



ACQUIRED
BRAIN INJURY
IRELAND

Submission to HIQA

Draft National Standards
for Residential Care
Settings for Older People
in Ireland, 2014

September 2014



1. Introduction

Acquired Brain Injury Ireland (ABI Ireland, see Appendix 1) welcomes the opportunity to comment on the HIQA Draft National Standards for Residential Care Settings for Older People in Ireland.

The core messages in our submission relate to:

1. **The critical need for these Draft Standards to be inclusive of rehabilitation/neuro-rehabilitation¹ as a feature of life in residential homes and acknowledged an essential part of an improved quality of life for residents under 65 in particular;**
2. **The Draft Standards must explicitly recognise that moving out (discharge) of the residential setting back to the community is a possible option given the person's change in circumstances.**

2. Format of the Submission

Our submission is entirely focused on examining and analysing the Draft National Standards document from the perspective of a person living with an ABI in a residential setting for older people. It sets the context in the first instance by acknowledging the huge policy gap there is in Ireland in relation to appropriate responses for people with disabilities who are under 65 and need a particular level of care and support in their day-to-day lives. The submission then makes some overall comments on the Draft National Standards and moves on to make specific recommendations for changes to the themes, standard statement and the features, with the proposed changes/additions marked in red.

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

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 under 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 an acute hospital with varying levels of access to specialised rehabilitation.

ABI Ireland recognises that there is a complete lack of policy recognition or a policy response in relation to the specific needs of people with an ABI within the Irish health and social care system. They are generically responded to in relation to current disability policy. 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 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

¹ Neuro-rehabilitation is defined as a problem-solving process in which the person who experiences a neurological impairment or loss of function acquires the knowledge, skills and supports needed for their optimal physical, psychological, social and economic functioning. World health Organisation definition quoted in Department of Health (2011)

to reducing the number of people with disabilities living in congregated settings and supporting their inclusion in the mainstream community life. (Nolan, 2011)

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.

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. Ironically, it’s not a funding issue, as people with an ABI are accessing Fair Deal funding; it’s the consistent failure of 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. In our policy advocacy, 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))

There is specific gender and age related issue for those with ABI. Three quarters of people who acquire a brain injury are male with the peak in injury in males between 16-24 years of age. (Phillips, 2008). In addition, research indicates that almost half of the population with ABI also experience mental health difficulties. Anxiety and depression can follow an ABI as a result of biological, psychological and social factors that are altered by the injury itself. Individuals are not only faced with coming to terms with the traumatic event, but also the biological and psychological changes and multiple losses associated with the ABI. (Waldron et al, 2012).

4. HIQA Draft Standards – Overall Comments

ABI Ireland acknowledges the comprehensive and progressive nature of the Draft Standards. Clearly, they are building on the experience of the first set of standards (HIQA, 2009), are driven by a right-based and person-centred philosophy and supported by an evidence base. In addition, ABI Ireland welcomes the explicit acknowledgement in the document in relation to the fact that there

are people under 65 living in residential services designed for older people. It is also welcome that such services are subject to the National Standards for Residential Services for Children and Adults with Disabilities. (HIQA, 2013) Outcome based standards are very appropriate as well as the clarity that the specific ‘features’ bring to the understanding of how this outcome is achieved in practice. These in turn supports transparency for all the stakeholders involved in the relationship.

In relation to the new set of Draft Standards, ABI Ireland wants to challenge the notion that people who live in these residential settings are consigned there for the rest of their lives (apart from transferring to acute hospital for health reasons or another residential service if “challenging behaviour” is becoming an issue as the current Draft Standards reference). At no point in the draft document is discharge to the community or alternative accommodation/services referred to. To date, HIQA has been a significant catalyst for change in how health and social care services are delivered in Ireland. This is potentially another pivotal moment where the HIQA National Standards for Residential Care Settings for Older People could play a powerful role in acknowledging that discharge is possible and should be prepared for in terms of the younger person’s life plans to move out of long term care designed for older people. It is acknowledged that there is a dearth in alternative and suitable community/residential services, but the health and social care system needs to strive towards radically changing this landscape and policy initiatives such as these Standards can start to pave the way towards having the issue recognised and validated. ABI Ireland also wants to challenge the traditional notion of care which typically revolves around meeting physical, social and emotional needs to one that includes a commitment to rehabilitation. The common adage in these settings is that people (and especially older people) don’t need/benefit from rehabilitation. Rarely do you see reference to rehabilitation in relation to long term care settings for older people. This needs to be challenged and reference to it in the newly developed HIQA standards would serve to have rehabilitation (and specifically neuro-rehabilitation) recognised as a legitimate element of care planning in the residential settings.

