

DELIVERING
THE VISION OF
SLÁINTECARE
THROUGH
NEUROLOGICAL
CARE SERVICES

REPORT FROM NAI
SEMINAR JANUARY 2020



An Roinn Forbartha
Tuaithe agus Pobail
Department of Rural and
Community Development



government supporting communities

FOREWORD

We are delighted to present this report on our half day conference earlier this year “Delivering the Vision of Slaintecare through neurological care services”. Since the publication of the Slaintecare framework each speciality within health and social care in Ireland has pondered what it means for them and the way they deliver care into the future. Neurological care is no exception. Many of the principles of Slaintecare speak to approaches which already embedded in the design and delivery of neurological care, with its strong emphasis on integration and the need for continuity of care across the entire pathway.

We have long been eager to host this event, an opportunity to highlight the features of service provision in neurological care which align so closely with the aims of Slaintecare reform. The four proposals funded under the 2019 Slaintecare Integration Form and showcased at the event are just some examples of the kinds of programmes and initiatives at work all across neurology, neurorehabilitation and other specialist services for people with

neurological conditions. Many involve the close partnerships between the statutory health services and voluntary organisations that represents such an integral feature of neurological care in Ireland. Across the country, a vibrant neurological community participates in shared models of service provision, research and innovation in order to meet the needs of people with neurological conditions and their families.

Our core message is that neurological care represents a key opportunity but also a vital test case for the successful implementation of Slaintecare reform. Integrated care can only be delivered successfully if each part of the pathway is appropriately resourced to deliver care. Gaps in service provision, a revolving door back to emergency care and long hospital stays due to lack of rehabilitation services are hallmarks of neurological care in this country.

The unprecedented events of the past number of months, with the outbreak of COVID19, add an urgency to the key messages conveyed in this report.

More than ever people with neurological conditions require an integrated response as a uniquely vulnerable group with complex health and social care needs. Once again neurological care services, including voluntary providers, have responded rapidly in innovative ways to ensure continuity of care.

The success of Slaintecare will depend not just on investment but on having clear examples of effective service provision to act as templates for reform across the health services. As a community of service providers we feel have much to share.

We wish to thank all our speakers and panellists for their contributions and insights and to Medical Journalist Ms June Shannon for her role in chairing a very vibrant panel discussion at the event. We would also like to convey our special thanks to the Slaintecare Implementation Office for their support and willingness to engage with us in developing the event. We acknowledge the assistance of Ms Priscilla Lynch, Medical Journalist, in preparing this report.



*Tom Scott,
Chair Of NAI*

*Mags Rogers,
Executive Director of NAI*



KEY RECOMMENDATIONS

- There is a need to increase awareness of the Sláintecare policy among the public.
- There is a need for more political support and funds to implement Sláintecare.
- Accurate, comprehensive data collection methods are needed by the HSE to paint a true picture of neurology-related waiting lists and usage of healthcare services.
- Better co-ordination and communication between HSE services and the voluntary sector is needed to recognise gaps/ repetition of services and to ensure best use of available funds.
- There must be proper recognition of the role of the voluntary sector in providing vital neurology support services for patients, and ringfenced secure funding is needed to enable continuation and expansion of these services.
- Formal pathways need to be set up across all disease areas to allow the voluntary sector to continue to provide evidenced-based, publicly-funded services that HSE clinicians can refer patients to.
- A more equal, collaborative partnership on shaping healthcare policies is needed, ie, more patient and voluntary sector involvement in designing services - 'nothing for us without us'.
- There should be further expansion of the multidisciplinary model of care in Ireland, which has been successfully utilised by the Clinical Care Programmes.
- Neurorehabilitation services must be funded and expanded as a priority.
- Expansion of electronic healthcare records across all neurological conditions should be progressed as a priority (can follow the success and learnings of the Epilepsy EPR).
- Social prescribing for neurology patients should be adopted across the Irish healthcare system (on an evidenced basis).
- Successful pilot initiatives need to be funded to be rolled out nationally to ensure equality of access.

