practical help in navigating the services and providers at a time in their lives where they are extremely vulnerable.

4.7 Should home care services be standardised across the country?

A much more systematic approach is required to improve home care service provision and move towards standardisation with monitoring and regulation is needed. The appropriate level of flexibility and ability to respond to the specific scenarios is necessary. Any reform of home care services to place them on a statutory basis must reflect the principles of equity, fairness and maximizing quality of life.

4.8 Should there be national quality standards applied to all providers of home care?

National quality standards/monitoring/regulation for home care services should be developed as part of this review of home care services in Ireland.

4.9 Should there be a minimum level of training required to work as a home care worker?

Home care workers need to have training in the range of caring skills as well as on-going training that relates to the specific situations they work in. For example, those working with people with ABI should receive training/education on understanding brain injury. The training needs to be linked to a progressive pay scale that allows the development of a career pathway for people working in the area. Worker retention and consistency is an important feature of the service.

The BSRM standards states that care services should be provided by skilled workers, trained in the needs of people with long term conditions to ensure the support is relevant and appropriate to meet needs and care provision takes into account the needs of those with cognitive and communication problems. (BSRM, 2009: p.9)

4.10 Should people who use home care make a contribution to the cost, based on their ability to pay?

Meeting the costs of home care services needs further research and should be subject to health economic analysis so that the parameters are clearly understood by policy makers before any decisions are made about co-payment arrangements. The whole 'eligibility' and 'entitlement' issues will emerge as part of the legislative framing. ABI Ireland believes that home care services should universally available and free to all regardless of income.

References

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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.

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