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The 2019 neuro-rehabilitation implementation framework in Ireland: Challenges for implementation and the implications for people with brain injuries☆

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ABSTRACT

In 2019, eight years after the publication of Ireland's first neuro-rehabilitation strategy, an implementation framework was published. This paper describes and assesses the Irish health policy journey to the publication of the 2019 Implementation Framework with a particular focus on tracking the rehabilitation needs of people with acquired brain injury (ABI).

Internationally, rehabilitation services are a low priority for governments, with policy makers having limited knowledge and understanding of rehabilitation. This low political priority and policy understanding contributes to under-developed and poorly co-ordinated services for people who need neuro-rehabilitation services, including people with Acquired Brain Injury (ABI).

Despite the publication of the 2019 neuro-rehabilitation implementation framework, key challenges remain for people with ABI in Ireland, including the absence of services across the 'pathway', the under-resourcing of specialist rehabilitation services, the impact on the lives of people with brain injury of poor or no access to services, and the lack of good data on this population. The paper concludes with recommendations on how increased political priority of the rehabilitation needs of people with ABI could enhance implementation of the neuro-rehabilitation implementation framework.

1. Introduction

Brain injury will surpass many diseases as the major cause of death and disability worldwide by 2020 [1]. Globally, it is estimated that traumatic brain injury (i.e. injury that is caused by an external force) affects 10 million people annually leading to mortality or hospitalisation [1]. In the UK, brain injuries which result in hospital admission occur in about 270 per 100,000 population per year [2].

Neuro-rehabilitation services are essential to enable the person with brain injury to address the cognitive, emotional, psychological and physical consequences of their brain injury [3]. The World Health Organisation (WHO) defines neuro-rehabilitation as an interdisciplinary clinical process, that ensures those who need it acquire the knowledge, skills and supports for their optimal physical, psychological, social and economic functioning [4]. Neuro-rehabilitation services are aimed at people with neurological conditions who require individualised, goal focused rehabilitation input [4]. A Cochrane Review found that access to earlier and intensive rehabilitation by multi-disciplinary rehabilitation team improves outcomes [3,5].

This paper describes the policy process that led to the publication of the National Strategy and Policy for the Provision of Neuro-Rehabilitation Services in Ireland, Implementation Framework 2019-2021 (referred to as the neuro-rehabilitation implementation framework from here on in) [20]. This details the challenges that persist in meeting the neuro-rehabilitation needs of adults with acquired brain injury (ABI) in Ireland. ABI differs from other neurological conditions in that it is non-progressive, and as a result, people can make significant gains when they have access to the appropriate and timely neuro-rehabilitation services [3,5]. Rather than preventing or delaying disability, neuro-rehabilitation focuses on recovery after brain injury. Effective policy implementation is critical to ensure the delivery of quality neuro-rehabilitation services. According to the WHO, rehabilitation has been a low

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priority for many governments with policy makers having a limited knowledge and understanding of rehabilitation resulting in underdeveloped, poorly coordinated services [6]. There have been renewed calls from the WHO for national governments to scale and deliver rehabilitation services [7,8].

Through documentary analysis and a policy roundtable dialogue with 25 stakeholders, conducted in February 2019, this paper describes, and critiques the challenges of implementing improved neuro-rehabilitation services in Ireland. Nine key policy documents were analysed (Fig. 1) to capture the current policy process, as well as a range of relevant academic literature. A policy roundtable hosted by Acquired Brain Injury Ireland enabled frontline analysis of existing services, including identification of service gaps by the ABI and related population [9]. While the focus of this paper is Ireland, literature shows the challenges relating to implementing effective rehabilitation services are universal [10].

2. Health policy in Ireland relevant to the rehabilitation needs of people with ABI

The Irish health system is unusual in a high income country context for its inequitable access to healthcare [11]. Interestingly, the biggest challenge for people with ABI in terms of health services is that regardless of their income, their private health insurance or medical card status, the quantum of specialist generalist rehabilitation services are extremely difficult to access, as in many instances, they simply do not exist [12].

