

Summary Report on the Neuro-Mapping Project Phase 2

Working together towards integrated care in the community for people with neuro-rehabilitative needs



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This report, led by the Health Service Executive, Disability Federation of Ireland and the Neurological Alliance of Ireland engaged with 56 people with neurological conditions and 137 service providers to establish the current picture of community Neuro-Rehabilitation services in Ireland.

Martin, a person with a neurological condition

I have to contact multiple different organisations for different things, none of which are connected and there is no one point of contact that I can contact that knows the system, I have to figure out what it is that I maybe want and then figure out how to access it. I spend so much time phoning and contacting people just to get a basic level of service delivery.

Lucy, a service provider

I think it's well within patients' rights to expect specialist services, that's what these kinds of conditions require. It isn't just run-of-the-mill often, and they're often quite complex patients, and I suppose it's to also support staff that they feel specialist enough to help these patients effectively and I think there's a big investment in that for staff that we ensure that we provide them with training and education to feel that specialist and to be able to operate at that specialist level.

The voices of people with lived experience, as well as service providers, have been instrumental in shaping the recommendations in the report.

Who did this project?

This project is a joint project between the **Health Service Executive (HSE)**, **Disability Federation of Ireland (DFI)** and the **Neurological Alliance of Ireland (NAI)**. This project is governed by the **HSE National Neuro-Rehabilitation Steering Group**.

What is this project about?

There are over 860,000 people with neurological conditions living across Ireland.

These individuals predominantly live and manage their conditions within community settings.

This project is about experiences of **community Neuro-Rehabilitation services** in Ireland.

It is about the **views of people with neurological conditions** who access these services and the **views of staff who provide these services**.

It is about what they think is good and what they think could be improved.

Importantly, it is also about **what changes people would like to see**.



What we did – Part 1

For Part 1, we wanted to find ways to standardise the wording used to describe services for people with neurological conditions.

In 2023, the Neuro-Mapping Project Partners (HSE, NAI, and DFI) collaborated to create a [Service Mapping Template](#) that categorises and describes the various community services available to people with neurological conditions.

We met with a group of key stakeholders and asked them about potential uses for this Service Mapping Template.



What we found – Part 1

There were several potential uses suggested for the Service Mapping Template.

The main suggestions related to using it to **increase knowledge of services** available in different areas and help with **signposting**.

What we did – Part 2

For Part 2, we spoke with people with neurological conditions and staff who provide community Neuro-Rehabilitation services in three distinct geographical areas (CHO 2, 3 and 6). We wanted to find out about their experiences of community Neuro-Rehabilitation services.

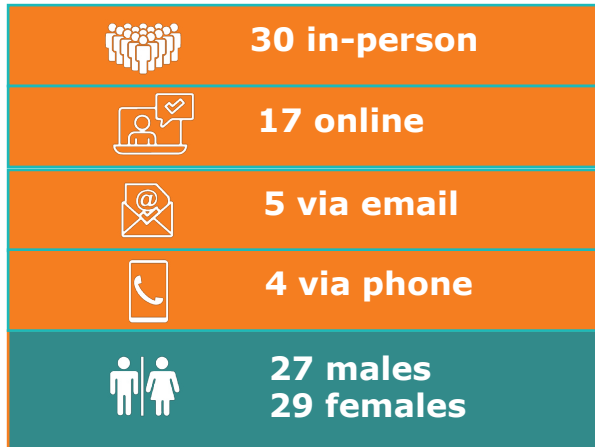
How did we find people to take part?

We engaged with voluntary organisations to reach individuals with neurological conditions with information about the project.

We also contacted staff who provide community Neuro-Rehabilitation services, working for the HSE or voluntary organisations, to participate in the project.



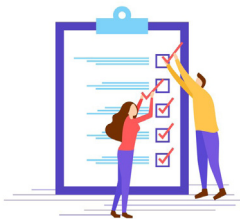
Who participated?



- The neurological diagnoses of participants included:

- multiple sclerosis: 18 people
- stroke: 17 people
- traumatic brain injury: 12 people
- spinal cord injury: 3 people
- functional neurological disorder: 2 people
- epilepsy: 2 people
- rare neurological condition: 2 people
- progressive supranuclear palsy: 1 person
- brain aneurysm: 1 person
- brain tumour: 1 person
- Parkinson's disease: 1 person

- The number of community Neuro-Rehabilitation service staff who participated was as follows:



137 service providers completed a questionnaire.



106 service providers attended online meetings.

What we found – Part 2

There were many similarities in the feedback from **people with neurological conditions** and **staff who provide services** about their experiences of community Neuro-Rehabilitation services. The five main themes are listed below.

1. There are **not enough specialist community Neuro-Rehabilitation services**.

Lily, a person with a neurological condition

I lost my swallow when I had my stroke and had speech and language therapy, I was meant to have speech and language therapy when I left the hospital and I didn't. I wasn't referred to any more physiotherapy after I left hospital so I am going privately. I am also doing some private counselling because those things aren't there for you after. It feels like when the emergency is over, there are no services. We go home and live with the disability every day.

Mandy, a service provider

we have a speech and language therapy post that's waiting to be filled but you know that's been vacant since about November time and I've even noticed the times that I've been working with sheer frustration of not being able to provide a full service from my view point as an occupational therapist because I don't have a speech therapist to work alongside.