5. HIQA – Draft Standards – Specific Comments

Theme 2

In Theme 2, Effective Services under Standard 2.1 Individualised Care Planning in point **2.1.4** ABI Ireland recommends that the word rehabilitation is included here “.....physical and mental health, **rehabilitation needs**, personal and social care needs.....as identified in ongoing **appropriate assessment and based on their clinical and rehabilitative needs at the time**”

These changes acknowledge that rehabilitation should, where appropriate, be part of the responses of nursing homes. Rehabilitation, and in particular, neuro-rehabilitation is an essential part of the lives of people with an ABI as they can continue to recover functioning and independence with the appropriate type of neuro-rehabilitation interventions. This inclusion would allow for example a neuro-psychological assessment by the relevant specialist (see reference to full multi-disciplinary team (MDT) in **2.1.6**). It would also acknowledge the need for vocational assessment.

2.1.6 in relation to the make-up of the MDT needs clarity. Is this the MDT within the residential service setting? So who makes up the MDT - is it only those associated with the residential setting or does it allowing for the involvement of outside specialists? In terms of people with an ABI, could the

MDT include, for example, an ABI case manager in the HSE area? Or if the person has been/is involved in services of a specialist neuro-rehabilitation team/healthcare professional (s.a. neuropsychologist), then can this person be included in the residential settings MDT assessments? Therefore suggested changes to the wording of 2.1.6 is as follows “The review of the individual care plan is multi-disciplinary (to include those clinicians who work/are associated with the residential setting as well as others from the outside who are been involved in the person’s care) and is conducted in a manner.....”

2.1.7 deals with the review of the individualised care plan including at times of changes in circumstances, new developments and outcomes achieved. There is a real possibility here to reflect the opportunity to promote a pro-active approach to discharge to alternative forms of care for younger people in particular. Specifically, if a person with an ABI is receiving support in terms of their rehabilitation they may well have made progress in increasing their independence and enhancing their abilities and capabilities which would no doubt fall into the category of “changes in circumstances”. The person should be assessed on an on-going basis in relation to being discharged to another service. This section links directly to Standard 2.7 (access to services determined on the basis of fair and transparent criteria) and specifically Feature 2.7.4.

Standard 2.3 refers to the physical and psychological wellbeing for those who are cognitively impaired. People with an ABI may have cognitive impairment and therefore this standard is of central importance to their health and well-being. The difference between the cognitive impairment as experienced by the person with an ABI and those with neurodegenerative diseases (s.a. Alzheimer’s disease and other dementias) is that their impairment is not in a state of progressive decline. Therefore this standard needs to reflect that experience. We recommend an addition to the wording of **Standard 2.3** “promotes physical, cognitive rehabilitation and psychological well-being for those who are cognitively impaired....” Cognitive rehabilitation interventions are proven to be effective in terms of the international evidenced-base and accepted in cognitive health practice in many countries.

In addition, in Feature **2.3.1** we recommend the following addition “The environment is enabling and rehabilitative, aids orientation and promotes independence....”

2.3.2 should be added to “...staff with the appropriate skills and training to deliver evidence based interventions to those with cognitive impairments”.

Standard 2.7 refers to access to services on the basis of fair and transparent criteria. We are suggesting a wording addition to this Standard “fair and transparent criteria with the residential service provider providing evidence that it has the capacity to deliver the service to that individual.”

The HSE (2011) report, Time to Move On from Congregated Settings, concluded that there is no evidence once person is placed in residential setting (for people with disabilities) there is no process, system or practice for a thorough external review of the placement, unless a person’s health/behaviour deteriorated to assess if the person was progressing or what supports the person needed. We do not have similar evidence for the residential services for older people but anecdotally we know that it is a similar scenario in this sector. Discharge of the person to alternative accommodation/services (that’s not an acute hospital) is very rare in the nursing home world. This is understandable as the majority of residents are older people with high levels of dependency. The

challenge here is that younger people with an ABI do not fit into this grouping, are most likely stable in terms of their condition, have the capacity to be rehabilitated and should therefore have options for discharge. ABI Ireland is acutely aware of the lack of alternative service for people with an ABI and this under-developed and under-resourced area of service provision needs addressing. ABI Ireland strongly recommends the HIQA standards to embrace and support the concept of discharge which can in turn be a policy lever for change. ABI Ireland as a service provider has supported individuals to move from nursing home settings back to their communities. However, these are exceptions and not the norm. People with an ABI should not be living in these settings. However, there is still have a phase of development in terms of ABI-specific services and until there is policy recognition and investment in ABI community services, people with an ABI will continue to live in these highly inappropriate residential settings.