There are several health policy documents relevant to the development (and absence of development) of neuro-rehabilitation services for people with ABI in Ireland, as well as some specific to neuro-rehabilitation, these are outlined below.

2.1. Quality and fairness

The national health strategy published in 2001, Quality and Fairness, A Health System for You set out a series of national goals including a commitment to develop an action plan for rehabilitation [13]. It acknowledged there were many gaps in the services, both inpatient and in the community [13]. It also explicitly stated the importance of rehabilitation for people with ABI [13].

2.2. Sláintecare reforms

In 2017, the final report of the Irish all-party Oireachtas (parliamentary) Committee on the Future of Healthcare, Sláintecare, was published [14]. This set out a high-level, costed roadmap to deliver whole system reform and universal healthcare over a ten-year period devised through political consensus [14]. Sláintecare, if implemented will deliver a universal single-tier health service where patients are treated solely based on need. The re-orientation of the health system towards integrated primary and community care is recognised as an important enabler of universal access [14,15].

In 2018, the Irish Government published the Sláintecare Implementation Strategy [16]. This made explicit reference to the implementation of 'the Neuro-Rehabilitation Strategy in accordance with the agreed implementation plan' [16,17]. Subsequent to the Implementation Strategy, the first Sláintecare Action Plan was published in March 2019 [18]. The implementation of specific actions from the neuro-rehabilitation implementation framework (see below) are included in the Sláintecare Action Plan [18].

2.3. National trauma strategy

The roll-out of a National Trauma Strategy in 2019 focussed the need to develop rehabilitation services, both in hospital and community [19]. This strategy details the development of a trauma network in Ireland and points to the need for a comprehensive pathway of care for major trauma patients. This has direct relevance for those with brain injuries [19].

2.4. Neuro-rehabilitation strategy and policy 2011–2015

The National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011–2015 (hereinafter referred to as the neuro-rehabilitation strategy) was published by the Department of Health and the Health Service Executive (HSE) in 2011 [17]. It set out a policy framework in terms of developing neuro-rehabilitation services in Ireland for the period 2011–2015. Previously, there was no distinct neuro-rehabilitation policy in Ireland.

The overall purpose of the document is to provide a single national policy and strategy to guide, govern and determine neuro-rehabilitation service responses and structures. The vision is to support people with neuro-rehabilitation needs to be part of the community and to enhance their quality of life and well-being. The report recommends services should be delivered locally, be individualised, timely and integrated provided by a flexible and responsive health system.

The model proposes a continuum of services; where and when the person accesses services depends on their condition and age as well as on the type of services they need (e.g. expertise, complexity). This model suggests people access services at four levels:

1 Primary care team (for general services and low levels of therapy needs)
2 Geographic based community neuro-rehabilitation teams (for specialist services and moderate levels of therapy need)
3 Regional neuro-rehabilitation services (for high level of therapy need, inpatient and outpatient services)
4 National neuro-rehabilitation services (complex cases).

The 2011 neuro-rehabilitation strategy specified the need for an implementation plan to set out clear actions, timeframes and targets.

2.5. Rehabilitation medicine programme and model of care 2018

The neuro-rehabilitation strategy recognises the combined role of rehabilitation medicine and social care in delivering a continuum of rehabilitation services [17]. Integrated services support the timely transition of persons with brain injury from hospital to home, maximise their recovery and support, and enables re-entry into family and community life. In this regard, the HSE established the National Clinical Programme for Rehabilitation Medicine (NCPRM) in 2011 and appointed a Consultant in Rehabilitation Medicine as clinical lead.

Seven years later, the NCPRM published the Model of Care for the Provision of Specialist Rehabilitation Services in March 2018 (i.e. the Model of Care) [21]. The Model of Care proposes three levels of specialist rehabilitation: complex specialist service at national level, local/regional specialist rehabilitation and community rehabilitation services [21]. It recognises the limitations of existing services across the care pathway and outlines a framework for delivery, including case management and establishment of Managed Clinical Rehabilitation Networks.