COVID-19 POSTSCRIPT

This conference was held in January 2020, before the onset of the COVID-19 pandemic in Ireland in March of this year.

We felt it was important in the Neurological Alliance to reflect on the recommendations of this report in the context of COVID-19. With growing understanding and research into the effects of the virus, it is clear that there are potentially serious neurological consequences for some patients. Neurological care has become a vital tool in the fight against COVID-19, increasing the burden on neurology and neurorehabilitation services worldwide.

As this report has already highlighted, neurological care services in Ireland were already significantly underresourced and underdeveloped pre COVID-19. Neurology services already had one of the highest OPD waiting lists of any medical speciality pre COVID-19. Lack of proper investment means that hospital and community neurorehabilitation services in Ireland are completely inadequate with less than half of the inpatient beds required for a population of our size. Six out of nine Community Health Organisation (CHO) areas have no community neurorehabilitation team in

place, the remainder have only partially staffed teams. There is a huge dearth of appropriate residential, transitional, day and vocational neurorehabilitation services.

One of the most serious implications for neurological care post COVID-19 is the devastating impact on public fundraising to sustain the work of not for profit providers. Not for profit organisations are essential to the delivery of neurological care services in Ireland, providing services ranging from specialist nurses to neurorehabilitation services, respite, day services and residential care, helpline and counselling supports as well as raising vital funds for research into neurological conditions. The entire model of service provision in the community for people with neurological conditions in Ireland is critically reliant on not for profit neurological organisations and completely unsustainable if these organisations are forced to close or curtail their services.

To all the messages in this report there must now be added an urgent message: to protect existing services and build much needed capacity throughout neurological care in Ireland as a key tool in our fight against COVID-19.

NEUROLOGICAL ALLIANCE OF IRELAND

The Neurological Alliance of Ireland is the national umbrella body for over thirty not for profit organisations working with people with neurological conditions and their families. It

works to promote the development of services and supports for people with neurological conditions in Ireland through advocacy, policy development, awareness and research.

SLÁINTECARE: AN OVERVIEW

Under the Programme for a Partnership Government, an All-Party Oireachtas Committee on the Future of Healthcare was established in June 2016 to create a cross-party vision for the future of our health and social care services. The Committee sat for almost a year, engaging with stakeholders across the system and published the Sláintecare Report in May 2017.

Sláintecare¹ represents the first cross-party political consensus on the future of Irish health and social care services and is thus unique in the history of the State. Built on consensus, Sláintecare is a ten-year programme to transform our health and social care services. Over the next ten years, Sláintecare will:

- promote the health of our population to prevent illness
- provide the majority of care at or closer to home
- create a system where care is provided on the basis of need not ability to pay
- move our system from long waiting times to a timely service – especially for those who need it most
- create an integrated system of care, with healthcare professionals working closely together.

The Sláintecare Implementation Strategy was eventually published in August 2018, setting out the framework within which a system-wide reform programme will be advanced.

The Sláintecare Integration Fund was part of the Sláintecare Action Plan 2019² that establishes the building blocks for a significant shift in the way in which health services are delivered in Ireland. The Sláintecare Integration Fund focuses on prevention, community care and integration of care across all health and social care settings. It seeks to:

- Promote the engagement and empowerment of citizens in the care of their own health
- Scale and share examples of best practice and processes for chronic disease management and care of older people

- Encourage innovations in the shift of care to the community or provide hospital avoidance measures.

The NAI event involved presentations from four initiatives in neurological care funded under the Sláintecare Integration Fund and announced in 2019.

Sláintecare.

¹ Committee on the Future of Healthcare: Sláintecare Report (May 2017) Houses of the Oireachtas Report

² Sláintecare Implementation Plan (2019) Department of Health

BACKGROUND INFORMATION: NEUROLOGICAL CARE IN IRELAND

Over 800,000³ people in Ireland live with neurological conditions including dementia, stroke, epilepsy, acquired brain injury, Parkinson's disease and multiple sclerosis as well as rare and genetic conditions.