2.7.10 has direct relevance to people with an ABI (some as young as their 20s) living in residential care settings for older people. Accommodating the lifestyle preferences and recreational interests of younger people with an ABI vary hugely and relative to older residents there is a stark contrast. This presents a real challenge to any residential setting where it is predominately older people who live there with a very small number of younger people.

Theme 3

Theme 3 refers to Safe Services. In **Standard 3.5, Feature 3.5.2** we believe should read “Each resident’s physical, behavioural, **rehabilitative** and psychological wellbeing is assessed and continuously reviewed as any supports put in place to address identified needs”.

Theme 4 Health and Well-being

Standard 4.2 to include “...stimulating activities, **including therapeutic interventions and rehabilitative programmes**, to meet their needs and preferences.”

Standard 4.2, Feature 4.2.8 What about inclusion of the options such work (volunteer/paid work), vocational opportunities/retraining/day services outside of the RC setting appropriate to their needs? ABI day care? So we recommend that 4.2.8 should read “Each resident has opportunities for education, lifelong learning, **vocational opportunities and services outside of the residential settings s.a. community day care where it is deemed appropriate.**”

Theme 5: Leadership, Governance and Management

Standard 5.3 refers to a statement of purpose that accurately and clearly describes the service provided. In Feature 5.3.3 the second bullet point should read “services and facilities provided in the designated centre, **including any specialists services s.a. (ABI, dementia, under 65s).**”

Theme 7: Responsive Workforce

In Standard 7.1 in the features an entirely new point should be added here: **7.1.10 “Where a residential service is providing a home for people under 65 years, then staff should be trained and educated in terms of how to work with, support and respond to their lifestyle that is age specific and appropriate.”**

In Standard 7.2, Feature 7.2.3 “...staff have the necessary skills, **and where also needed, specialist skills**, to provide care and support to residents”.

Standard 7.3, Feature 7.3.8 “Staff are provided with training **and education**.....to meet the needs of the residents, including those residents **who needs vary because of their specific age profile.**”

Standard 7.4, Feature 7.4.3.....includes specialist training.....in areas such as dementia, communication and **rehabilitation, the latter specifically targeting those under 65 years of age but not exclusively.**”

Research has indicated that staff working in nursing homes believe that the social, cognitive and rehabilitation aspects of care for people with an ABI were of greatest difficulty, and the areas in which the needs of this client group were being least catered for. Staff often identify difficulties with providing supervision, communicating with, and managing the emotions and moods of residents with an ABI, and dealing with their challenging behaviours such as disinhibition, verbal or physical aggression. It is often the frontline staff in these settings who are faced with providing this complex and ongoing support, with a lack of resources, inadequate levels of training and skills in the area of ABI, and limited access to specialised rehabilitation and community services. (Synapse Fact Sheet)

6. Final Comments

ABI Ireland believes that if HIQA adopts these changes for inclusion in the final Standards document that they will be more robust and inclusive. The Standards will then also contribute to an enhanced quality of life for people with an ABI and others under 65 who are compelled to live in residential settings designed for older people.

References

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Synapse Fact Sheet **Younger People Living in Nursing Homes** available on <http://synapse.org.au/get-the-facts/younger-people-in-nursing-homes-fact-sheet.aspx>

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Appendix 1

Background Information on ABI and ABI Ireland

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.

Living with an ABI

An ABI causes damage to your brain that may result in behavioural and physical changes which can affect memory, speech and language, mobility, sight, understanding of situations and decision-making. It may also affect concentration and ability to cope under pressure. Having an ABI is life-changing and requires massive adjustments on the part of the individual and their families to alter their life plans and to re-build and accommodate a new way of living.

About ABI Ireland

ABI Ireland is a national organisation providing a range of flexible and tailor-made neuro-rehabilitation services and supports to people with an ABI in communities across Ireland. It also works to create awareness of the people living with an ABI, provide information and support to families and engages in awareness raising, campaigning, research and advocacy.

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