2.6. Managed clinical rehabilitation network 2018

In 2018, as a way of commencing delivery of the Neuro-Rehabilitation Strategy, the HSE established a demonstrator site for a Managed Clinical Rehabilitation Network (MCRN). The MCRN

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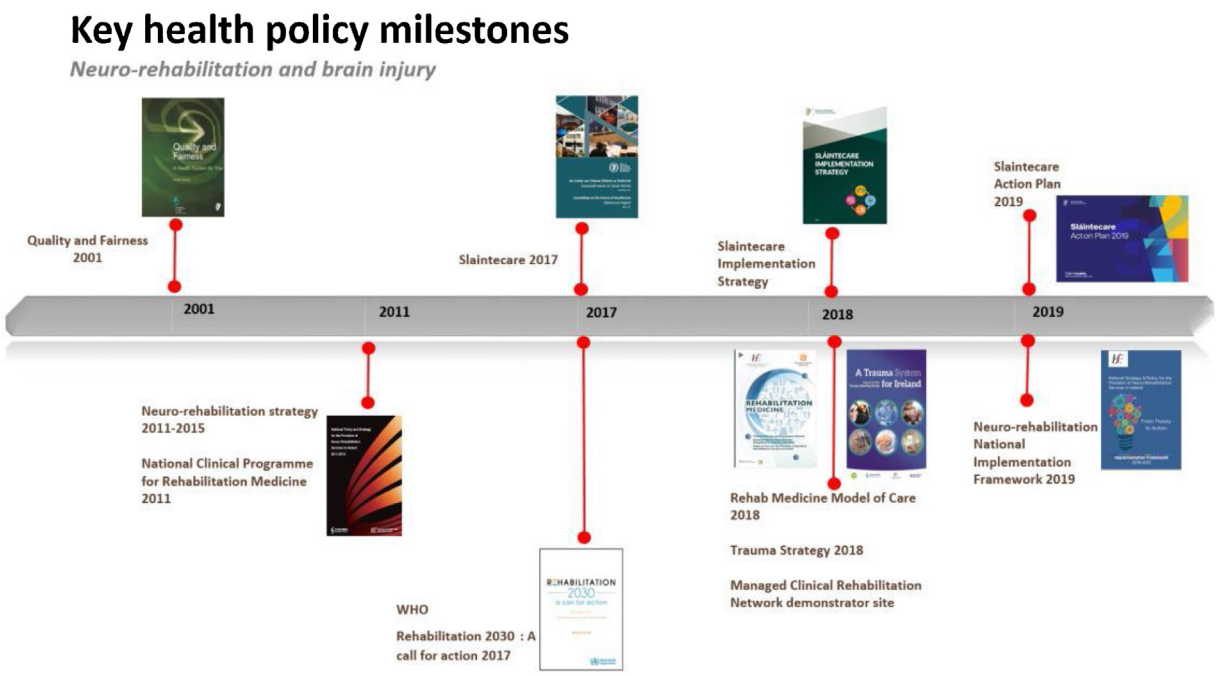

Fig. 1. Timeline of key health policy milestones.

model is effective in several European countries but a new concept to the Irish health system [24] and therefore a demonstrator site can assess the feasibility of the model and develop learning on how it can be scaled nationally. The first 'demonstrator' MCRN explores the development and integration of in-patient and community-based neuro-rehabilitation services in two HSE sub-regional structures. As outlined in the neuro-rehabilitation implementation framework, additional resources required to implement the MCRN demonstrator project will be sought from the Government in 2019 [24]. The HSE Service Plan for 2019 included a commitment to commence a pilot demonstrator project to implement the Neuro-Rehabilitation Strategy [25]. To date, no funding has been allocated to the project.