Neurological conditions account for:⁴

17%

of GP visits

10%

presentations to an emergency department

19%

of all hospital admissions

33%

of people living in residential care

Research published by the Neurological Alliance of Ireland in March 2020 highlighted the enormous challenges faced by these individuals and their families in accessing healthcare and other supports.

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The nationwide survey based on over 600 responses showed that:

37%

waited more than 12 months to see a neurologist to have their condition diagnosed

**ONE
IN
FIVE**

could not access vital services including:

counselling

20%

physiotherapy

18%

and nurse specialists

17%

double the percentage reporting this in 2011 at the height of the economic recession.

45%

of patients were paying more than €100 a month out of their own pocket for supports such as physiotherapy and medications.

Patients reported they needed to purchase but could not afford:

neuropsychology

18%

physiotherapy

15%

and counselling services

17%

**ONE
THIRD**

of carers reported their home care was not appropriate to the needs of a person with a neurological condition

In March 2020 (pre Covid-19 service restrictions), over 22,000 people were waiting to see a neurologist, 6,000 of whom had been waiting over 18 months⁶. Neurorehabilitation services are significantly underdeveloped at every level, from acute and postacute inpatient care to a dearth of long term rehabilitation supports in the community. A three year framework for neurorehabilitation services launched in 2019 has seen no commitment to investment to date.

Clearly things need to change and it is hoped that the implementation of the Sláintecare Reform Programme will help in reducing unacceptable waiting lists, improving outcomes and addressing critical staffing shortages that threaten the safe delivery of services. However, while broadly welcomed by the majority of healthcare stakeholders in Ireland, implementation of Sláintecare has been slow to date.

³ Strategic Review of Neurology and Neurophysiology Services in Ireland (2007) National Hospitals Office HSE

⁴ Neurology Commissioning Toolkit (2016) Association of British Neurologists

⁵ Living with a Neurological Condition in Ireland: Key Findings from a Nationwide Survey (2020) Neurological Alliance of Ireland website <https://www.nai.ie/go/news/12-3-2020-launch-of-latest-nai-research>

⁶ Outpatient Waiting List Data by Speciality (2020). National Treatment Purchase Fund. <https://www.ntpf.ie/home/pdf/2020/03/nationalnumbers/out-patient/Nationalo2.pdf>

CONFERENCE PROGRAMME: DELIVERING THE VISION OF SLÁINTECARE THROUGH NEUROLOGICAL CARE SERVICES

A seminar to explore the implications of Sláintecare in regards to neurological care (including neurology and neurorehabilitation services) was held on 21 January 2020.

The event focused on neurological care services as key drivers of many of the principles that underlie Sláintecare reform, including promoting integrated care, encouraging a shift to ongoing care in the community and better management of chronic disease.

Presentations were made on four neurology projects funded under the Sláintecare Integration Fund in 2019, which represent Sláintecare principles operating in practice: delivering an integrated, community-based approach to chronic long-term conditions.

There was also a presentation on the Implementation Framework for the Neurorehabilitation Strategy, and the state of neurorehabilitation services currently in Ireland.

An expert stakeholder panel debated how neurological services can benefit from the Sláintecare model, and discussed the current deficits in services and policy.

OPENING ADDRESS



The event was introduced by the Executive Director of the Neurological Alliance of Ireland, **Ms Mags Rogers**. She voiced her support for the Sláintecare policy, which was published in 2017, and quoted directly from the Sláintecare report: “The Committee’s vision requires a system that is integrated in terms of all stages of an individual’s life, from cradle to the grave, and also in terms of a comprehensive continuum of care from health promotion and disease prevention to diagnosis, treatment, disease management, rehabilitation and palliative care.”

This vision represents exactly how services for people with neurological conditions should be delivered.

