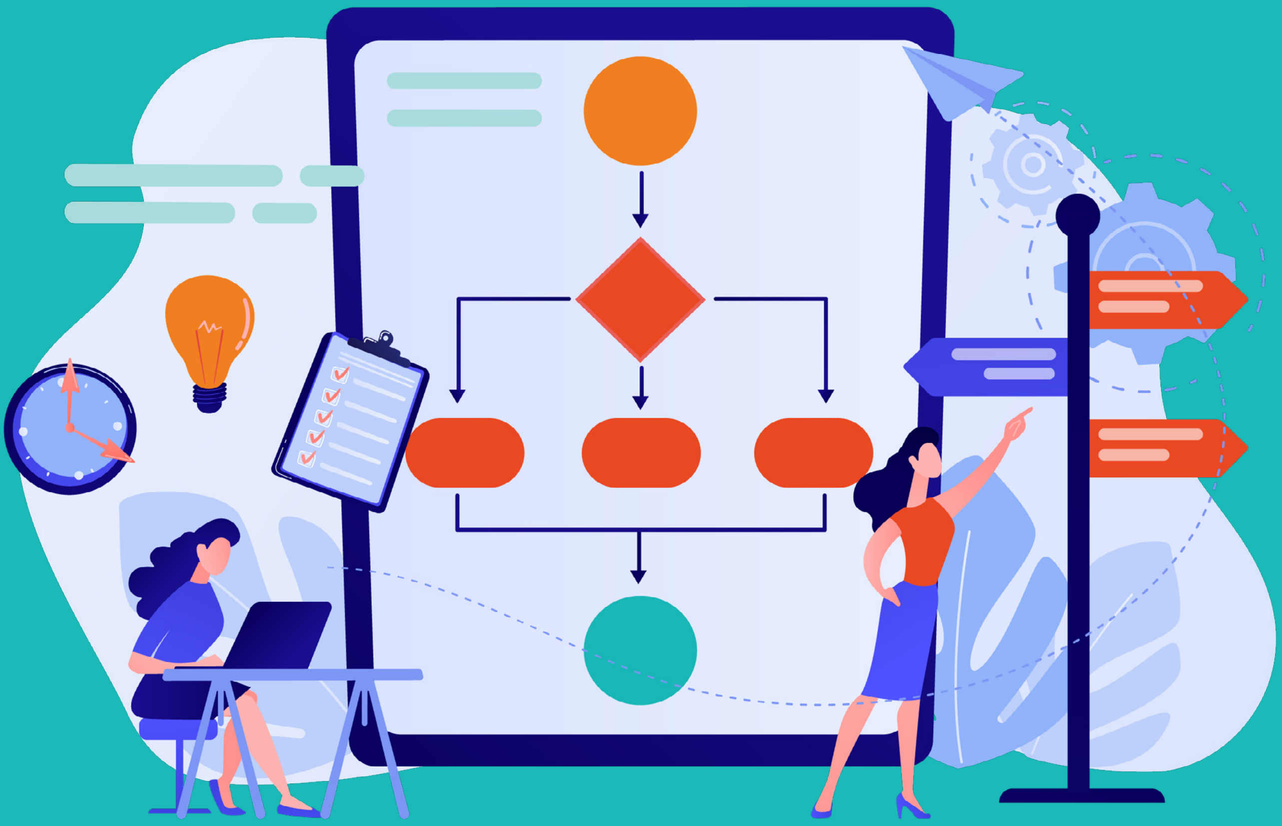
Report on the Neuro-Mapping Project Phase 2

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



NEUROLOGICAL ALLIANCE of IRELAND

DISABILITY FEDERATION OF IRELAND

Report on the Neuro-Mapping Project Phase 2

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

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.

Contents

Foreword

The Report on the Neuro-Mapping Project Phase 2 has highlighted the challenges, gaps and opportunities that, when acted on, will support the delivery of an improved experience for people with neuro-rehabilitative needs who live in the community.