2.7. Neuro-rehabilitation strategy implementation framework 2019–2021

The neuro-rehabilitation implementation framework, recommend in the 2011 neuro-rehabilitation strategy, was published eight years later in 2019 [17]. This was developed by an expert working group led by the HSE Social Care (disability) Division and the NCPRM [20]. The neuro-rehabilitation implementation framework adopted the 10-Step Framework developed by the Integrated Care Programme for Older Persons (ICPOP) [22,23]. It includes assessing population needs, mapping existing services and analysing service gaps in line with benchmarked best practice [20]. Table 1 provides a summary of the main elements of the Implementation Framework [20].

3. Discussion

This analysis of the policy process was presented to a policy roundtable of expert stakeholders in early 2019. The engagement of this group with the issues identified through policy analysis reinforced the findings and legitimises them in the context of front-line and patient experience. Through this dialogue, the following challenges to effective implementation of the neuro-rehabilitation implementation framework were further defined.

3.1. Policy progress

The publication of the Model of Care, the development of demonstrator site, and the publication of the neuro-rehabilitation implementation framework since 2018, along with some progress on Sláintecare reforms, are welcome developments and demonstrate the first impetus to implement key components of the 2011 neuro-rehabilitation strategy. In this vein according to the WHO Rehabilitation 2030, Ireland is at the final stage of a four stage policy process [10]. Despite evolving to this stage, progress has been at best extremely slow and key milestones for implementation since 2011 have been continually missed.

The extent to which the neuro-rehabilitation implementation framework will be fully implemented is unknown. A good indicator of implementation intent is priority for a specific action and clear budget allocation yet there was no extra funding ear-marked for neuro-rehabilitation services in the 2019 HSE Service Plan. This combined with limited funding for Sláintecare implementation means stakeholders' expectations for progress on the imeplementation of neuro-rehabilitation policy remain low [25].

The slowness of policy implementation and service reform can be partly explained by the lack of political or institutional leadership on implementing policy and services to meet the needs of people with brain injury over the last 18 years.

3.2. Gaps in rehabilitation services

Such slow policy progress means significant gaps persist in neuro-rehabilitation services. The 2011 neuro-rehabilitation strategy noted that neuro-rehabilitation services are underdeveloped and where they exist, have developed in an ad hoc manner, driven primarily by the voluntary sector [17]. Where developed by statutory health providers, the focus has been on medical rehabilitation and is therefore not comprehensive [20]. The 2011 neuro-rehabilitation strategy observed that specialised in-patient services are concentrated at national level whilst services in the community are very fragmented and uncoordinated [17]. The 2019 neuro-rehabilitation implementation framework references long waiting lists, the limited access to specialist rehabilitation, and the

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Table 1
Key Elements of the neuro-rehabilitation implementation framework.2019–2021.

Overall goal	Create a national network of acute, inpatient and specialist community rehabilitation services by: • Developing local implementation teams • Developing and enhancing neuro-rehabilitation services across the spectrum • Configuring services into a Managed Clinical Rehabilitation Network • Creating governance structures • Involving all stakeholders in implementation
Developing rehabilitation services	One of the steps (Step 4) provides details on the development of quality rehabilitation services and the need to grow services in all areas including: • Acute, early rehabilitation (in acute hospital setting) • Complex, specialist rehabilitation (National Rehabilitation Hospital) • Post-acute in-patient rehabilitation (Local hospital rehabilitation units) • Community specialists services (Community) • All services to be co-ordinated by Managed Clinical Rehabilitation Networks
Lead responsibility	It ascribes lead responsibility for the implementation of the Neuro-Rehabilitation Strategy to the HSE Disability Division and recognises the key role of the HSE Clinical Programmes given the cross-sectional and cross-divisional nature of the work required to implement the full plan
Delivery	Implementation teams to be established in each local HSE area made-up of a range of local stakeholders responsible for developing a localised plan to meet the needs of the population in their area needing neuro-rehabilitation.
Cost of implementation	There is no detail on the total cost of implementing the strategy or how it can be financed. Costings are provided for two key rehabilitation services - a community neuro-rehabilitation team and a post-acute specialist rehabilitation unit
Demonstrator site	The development of a demonstrator site for a Managed Clinical Rehabilitation Network (MCRN) is proposed. The demonstrator site would test the model given the fundamental changes proposed for rehabilitation services provision

dearth of community based specialist rehabilitation services [20]. It also refers to the inappropriate use of acute hospital beds due to the lack of neuro-rehabilitation services in the community. These factors, combined with the inappropriate placement of people with ABI in nursing homes, all inhibit individual's ability to make rehabilitation gains [9]. These findings are not unique to Ireland and are found in other national systems such as Finland, France, Australia, England and Denmark [26–28].