And, importantly, it echoes the innovative practices being developed and delivered across neurological care, both statutory and voluntary, which were showcased at this event, Ms Rogers said.

For example, neurological care continues to be at the forefront of promoting multidisciplinary management of chronic conditions, advancing the role of clinical nurse specialists and nurse- and GP-led clinics and working with the voluntary sector in

developing self-management and other long-term supports in the community, she pointed out.

Following Ms Rogers introduction, there were presentations from the four projects in neurological care funded under the 2019 Sláintecare Integration Fund, in epilepsy, multiple sclerosis and headache.

These projects all demonstrate what Sláintecare is aiming to achieve: better management of chronic conditions, a focus on the community and promoting seamless transitions and integrated care.



SLAINTECARE INTEGRATION FUND PROJECT: KEEPING PEOPLE WITH SEVERE EPILEPSY INDEPENDENT (ST JAMES HOSPITAL)



Dr Colin Doherty, Consultant Neurologist and Honorary Senior Lecturer in Neurology at St James's Hospital in Dublin, began by giving an update on the state of epilepsy care in Ireland and the development of the national epilepsy electronic patient record.

Of the approximately 40,000 citizens in Ireland have epilepsy, 15,000 are poorly controlled and access a lot of hospital-based care, and there are over 100 epilepsy-related deaths annually.

There are approximately 7,000 epilepsy-related emergency department admissions (2%) annually, and the average length of stay 3.4 days which averages out at 30,000 bed days/year.

He outlined the development of the electronic patient record (EPR) for epilepsy, which now has about 9,000 patients (mostly complex) signed up, and also detailed the progress being made in St James's in helping well-established epilepsy patients better self-manage their disease, through offering virtual clinics and online/phone support services so they rarely have to physically attend the hospital. "For people who choose to do that it has been very successful," he commented.

There is also an established care pathway in the emergency department (ED) in St James's for patients presenting with seizures, which has resulted in improved discharges Dr Doherty said, citing supportive data showing a slow steady decline in ED admissions for this cohort since 2014.

"That goes against everything we're told about the pressure on EDs and demographics - that more and more beds are needed. That is certainly not true for us. We want to stop patients coming in who don't need to be in and key to that is providing early access to care."

However, despite this success, vulnerable and marginalised patient populations with epilepsy remain a challenge. The Sláintecare Integration Fund epilepsy project in St James's seeks to extend the clinical pathway beyond the ED to start to prevent admissions rather than just reduce them at the source.

Two of the largest groups of patients who get admitted to hospital due to disease severity and deficits in primary care services are the intellectually disabled and people who are homeless, incarcerated or have addictions.

The prevalence of epilepsy in this cohort is eight times the rest of population and the risk of death due to epilepsy is 5/100 compared to 1/1000. The majority (78%) of those with epilepsy who die from a seizure in Ireland have no anti-epileptic drugs in their system, Dr Doherty pointed out, quoting Health Research Board data.

Most of the homeless/incarcerated with epilepsy are men aged between 40-50 years with frequent co-morbid addiction and psychotropic drug use, so they are complex to care for, Dr Doherty explained.

He outlined the success of the funded project to help improve care for these patients and reduce their attendance at EDs, which included the development of a seizure pro-forma that can be used by outreach health services (eg, SafetyNet) to help assess and manage these patients better. Once the filled-in form is received the referring service receives a prompt same-day reply from the St James's epilepsy team on how to manage the patient, and whether they need to attend hospital.

In addition, for epilepsy patients with intellectual disability who find it particularly stressful to attend hospital settings, outreach clinics have been set up in two independent intellectual disability service providers in Dublin. About 160 of these patients have had their data uploaded to the EPR and they are now treated in a setting that is calm and familiar to them, they have better support, and they don't have long waits to be seen. The Sláintecare fund has allowed the hiring of additional staff to support this service and it could be rolled-out in other areas if supported.