The findings from this project have incisively captured the experiences on the ground for those living with neurological conditions in the community as they seek to access services to address their neuro-rehabilitative need. The frustrations and concerns that they have articulated, and the suggestions they have put forward for future service provision are clearly laid out in the report. The experiences of service providers also give very helpful insights into what systems are working and what changes need to be made to enhance integration and continuity of care. I have been particularly struck with the consistent themes that have emerged from those with lived experience and service providers. This synchronicity provides comprehensive directions for the Health Service Executive (HSE) National Neuro-Rehabilitation Steering Group (NSG) and the Community Workstream developed under the NSG, as they incorporate the recommendations as part of their work plan.

The strong partnership between the HSE, Disability Federation of Ireland (DFI) and the Neurological Alliance of Ireland (NAI), in overseeing this project and delivering on the report is also evident, and commendable. We know that collaboration and cohesiveness between service providers is essential to support the continuity of care that people with neuro-rehabilitative needs require. I would like to thank the DFI and NAI for their commitment to this work, and I look forward to engaging with them further as we seek to implement the recommendations.

However, for me the most important part of this report is the benchmark that it gives for us, as we seek to develop and improve services for people with neurological conditions. I look forward to revisiting this work in 3 years and examine the progress we have made.

Finally, I would like to acknowledge all those who have contributed to this report, and particularly like to thank the lived experience participants.

Bernard O' Regan

Bernard O’Regan

Assistant National Director,

HSE Disability Services

October 2024

Acknowledgements

As chairperson of the Joint HSE, DFI and NAI Neuro-Mapping Project, I would like to thank all those who have engaged and participated in the work of the project over the past year.

I would like to thank DFI and NAI as Project Partners for the true spirit of collaboration and meaningful co-operation as we approached each milestone. I would also like to recognise the significant input from the Neuro-Mapping Steering Committee, who met six times throughout the duration of the project. Their guidance and wisdom were invaluable as we sought to ensure that we were achieving the project's objectives.

Finally, I would like to express my gratitude and deep appreciation to Nicola O'Malley who was the Research Officer for this project. As well as ensuring that we kept to our project timelines, her research methodologies helped to ensure that we could engage and capture the experiences of all the key stakeholders.

Ciara Lynch

Ciara Lynch

Chairperson Neuro-Mapping Steering Committee,

HSE Programme Manager, Neurorehabilitation Strategy and Managed Clinical Rehabilitation Network

Acronyms

CHO	Community Health Organisation
CNRT	Community Neuro-Rehabilitation Team
DFI	Disability Federation of Ireland
HSE	Health Service Executive
MCRN	Managed Clinical Rehabilitation Network
NAI	Neurological Alliance of Ireland
NSG	National Neuro-Rehabilitation Steering Group
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organisation

Key messages

The Neuro-Mapping Project is a joint initiative between the Health Service Executive (HSE), Disability Federation of Ireland (DFI) and Neurological Alliance of Ireland (NAI). The overall governance for this project lies with the National Neuro-Rehabilitation Steering Group.

The principal objective of Phase 2 of the Neuro-Mapping Project was to engage with people with neuro-rehabilitative needs and service providers to establish the 'as is' picture of community Neuro-Rehabilitation services in Ireland.

These engagement sessions took place across three representative locations (CHO 2,3 and 6), with 56 people with neurological conditions participating, in addition to 137 service providers sending responses to a pre-cursor questionnaire and 106 service providers attending online sessions.

Engagement sessions with people with neuro-rehabilitative needs highlighted the current lack of specialist services available in the community, the complexity of navigating services in the community, current gaps in the provision of long-term care for people with neuro-rehabilitative needs, the obstacles encountered by individuals when trying to access services, and the value and importance of social support.

The feedback from people with neuro-rehabilitative needs was mirrored by the service providers who also emphasised the current underinvestment in the development of specialist services, the challenges of transitioning between services and the inequitable access to services for people with neuro-rehabilitative needs.

Through engagement with key stakeholders, five key areas for improvement have been identified that would enhance 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 enhancements to how information is gathered and shared between services, to enable a more seamless service-user journey.
3. Providing equitable 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 to people with neuro-rehabilitative needs.
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.