2. It is **difficult to find what services are available** in the community.

Fred, a person with a neurological condition

I have to contact multiple different organisations for different things, none of which are connected and there is no one point of contact that I can contact that knows the system, I have to figure out what it is that I maybe want and then figure out how to access it. I spend so much time phoning and contacting people just to get a basic level of service delivery.

Tara, a service provider

I myself find it difficult to navigate what services are out there and I've worked in brain injury since the turn of the century, so I can only imagine the struggles that people have.



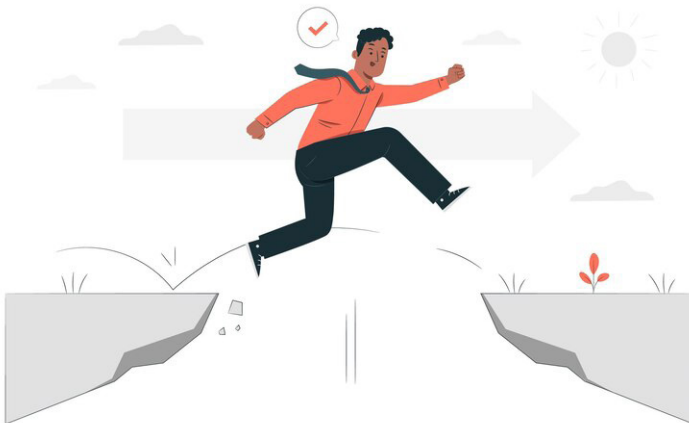
3. There are **obstacles to attending services**, including waiting lists, where you live and if you have access to transport.

Sharon, a person with a neurological condition

It is difficult to attend in-person services as transport is not provided and so I am relying on my son who does not live with me to drive.

Angela, a service provider

accessing services to follow on can be challenging and I suppose it depends on multiple factors in terms of where they're living, you know, their age, what services are available to them



4. There are **not enough long-term supports**, particularly for physical and psychological well-being.

Sharon, a person with a neurological condition

So many years have passed since my injury, and we get discharged, but we still live with our disability forever, the issues affect us every second of every day. When you are discharged, you are just left. The disability is forever there's no ending for us.

5. Having a **support network is important.**

Kevin, a person with a neurological condition

We formed a very good group of patients in there because we could share our experiences with each other.

*The names of people who participated in this project have been changed for privacy.



Areas for improvement

People with neurological conditions and staff who provide services gave suggestions for what changes should be made to improve community Neuro-Rehabilitation services.

Five key areas have been identified that would improve the experiences of those providing and accessing services.

1. Increasing knowledge and information of services that are available in the community for people with neurological conditions.
2. Improving how services work together with changes to how information is gathered and shared between services, to enable a more seamless service-user journey.
3. Providing equal access to services based on rehabilitative need and preference of the individual.
4. Adequately staffing and resourcing specialist services in the community so that they can provide timely and high-quality interventions.
5. Redesigning and restructuring community Neuro-Rehabilitation services, in addition to adequate resourcing of supports such as Personal Assistance hours and transport services, to facilitate the continuum of care for people with neurological conditions.



Specific recommendations relating to each of the above five areas are presented in the main report.

What will be happening next?

The findings of this project will be shared with people who make decisions about healthcare in Ireland, people with neurological conditions and people who provide Neuro-Rehabilitation services.

The recommendations from this project will be developed into actions in the workplans of the HSE National Neuro-Rehabilitation Steering Group and the Community Workstream under the National Neuro-Rehabilitation Strategy.

A commitment has been given to complete a similar project again in three years' time to see if there have been any changes.



How can I find out more?

A copy of the main report is available [here](#).

If you would like to find out more about the Neuro-Mapping Project, please scan the following:



Disability Federation of Ireland

The Disability Federation of Ireland, DFI, is a federation of over 100 member organisations working with others to achieve a vision of an Ireland where people with disabilities are participating fully in all aspects of society. Our mission is to work with people with disabilities to implement the United Nations Convention on the Rights of People with Disabilities and ensure their equal participation in society. Our work includes information provision, advocacy and representation, research, policy development and implementation, as well as providing support for our member organisations including training, networking and organisation and management development. Through our work we contribute to:

- Policy implementation developments at national level spanning income and access to community participation.
- Member organisations being sustainable and in a stronger position to support people with disabilities to have a full life.
- People with disabilities being more active within their communities, as participants, advocates, and representatives.

<https://www.disability-federation.ie/>

The Neurological Alliance of Ireland

The Neurological Alliance of Ireland (NAI) brings together 30 non-profit organisations to advocate for the rights of 860,000 people in Ireland living with a neurological condition. Neurological conditions affect the brain and spinal cord. They are the leading cause of disability throughout the world and include many common conditions such as stroke, dementia, migraine, epilepsy and acquired brain injury as well as rare and genetic conditions. Founded in 2003, the NAI advocates for the development of quality services for people with neurological conditions. Our campaigns are rooted in the experience of our members and the people and families with whom they work. We provide a united and expert voice on neurological care through advocacy, policy development, and awareness raising.

<https://www.nai.ie/>

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