SLAINTECARE INTEGRATION FUND PROJECT: DEVELOPING A PATHWAY OF COMMUNITY CARE SUPPORTS FOR PEOPLE WITH EPILEPSY IN IRELAND (EPILEPSY IRELAND)

Epilepsy is one of the most common neurology conditions, affecting approximately 40,000 people in Ireland. Epilepsy Ireland's vision is to achieve a society where no person's life is limited by epilepsy, and it provides a number of practical supports for people with epilepsy as well as self-management programmes.



Ms Tara Smith, Director of Services with Epilepsy Ireland, discussed the organisation's Sláintecare Innovation Fund-funded project on developing a pathway of community care supports for people with epilepsy in Ireland.

Using a joint approach the project aims to demonstrate how staff based in hospital, primary care and the community can work together, complement each other's work, minimise duplication, and make the best use of limited resources thereby maximising value for money while improving the level and depth of contact with people with epilepsy.

The project, which is in the early stages, has two cohorts:

Early intervention (120 people), which involves the development of a referral pathway for patients newly diagnosed with epilepsy so that within six-12 weeks of their diagnosis they can access an education programme to enhance self-management. Community Resource Officers (CROs) will team up with HSE epilepsy nurse specialists to jointly deliver a series of education sessions covering the wide range of medical and non-medical issues that accompany a new diagnosis of epilepsy.

Established epilepsy (50 people), which involves the development of a patient-led consultation guide ('Checklist') to guide consultation between people with epilepsy and GPs; checklist training for people with epilepsy; and the creation of a digital training tool developed to foster epilepsy monitoring and care in general practice.

The key partners in the project are Dublin hospitals Connolly Memorial Hospital, Blanchardstown; St James Hospital; the Mater Hospital; and Beaumont Hospital, as well as the Department of General Practice, University College Cork.

Ms Smith outlined the expected outcomes of the project, which include that participants will report more awareness of epilepsy and

greater control over their condition through the provision of information, education, self-management and self-care supports; participants will report improved self-reported stress levels/personal confidence and wellbeing levels due to engagement in programme and enhanced links to local CROs; and participants will be more empowered in the management of their medical appointments through having completed the 'checklist' which will guide their medical consultations.

SLAINTECARE INTEGRATION FUND PROJECT: TOWARDS SELF-CARE IN HEADACHE (CLINICAL STRATEGY AND PROGRAMMES DIVISION)



Ms Dervla Kenny, National Programme Manager, National Clinical Programme for Neurology outlined the details of the funded Towards Self-care in Headache project which kicked off in January. The Clinical Programme for Neurology in partnership with the Irish Pharmacy Union (IPU) and the Migraine Association of Ireland (MAI) have joined forces to deliver this innovative approach to headache self-management.

This evidence-based care pathway for headache seeks to improve headache outcomes and reduce hospital visits and costs and reduce reliance on secondary/tertiary care by harnessing existing resources within

the community healthcare network in supporting recently diagnosed patients. It also promotes a programme of self-care and self-management for those with chronic headache.

Ms Kenny pointed out that headaches are one of the most common neurological presentations to emergency departments and acute medical assessment units in Ireland. The Towards Self-care in Headache project aims to lead to a reduction in unscheduled care for persons with a primary diagnosis of headache; optimised use of skills and expertise of community pharmacies; reduction in the return:new ratio in neurology clinics; increase in nurse triage in EDs in participating sites; optimise use of nurse-led headache clinics, create additional headache self-management support groups nationally in the community via the MAI in collaboration with the multidisciplinary team; and reduce variation from service to service within pilot sites.

The Towards Self Care in Headache programme will have three components: 1) Implementation of nurse-led clinics 2) collaboration with selected community pharmacies who

will support patient care pathways (eg, triaging the patients as part of the initial diagnostic pathway, which can include referral to a specialist nurse-led clinic, managing and treating symptoms, and medicines optimisation, etc) and 3) self-management training sessions and peer support groups in partnership with MAI.