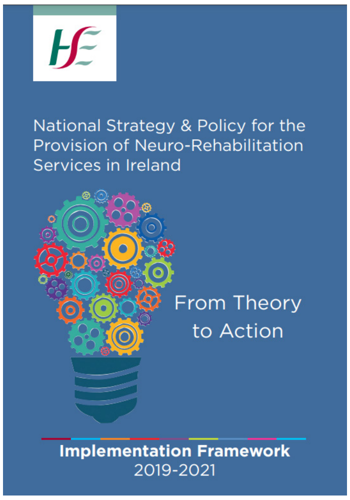
Specific recommendations relating to each area are presented in Chapter 8.
The recommendations of this report will be developed into actionable objectives in the workplan of the National Neuro-Rehabilitation Steering Group and the Community Workstream.

A similar project will be undertaken in three years' time to examine what progress has been made in the field of community Neuro-Rehabilitation service provision.

1. Introduction

1.1 Context

There are approximately 860,000 people with neurological conditions living in Ireland, the vast majority of whom live in the community. While most of these people will at some point need access to specialist inpatient or acute services, they will spend their time predominantly in the community. As they seek to retain their independence for as long as possible, many people with neurological conditions rely on a range of services to maintain function and have a good quality of life.



National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland

From Theory to Action

Implementation Framework
2019-2021

Neuro-Rehabilitation is 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[1]. The landscape of Neuro-Rehabilitation service provision in Ireland is evolving with the Health Service Executive (HSE) leading on the implementation of the recommendations of the 'National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011-2015'[1]. In 2017, the National Neuro-Rehabilitation Steering Group, a multistakeholder group within the HSE, was established to develop an implementation plan and oversee the implementation of the National Neuro-Rehabilitation Strategy. Following this, in February 2019, the 'National Strategy and Policy for the Provision of Neuro-Rehabilitation Services in Ireland – Implementation Framework'[2] was published. It highlights that Neuro-Rehabilitation services in Ireland:

- Are inconsistent and underdeveloped
- Have long-waiting times and limited access
- Lead to delayed discharges from acute care and poor patient outcomes

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)[3] recognises the right of persons with disabilities to services that enable them to attain and maintain maximum independence, ability and participation. Furthermore, the World Health Organisation (WHO) Rehabilitation 2030 Initiative[4] emphasises that rehabilitation is an essential health service that should be available for all the population throughout the life course. The overarching aim of the Strategy is the development of Neuro-Rehabilitation services to improve outcomes for people by providing safe, high-quality, person-centred Neuro-Rehabilitation at the lowest appropriate level of complexity. This must be integrated across the health and social care pathway and provided as close to home as possible. These services are to be configured into population based Managed Clinical Rehabilitation Networks (MCRNs). The new model would see the introduction of a multi-tiered system, with access to services based on clinically assessed need. Services would work together across organisational boundaries with people moving across the continuum of care seamlessly based on their needs. The MCRN model consists of a multi-tiered system of Neuro-Rehabilitation services. A core element of this system is the development of Community Neuro-Rehabilitation Teams (CNRTs); multidisciplinary teams delivering a short period of intensive Neuro-Rehabilitation in the community. The National Neuro-Rehabilitation Steering Group recognise that for the majority of those with neuro-rehabilitative needs, the time in which they are engaged with network services is minimal when compared to their lifespan living in the community. There is an awareness that the Implementation Framework and Strategy itself are relatively vague on the integration of MCRN services with existing Neuro-Rehabilitation service provision in the community.

To address this, the National Neuro-Rehabilitation Steering Group have established a Community Workstream that is tasked with further exploring how MCRN services can integrate and align with all existing community Neuro-Rehabilitation services to ensure a streamlined service-user journey. To progress the work of the Community Workstream, an understanding of existing community service protocols and service-user pathways is urgently required to optimise integration and flow between the existing and developing services and, most importantly, the experience of people with neuro-rehabilitative needs and their families as they navigate the services.