3.3. The data challenge

The complete lack of data on the ABI population has major implications for policy development, service planning and delivery. The data challenge was highlighted by the stakeholders at the policy roundtable [9] and is also a feature internationally [10]. WHO Rehabilitation 2030 states 'data in health information systems underpin decisions in health policy, management and clinical care' [7]. The 2011 neuro-rehabilitation strategy specifies how the absence of epidemiological data on the ABI population is a major challenge to strategic, coherent and evidence-based planning for neuro-rehabilitation services [17]. This in turn, presents difficulties in terms of costing and financing services. The neuro-rehabilitation strategy and the neuro-rehabilitation implementation framework also both identify the lack of basic data on how many people need neuro-rehabilitation services [20]. It concludes that due to lack of reliable information it is not possible to map out the precise levels of services that should be provided to meet needs.

Other key pieces of data required not only as a hallmark of evidenced-based practice but to improve policy makers' understanding of rehabilitation, is for service providers to demonstrate the effectiveness of neuro-rehabilitation services using internationally validated measurement tools. The WHO International Classification of Functioning, Disability and Health (ICF) measures health condition (impairments, activity limitation and participation) in addition to contextual factors (environmental and personal factors) to provide internationally comparable data [29]. If generated this data could provide evidence on the impact of rehabilitation interventions and verify improved outcomes for people with ABI. This approach is acknowledged in the neuro-rehabilitation implementation framework [20].

3.4. Resourcing neuro-rehabilitation services

Financing and the level of investment required for full delivery is not quantified in any of the policy documents analysed above. Some services are costed in the 2019 neuro-rehabilitation implementation framework but there is no attempt to provide an overall figure [20]. The implementation framework references the need for new and additional investment and notes that requests for funding for specific projects are being sought from Government. It also recognises that continued additional investment needs priority beyond the three-year implementation period to address the significant lack of capacity within existing services [20].

Sláintecare outlines a new funding model that integrates funding for primary, hospital, community and social care through regional structures allocated on the basis of population health need. The 2017 Sláintecare report details an additional €20 billion over the next ten years required to implement the policy [18]. This policy direction towards integrated into the community care, if implemented could have a significant positive impact on how neuro-rehabilitation services are designed, funded and delivered.

3.5. Implications for people living with ABI

The lack of rehabilitation services has a direct impact on the lives of people with ABI and their families amounting to "lost potential" [9]. People with ABI experience delays at every point of the pathway from hospital to home. In some instances, they do not have access to necessary neuro-rehabilitation services due to lack of availability and access is often based on a geographic lottery. The lost potential has serious implications not just for the individual with ABI but for their families and society [12].

Through direct engagement with people with ABI, research shows the range of challenges people face with life altering, traumatic change. It also describes how they strive to live a meaningful life in the aftermath of brain injury. It highlights the barriers faced, the lack of services that people contend with and difficulties experienced in trying to get access to neuro-rehabilitation services [12]. Muldoon et al. describe how people with ABI have difficulty in navigating the system [12]. A particular point of difficulty relates to the move from acute care and rehabilitation towards long-term support in the community. People also describe their difficulties in finding and accessing appropriate services, and their challenges in proving their need for those services. As a result, there are extremely long gaps for people living with ABI in getting rehabilitation after the acute phase of their injury.