In order to improve diagnosis, referral and support in the primary care setting there will be community-based education sessions for GPs in the pilot clinics and educational sessions for pharmacists by the MAI, IPU and National Clinical Programme in Neurology.

Towards Self Care in Headache will be piloted in four locations; Tallaght University Hospital, St James University Hospital, Galway University Hospital and Beaumont Hospital. Funding will also be provided for a psychologist who will provide support for those with psychological factors, contributing to poor management of headache syndrome.

The project will demonstrate core Sláintecare values by providing care more appropriately and closer to the home; leading to improved patient experiences; improved access times to neurology services; reduced variation from service to service, and better, more efficient use of resources.

SLAINTECARE INTEGRATION FUND PROJECT: PROMOTING PHYSICAL ACTIVITY PROGRAMMES FOR PEOPLE WITH NEUROLOGICAL CONDITIONS IN THE COMMUNITY (MULTIPLE SCLEROSIS SOCIETY OF IRELAND)



Ms Mary McCusker, Regional Community Worker with MS Ireland, outlined how the Slaintecare-funded project will take an integrated care approach to delivering health-promoting, evidenced-based physical activity programmes for people with neurological conditions in the community.

Post-rehabilitation exercise and physical activity programmes improve symptoms, optimise participation and reduce consequences of inactivity in patients, she explained. Prevention and self-management are key in dealing with the impact of neurological conditions

and these exercise initiatives need to be integrated across health, recreation and social care sectors; taking a health-promoting settings approach.

MS Ireland has been running its own physiotherapy and exercise programme designed for people with MS called “Getting the Balance Right” since 2007 and provided 3,565 exercise sessions in 2019. However the association is reliant on fundraised income for the service, and has become a victim of its own success in that many people attending programmes are not linking with primary care, Ms McCusker said.

MS Ireland aims to use its experience with its “Getting the Balance Right” service to broaden it out to other neurological conditions under the funded project, which will be piloted in the mid-west, and will leverage best practice examples nationally and internationally. This will involve setting up a cross sector interagency forum which will allow mapping and identifying gaps in current provision, and then explore possibilities and

potential for collaboration. A patient/participant forum will also be set up to input in the roll-out of the physical activity programmes. People will be able to self-refer or be referred by their other care providers including voluntary sector organisations.

This project benefits people in delivering the Sláintecare mantra of ‘providing the right care at the right time in the right place’, Ms McCusker noted:

Right care – there is strong evidence for exercise in the community for people with neurological conditions in reducing symptom severity, increasing well-being and QOL, preventing secondary complications of inactivity, community reintegration and participation.

Right time – the programmes will be available post rehabilitation, when people are at home and reintegrating into the community. Timing wise the implementation of the Neurorehabilitation Model of Care is imminent and the project fits with the

ethos of the Healthy Ireland Physical Activity strategy and National Exercise Referral Framework.

Right place – people will be able to access these programmes in their community, in collaboration with recreation and social care agencies locally.

NEUROREHABILITATION: INTEGRATED CARE IN ACTION

While referenced in both Slaintecare & Slaintecare Implementation Programme, Neurorehabilitation, and specifically, the managed clinical rehabilitation network demonstrator project was not successful in securing slaintecare funding in 2019. Project Lead with the Neurorehabilitation Network Demonstrator Project, **Ms Edina O'Driscoll** highlighted the lack of neurorehabilitation services in Ireland, the increasing demand for these services, excessive waiting times and the fact that hospital data is not correctly capturing who needs neurorehabilitation, thus published delayed discharge figures are incorrect.



HSE hospital discharge data shows that only 9% of trauma patients and 1.5% of those discharged from acute hospitals with neurological conditions in 2016 were discharged to a rehabilitation facility.

A significant number of these patients remain 'stuck' in the acute hospital setting because they cannot access neurorehabilitation services as evidenced by a recent audit. The audit of eight hospitals identified 110 patients as being delayed in acute hospital secondary to lack of access to neurorehabilitation services. Only 18 per cent were recorded on the HSE's delayed discharge report. "If we apply that percentage to a national reported figure of 66, the numbers of people delayed in acute hospital due to lack of access to neurorehabilitation could be close to 400," she said.