1.2 The Neuro-Mapping Project

This is a joint project between the Disability Federation of Ireland (DFI), the Neurological Alliance of Ireland (NAI) and the HSE. Phase 1 of this project was launched in March 2023 and looked at the breadth of voluntary organisation service provision and creating a common language for service provision through the development of a service mapping template[5].


Neuro-Mapping Project
Service Mapping Template 2023

Phase 2 of the Neuro-Mapping Project builds on the report and outputs of Phase 1. This phase aims to further understand current service and support pathways that occur between existing and developing community services for those with neuro-rehabilitative needs through engagement with the people who use these services and service providers. The outputs of this project, with projected completion in Quarter 4 2024, will inform the work of the Community Workstream of the National Neuro-Rehabilitation Strategy Steering Group, to enhance integration between MCRN services, including the new CNRTs, and statutory and non-statutory providers in the community for the benefit of people with neuro-rehabilitative needs.

2. Governance

2.1 Introduction

This chapter provides an outline of the governance structure for this project. Additionally, an overview of the project scope and primary aim and objectives is detailed. Lastly, a summary of the outputs from Phase 2 of the Neuro-Mapping Project is presented.

2.2 Project management and project governance

The overall project oversight includes:

- National Neuro-Rehabilitation Strategy Steering Group hold the overall governance for this project.
- Project Partners: Health Service Executive (HSE), Disability Federation of Ireland (DFI), Neurological Alliance of Ireland (NAI) (see Appendix 1)
- Neuro-Mapping Project Steering Group: HSE, DFI, NAI, service-user representatives, voluntary organisation representatives, nominee from National Neuro-Rehabilitation Strategy Steering Group (see Appendix 1)

The Terms of Reference of the Project Steering Group are detailed in Appendix 1.

2.3 Project scope

The scope of Phase 2 of the Neuro-Mapping Project focused specifically on community Neuro-Rehabilitation services for individuals with a neurological condition aged 18 years and over. These services are neuro-specific or support individuals with a specific neuro-rehabilitative need. Inpatient services and services for those aged under 18 years of age were out of scope for Phase 2.

2.4 Project aim

The aim of this project was to further understand current service/support pathways, between existing and developing statutory and voluntary community services for people with neuro-rehabilitative needs in selected Community Health Organisation (CHO) areas. This will support the work of the Community Workstream of the Neuro-Rehabilitation Strategy.

2.4.1 Project objectives

The primary objectives of this project were as follows:

1. To carry out an engagement exercise with a representative sample of statutory service providers to ensure that the terminology utilised in the Service Mapping Template is reflective of their service provision.
2. To conduct consultation sessions with a representative sample of people living with neurological conditions in the community in CHO areas 2, 3 and 6, to capture their experience of navigating services and identify challenges and enablers from their perspective.
3. To complete a comprehensive engagement exercise with service providers in CHO areas 2, 3 and 6 in order to increase understanding of the existing and potential service pathways in the community between voluntary and statutory services.
4. To conduct an engagement exercise to address the feasibility of using a common set of terminology across community services that can be used in the design of future service frameworks, pathways of care, needs assessments, referral processes and guidance for service-users.

2.5 Project outputs

The outputs of this project include:

1. An updated Service Mapping Template.
2. A report on the findings from engagement sessions with people with neuro-rehabilitative needs and service providers.
3. An overview of the feasibility of using a common set of terminology across community services.

3. Objectives 1 and 4 – Service Mapping Template

3.1 Introduction

The Service Mapping Template was developed in Phase 1 of the Neuro-Mapping Project to capture the breadth of services available from voluntary providers in the community. Prior to the development of the Service Mapping Template, there was no framework for capturing the range and scale of services in the community for people with neurological conditions. The lack of consistency in use of a common set of terminology for services resulted in challenges with signposting and capturing what services are available. The existing Service Mapping Template reflects all the service types provided by voluntary organisations in the community to people with neurological conditions and their families, not just those specific to Neuro-Rehabilitation. The Service Mapping Template comprises of 10 categories and 98 service types.