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4. Recommendations

This paper traces a slow policy process up to the publication of a neuro-rehabilitation implementation framework in Ireland. It finds that neuro-rehabilitation services in Ireland are greatly limited by the lack of political priority and this protracted policy process. More robust policy implementation driven by political priority could ensure the delivery of better care and rehabilitation for people with ABI. This conclusion reflects the international evidence that rehabilitation services are a low priority for many governments which in turn contributes to the limited knowledge and understanding policy makers display in relation to neuro-rehabilitation and adequate service provision [6]. We conclude that this lack of policy implementation is a major contributor to the under-development and poor co-ordination of appropriate and timely services [6].

Based on the analysis of this paper we suggest that increased political priority and better neuro-rehabilitation policy implementation can be achieved through the following strategic recommendations.

4.1. Gather better data to inform policy and neuro-rehabilitation service developments

Epidemiological data on the ABI population is critical for policy development, service planning, and advocacy and as evidence for making the case for better use of existing resources and new investment. Data on the outcomes, including utilisation of WHO ICF measures, are vital to gathering evidence of effectiveness and ensure comparable data across jurisdictions. Health economic data is also critical to generate evidence on the efficiency, effectiveness and equity associated with investing in neuro-rehabilitation services.

Stakeholders participating in the policy roundtable discussed the need for service providers to be proactive in exposing the failures and gaps in services, highlighting the numbers on waiting lists, waiting times and the numbers of people who have rehabilitation needs but never get access to a specialist service [9].

4.2. Support the visibility of people with brain injury

The direct involvement of people with brain injury in advocacy and influencing neuro-rehabilitation policy development, service planning and delivery has the potential to increase political priority on neuro-rehabilitation resulting in services that better meet the needs of people with ABI and their families.

4.3. Develop a collective vision, alliances and leadership for neuro-rehabilitation service reform

The process of bringing about large-scale change in neuro-rehabilitation services provision requires a collective vision, the formation of alliances and leadership. Clinical leadership is necessary to create alliances and drive reform within the health services.. The brain injury community needs to work collaboratively and collectively to ensure effective political engagement as identified by the policy roundtable, and noted in WHO-Rehabilitation 2030: A call for action. This welcome step towards long term planning will most likely be driven by a collective vision and leadership that includes a wide range of actors with an advocacy remit [9,10,30].

4.4. Influence broader health system reform

Finally, the wider policy agenda in particular delivering on Sláintecare with its goals of universal access to timely, quality, integrated care pathways is a critical element in shaping the future lives of people with ABI. Systemic change in health service delivery and integrated care models are essential to meeting the neuro-rehabilitation needs of the population.

5. Conclusions

The evidence is clear that early access to specialised, intensive neuro-rehabilitation services enables people with ABI to recover faster and better and achieve the best outcome for them, their families and society at large. They can regain independence, maximise their potential, and in some instances return to normal living. The lack of political priority, slow policy process and implementation identified and linked here with experiences of insufficient and fragmented services indicates a costly and inhumane mistake of many national governments, including Ireland. If governments can overcome what is often short-term thinking and prioritise the implementation of neuro-rehabilitation services through a robust policy process, they can make a life-changing difference for people with brain injury who need rehabilitation services.

CRediT authorship contribution statement

Sara Burke: Conceptualization, Formal analysis, Investigation, Methodology, Resources, Software, Supervision, Validation, Visualization, Writing - original draft, Writing - review & editing. **Grainne McGettrick:** Conceptualization, Data curation, Formal analysis, Investigation, Project administration, Writing - original draft, Writing - review & editing. **Karen Foley:** Data curation, Formal analysis, Writing - original draft, Writing - review & editing. **Manjula Manikandan:** Software, Writing - review & editing. **Sarah Barry:** Conceptualization, Formal analysis, Investigation, Methodology, Supervision, Validation, Visualization, Writing - original draft, Writing - review & editing.

Declaration of Competing Interest

Grainne McGettrick and Dr Karen Foley are employed by Acquired Brain Injury Ireland. Karen Foley was a member of the HSE Working Group that wrote the Implementation Framework 2018–2021.

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