Over half (56%) of those delayed waiting in hospitals for neurorehabilitation are in the 18-64 age group with diagnoses of stroke, acquired brain injury and spinal cord injury. The audited group, on the day

of data collection, had collectively accumulated 18,121 days in hospital, she reported.

Ms O'Driscoll referenced the Implementation Framework for the Neurorehabilitation Strategy which was launched in February 2019. The overarching aim of the Strategy is the development of neurorehabilitation services nationally to improve patient outcomes, with services being configured into population-based managed clinical rehabilitation networks. The framework describes the need for interdisciplinary services to provide the appropriate continuum of integrated care across Community Health Organisations (CHOs), acute hospital and post-acute rehabilitation services. The provision of services is intended to ensure equity of access to high-quality, reliable, person-centred care, delivered as close to the home as possible - in line with the key objectives of Slaintecare.

She said the Framework urgently needs to be progressed, and noted how currently services are very disjointed and operate in silos, with lack of communication, absence of national pathways, and repeating of patient histories, etc, a key issue.

Under the managed clinical rehabilitation network framework patients will be able to move from one service to another seamlessly. Ms O'Driscoll detailed how this will work, using the example from the demonstrator project, which, if funded, will see the development of inpatient and community-based neurorehabilitation services across CHO 6 and 7.

In addition, the funding of better community services and home care packages will free up hospital beds in the acute sector, leading to savings there, she said.

PANEL DEBATE

An experienced panel explored the implications of Sláintecare for neurological care with representatives from neurology and neurorehabilitation services, voluntary providers and representatives from the Sláintecare Implementation Office and the Office of the Clinical Lead for Acute Hospitals.

The panel participants were:

Prof Orla Hardiman: Clinical Lead, HSE National Clinical Programme in Neurology

Mr Tom Scott: Chair of the Neurological Alliance of Ireland

Ms Edina O'Driscoll: Project Lead, Neurorehabilitation Demonstrator Project

Ms Muriel Farrell: Project Lead, Sláintecare Integration Fund

Ms Emma Benton: Office of HSE Acute Hospitals, Clinical Lead (NCAGL)

Dr Colin Doherty: Consultant Neurologist St James Hospital and Trinity College Dublin

Ms Aoife Kirwan: Information, Research and Advocacy Officer, MS Society of Ireland

Medical Journalist **June Shannon** chaired the panel discussion.



The panel discussion and aforementioned presentations led to the drawing together of a series of proposals (see recommendations outlined at the beginning of this report) aimed at strengthening and supporting neurological care in transforming

approaches to the management of chronic disease and disability within Ireland's health services.

The focus of the panel discussion was on describing the future vision for neurology and neurorehabilitation services in Ireland, and outlining how Sláintecare and other stakeholders are supporting the work of the Clinical Programmes in delivering this vision, including the vital role being played by not-for-profit providers in the delivery of neurological care in the community.

Key themes to emerge from the debate were: the disconnect between many services (operating in silos) leading to patients falling between the cracks, poor usage of more expensive hospital-

based resources and a lack of suitable community-based supports.

Ms O'Driscoll reiterated that a key focus of the HSE Clinical Care Programmes is providing care as close to people's home as possible, in line with Sláintecare, which is very important for those in need of neurorehabilitation who can find it very difficult to travel. At-home interventions and therapy access should be an option for neurology patients where possible, and Ireland can learn from other countries on this, she said.

Prof Hardiman praised the work of the voluntary sector in playing a vital role in supporting and providing specialised care for patients, filling in gaps in State-provided care which relies heavily on the sector – something which she said is not adequately realised/recognised. She acknowledged that there is still a level of distrust between the two sectors and that the HSE needs to properly assess and document the work of the voluntary sector. ►►

PANEL DEBATE



This should then enable the HSE to build up well governed, integrated structures to ensure the continuity and security of the vital services offered by the voluntary sector, while at the same time recognising their autonomy.