Neuro-Mapping Project

Service Mapping Template 2023

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Categories in Service Mapping Template

Category	Definition
1. Assessment and Planning	Services which include formal and informal assessments, or the development of individual service or person-centred plans.
2. Therapeutic and Clinical Supports	Service interventions to improve health or reduce disability, whether from a healthcare professional, allied health professional or other qualified professional.
3. Supported Living/ Accommodation Support	Services offering places to live or that help to promote and maintain independent living.
4. Respite	Services which provide a break from normal routine to reduce stress for the person or family member.
5. Accessibility Supports, Activities of Daily Living and Long-term supports	Services which provide a break from normal routine to reduce stress for the person or family member.
6. Community Integration and Participation	Services which reduce the barriers to participating in a person's local community or maximise involvement in local community life.
7. Vocational/ Employment/ Training/ Rehabilitave Supports	Services which help a person access, or retain employment, further education or training or other meaningful occupation e.g. volunteering
8. Information, Advocacy and Education	Formal or informal provision of relevant information, education, or representation to assist a person excercise their rights.
9. Family and Caregiver Supports	Services which enable family members or caregivers to adjust to a person's situation or that reduce the burden of care.
10. Co-ordination and Point of Contact	Services which assist in the coordination of other services for a person or assist a person to communicate with a service provider.

Example of Service Types in Service Mapping Template

2. Therapeutic and Clinical Supports
a) Specialist Nurse (condition specific)
b) Sepcialist Nurse-Led Helpline
c) Palliative Care Nursing
d) Mental Health Nurse
e) Nurse (other than listed above)
f) Physiotherapy
g) Speech and Language Therapy
h) Occupational Therapy
i) Dietician Services
j) Neuropsychological Therapy
k) Social Work
l) Counselling and Psycotherapy
m) Cognitive Rehabilitation
n) Specialist Excercise Programmes
o) Community Rehabilitation
p) Continence Service
q) Group-Excercise Programmes in the Community
r) Provision of Complimentary Therapies
s) Music Therapy, Art Therapy, Horticultural Therapy, Drama Therapy

Standardisation of terminology will help inform and guide the development of service directories, facilitating signposting of available services. Consequently, there were two key actions in Phase 2 of the Neuro-Mapping Project relating to the Service Mapping Template; updating the Service Mapping Template with statutory service providers to ensure that the terminology used is also reflective of their service provision and to explore ways to assimilate the language used in the Service Mapping Template into future frameworks.

The methods and findings relating to these objectives are outlined in the below sections.

3.2 Updating the Service Mapping Template

The existing Service Mapping Template relates solely to voluntary organisation service provision in the community for individuals with neurological conditions under the age of 65. The below sections outline the methods and findings of an exercise undertaken with statutory service providers to update the Service Mapping Template.

3.2.1 Approach

A representative sample of statutory service providers, working across a range of settings and disciplines, were contacted and asked to review the Service Mapping Template to identify if any additional categories or service types should be included to reflect statutory service provision.

3.2.2 Findings

No additional categories or service types relevant to statutory service provision were identified by participants, suggesting that the existing Service Mapping Template includes a comprehensive list of services available from statutory and voluntary organisations to individuals with neurological conditions living in the community.

3.3 Assimilation of the Service Mapping Template into future frameworks

Following the update to the Service Mapping Template, an engagement exercise was carried out with key stakeholders to address the feasibility of using a common set of terminology across community services that can be used in the design of future service frameworks, pathways of care, needs assessments, referral processes and guidance for individuals with neurological conditions.

