

Neurorehabilitation Strategy Briefing Document and Position Paper

Background

What is neurorehabilitation?

The World Health Organisation defines neurorehabilitation 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”

Neurorehabilitation consists of a range of community and hospital-based treatments and supports such as physiotherapy, occupational therapy, speech and language therapy and psychological and cognitive assessments and interventions. It ranges from intensive treatment in acute hospital settings to long-term community-based rehabilitation. The function of neurorehabilitation is to both prevent unnecessary deterioration in a person’s condition and functioning, and to help compensate for any function that has been lost as a result of a neurological condition.

Why is neurorehabilitation vital for maintaining independence for people with MS?

Neurorehabilitation services are essential for helping people with MS recover from relapses and to slow disease progression. The societal costs of MS increase sharply as the illness progresses, from €34,942 per person per year for those with mild MS to €100,554 per person per year for those with severe MS (MS Ireland, 2015) Slowing disease progression could drastically improve the quality of life for those living with MS as well as resulting in substantial savings to society.

Two particular studies demonstrating the cost-effectiveness of neurorehabilitation for Multiple Sclerosis are referenced in the National Neurorehabilitation Strategy document – Ward et al. (2009) evaluated a community-based multidisciplinary rehabilitation team and found that savings made from reduced hospital admissions and outpatient visits rendered the team cost-neutral. Pozzilli et al. (2002) found that home-based care was considerably more cost-effective than hospital –based care.

The National Neurorehabilitation Strategy – background and progress to date

The HSE produced a detailed document, “National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011-2015”, which outlined the current provision of neurorehabilitation services in Ireland and provided a strategy for developing future services. However, no specific implementation plan accompanied the strategy document.

A joint HSE/Department of Health implementation group was established in March 2014 with representatives from the Social Care, the Rehabilitation Medicine Clinical Programme and the

Department of Health. A draft implementation plan is currently in the process of being developed by this group.

Content of the report and strategy

Current neurorehabilitation services

The report found that current neurorehabilitation services are provided in a range of different settings, by many organisations including acute medical services, community-based health services, voluntary sector organisations and informal carers. Existing services are critically underdeveloped and often develop on an unplanned basis. Statutory services are focused heavily on medical rehabilitation, which whilst crucial, is not sufficient in isolation. People who require neurorehabilitation have a need for ongoing therapeutic supports as well as acute, specialised hospital care. Some specialised acute services do exist but are limited and there is currently a serious lack of ongoing supports across all settings. The report also noted high levels of ‘condition-specific’ services; i.e. services limited to supporting individual conditions.

Planning for future services

The report identified a lack of adequate data on the prevalence of neurological conditions which makes planning for future services difficult. It estimates that 150,000 people nationally will need neurorehabilitation services on an annual basis. The lack of reliable data meant it was not possible to precisely map out the levels and types of services being provided in the neurorehabilitation strategy.

Developing future services

The report recommends that each person requiring neurorehabilitation has access to a continuum of supports from the point of diagnosis. Services should be:

- Local – services should be located within communities so that the person served should not have to travel long distances to access appropriate care and support
- Individualised – services should be tailored to the needs of the individual, taking into account the nature of their condition and likely future developments
- Timely – services should be available when people need them, without undue delays
- Integrated – needs assessments should be holistic and should take account of all the needs of the individual, regardless of whether all the needs can be met in that particular setting. This will require services to be integrated with common policies and protocols, so that all services can work together efficiently to meet the person’s needs

The report identifies that a number of elements are required to achieve this:

1. Health prevention strategies – in the case of MS, this might be strategies to slow and prevent disability progression

2. Managed networks – the proposed amount of networks is 4 per 1 million population, established regionally
3. Community-based rehabilitation approach – a collaborative approach to rehabilitation between the person needing the services, their families and care providers, community organisations and voluntary and statutory service providers
4. Linkages and pathways across all services and settings so as to account for a range of needs including housing, education, employment, vocational training, transport and mental health
5. Use of research and technology
6. Quality frameworks, to ensure services are of a high standard
7. Intersectoral commitment – different state bodies need to work together to deliver outcomes for individuals, across a variety of policy areas