Dr Doherty said building trust and ‘buy in’ for new healthcare programmes takes time and work, and must be based on consistent collaboration and an openness to listening to others. He cited regular multidisciplinary team meetings as key to the success of the HSE Clinical Care Programme for Epilepsy. He reiterated that rather than putting more money into the acute system, better ways of managing capacity are needed such as less reliance on EDs as a way to access services, and that expanded community management which keeps people well



and out of hospital is clearly needed. (Insert image: Colin Panel)

Mr Scott pointed out that patients are so busy fighting for basic healthcare for themselves/family members it is hard for them to be involved in shaping and advocating the bigger picture of Sláintecare. He highlighted



the difficulties small voluntary organisations have in putting together detailed proposals for projects and funding support (eg, the Sláintecare Innovation Fund) and said that resources to help them with this would be very useful.

Ms Farrell spoke of the fundamental goal of Sláintecare is to provide the right care in the right place at the right time by the right team and this involves a shift of care to the community. Slaintecare is about working collaboratively in the co-design of future services, engaging and listening to patients and staff. It is important to note we are not starting from scratch and we know we have a highly skilled and motivated workforce across the

statutory and voluntary sector who are solution focussed and committed to improving services locally through innovative ways of working with a focus on optimising existing resources, demonstrating safe and effective evidence based care, value for money and good patient outcomes. This was evidenced recently when we made a call last year for health and social care providers to come forward with ideas on how to make the Sláintecare

vision a reality, through the Sláintecare Integration Fund. We received 500 applications and the 122 successful projects, some of which you have heard from today, show how joined-up thinking and working in partnership can help us reach Sláintecare’s goals to bring care closer to home, including putting the patient at the centre of service design and delivery.

Ms Kirwan said that the public and patients don’t really understand what Sláintecare is, how it will work and what it aims to achieve. This needs to change for it to be truly successful and to maintain public pressure for its implementation and acceptance. ▶▶

PANEL DEBATE

There were also a number of valuable contributions from the audience, including one from a man with Parkinson's who pointed out that all interventions don't have to be expensive or complex – he has found Irish dancing classes to be very effective in maintaining his mobility and said local access nationwide to such classes would be incredibly beneficial to this patient population. He also spoke of the need for better communication and positivity around our health services and about what they do for patients, not only what they do not do.

The panel agreed and contributors said there is a negative view and suspicion about new healthcare policies due to consistent negative media coverage of endless waiting lists and trolleys numbers, as well as the fact that previous healthcare strategies have been abandoned and recent attempts at reform of our health services have been portrayed negatively. The positive aspects of Sláintecare and what it aims to achieve needs to be communicated



widely, as well as examples of what we can be proud of in our health service, such as the models of care, many of which are world leaders in their approach.



NAI MEMBER ORGANISATIONS

Acquired Brain injury Ireland

Alzheimer Society of Ireland

An Saol

Aphasia Ireland

Ataxia Ireland

Aware

Bloomfield Health Services

Cheshire Ireland

Chronic Pain Ireland

Dystonia Ireland

Enable Ireland

Epilepsy Ireland

Headway

*Huntington's Disease Association of
Ireland*

Irish Heart Foundation

Irish Hospice Foundation

Irish Motor Neurone Disease Association

Migraine Association of Ireland

Move4Parkinsons

Multiple Sclerosis Society of Ireland

Muscular Dystrophy Ireland

National Council for the Blind

Neurofibromatosis Association of Ireland

North West MS Therapy Centre

Parkinson's Association of Ireland

Polio Survivors Ireland

PSPA Ireland

Spinal Injuries Ireland

Spina Bifida Hydrocephalus Ireland

The Rehab Group

Associate Members

Brain Tumour Ireland

*Syringomyelia Chiara Malformation
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