The proposed future model of services consists of 4 service levels at which people can access neurorehabilitation with a continuum of care between the services as required. Which level someone enters the services at will depend on a number of factors such as the nature of their condition and their age. The 4 service levels are:

1. Primary care team – for general medical services and low levels of therapy needs
2. Geographically-based community neurorehabilitation teams (CNT) for specialist medical services and those requiring moderate levels of therapy
3. Regional neurorehabilitation services - referrals from acute hospitals, specialist centre(s) and community teams for high level of therapy need, in patient and out-patient services
4. National neurorehabilitation services which deal with complex cases that are beyond the expertise of the regional services

In order to achieve this, significant reconfiguration of existing services will be required. The report proposes that each of the HSE regions should determine what services are currently available in their area, and work with those services to reconfigure them to form CNTs in line with the model outlined above. CNTs should retain any existing expertise on specific conditions but should also broaden their remit to offer neurorehabilitation services to anyone in the region who requires them. Each region should have a leader on neurorehabilitation who will direct this work.

Implementation of the policy and strategy

The report concludes that a specific implementation plan for the strategy is required, with set actions, timescales and outcomes. Implementation should focus on the reconfiguration of existing services. The report specifically states that clinical and corporate leadership is required. However, one of the issues to date in the implementation process has been a lack of clarity around leadership and responsibility.

What the strategy says about Multiple Sclerosis and MS Ireland

Multiple Sclerosis is one of 5 conditions selected by the report for detailed analysis. The report estimated the number of people with Multiple Sclerosis in Ireland to be 7,000. We now know this figure to be higher, at approximately 9,000 (MS Ireland, 2015).

The strategy describes Multiple Sclerosis as “moderately prevalent with variable complexity” (p.59). The document also identifies MS Ireland’s ‘Getting the Balance Right’ project as a good example of a programme that demonstrates the benefits of exercise for people with MS.

MS Ireland is identified as a provider of neurorehabilitation services through the MS Care Centre and the casework carried out by the Regional Community Workers. It also references community-based educational and symptom management programmes, counselling services, the MS Ireland branch network and the national MS information line.

MS Ireland’s position on the neurorehabilitation strategy

MS Ireland believes it is extremely disappointing that no action has been taken to implement the neurorehabilitation strategy to date. Without access to vital neurorehabilitation services, people with MS face deterioration of their condition and loss of independence which, with the right supports, could be prevented or delayed. Furthermore, recent studies have shown that the financial costs of MS increase steeply as the illness progresses. It is in the interests of wider society that the government take action to address the urgent need for timely interventions that reduce the impact of MS.

MS Ireland supports the campaign of the Neurological Alliance of Ireland (NAI) in calling on the government to:

- Develop inpatient rehabilitation services at both national and regional level to ensure timely access to rehabilitation
- Establish all of the overdue Community Neurorehabilitation Teams (CNTs) in each of the 9 Community Health Organisations by the end of 2016
- Invest in long-term rehabilitation specific services in the community, to provide lifelong support in appropriate settings

References

Adapted from “National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011 – 2015 – Policy Briefing Paper No 2” by Acquired Brain Injury Ireland, with kind permission.

The National Neurorehabilitation Strategy is available at http://health.gov.ie/wp-content/uploads/2014/03/NeuroRehab_Services1.pdf

“Societal Cost of Multiple Sclerosis in Ireland 2015” can be downloaded here: <http://www.ms-society.ie/pages/living-with-ms/information-centre/our-publications>

Further information on NAI’s campaign for neurorehabilitation services can be found here: http://www.nai.ie/go/resources/nai_documents/nai-election-campaign-leaflet-on-neurorehabilitation-services

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