3.3.1 Approach

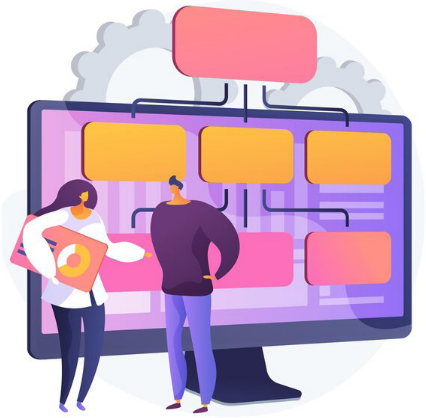
An online engagement exercise was completed with the Community Workstream of the National Neuro-Rehabilitation Strategy Steering Group. This group was selected as it consists of key stakeholders, including representatives from statutory and community-based disability organisations, in addition to individuals with a neurological diagnosis who are representatives of the lived experience. Firstly, a copy of the Service Mapping Template was sent to members of the Community Workstream along with a questionnaire on potential uses of the Service Mapping Template and potential barriers to its uptake. The responses to this formed the basis of the discussion during an online engagement session completed with the Community Workstream in September 2024.

3.3.2 Findings

The general consensus from members of the Community Workstream was that the Service Mapping Template could be a useful resource and could have a range of potential applications, particularly in relation to increasing knowledge of services. Many expressed that the Service Mapping Template would be useful for signposting of services and also to highlight what services are/are not available in certain areas. Additionally, some individuals stated that the Service Mapping Template could form the basis for a detailed taxonomy of services available to people with neurological conditions living in the community. There was some discussion among attendees as to whether the Service Mapping Template should be more specific, showing specialist versus general services and services based on type of neurological diagnosis. Some individuals felt that having a more detailed/specific breakdown would help with navigating services and that it would be important in highlighting the level of specialism of services available. Others believed that the Service Mapping Template should remain in its current generalist form so that it covers a broader range of service provision. It was also stated that outlining services for specific neurological diagnoses would lean back into the condition-specific model of care. In any case, it was noted that language and accessibility are important and could be reviewed prior to further rollout of the Service Mapping Template. For example, it was stated that service types could be interpreted differently by individuals using the Service Mapping Template and it was suggested that having further explanations of some of the terminology would be useful. In a similar vein, it was emphasised that as other mapping exercises are being conducted for disability services, it is important that they are completed in tandem to ensure cohesion and consistency in language. Lastly, those in attendance at the meeting suggested that it was important that the future use and implementation of the Service Mapping Template should align with the restructuring of the HSE.

3.4 Summary

Engagement with key stakeholders has highlighted that the Service Mapping Template established during Phase 1 of the Neuro-Mapping Project represents a comprehensive list of community-based services available to individuals with neurological conditions living across Ireland. The standardisation of terminology was viewed as a positive step towards enhancing knowledge of available services for service providers and people with neurological conditions. Future implementation of the Service Mapping Template is not restricted to one particular use; as the current version would be helpful for signposting for generalist services, while a further detailed iteration of the Service Mapping Template could be used to form the basis of a complete taxonomy of services. However, some minor editing to enhance the accessibility and clarify the language used in the Service Mapping Template would facilitate its application, and support alignment and cohesion with terminology used in other relevant mapping exercises.



4. Approach for Objectives 2 and 3

4.1 Introduction

To enhance understanding of the current landscape of community Neuro-Rehabilitation service provision, key actions of this project included briefing sessions for service providers, consultation sessions with adults with neuro-rehabilitative needs and consultation sessions with service providers whose services contribute to the neuro-rehabilitative needs of adults with neurological conditions. Participatory health research involves *"doing research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them"*[6]. Participatory health research has been shown to improve the design of health services so that they meet the needs and priorities of individuals accessing the services[7]. Consequently, the development of the methodology for this project was an iterative process underpinned by the principles of participatory health research, with input from key stakeholders, including service-users, on the Neuro-Mapping Project Steering Group shaping decision-making at all stages.

The following sections outline the methodology at each stage of the process.

4.2 Community Health Organisation (CHO) selection

In order to get a diverse picture of community services across the country it was suggested that the following should be sought:

- An area with an existing Community Neuro-Rehabilitation Team (CNRT)
- A demonstrator site (a CHO area that was selected to pilot the development of a Managed Clinical Rehabilitation Network (MCRN))
- A more rural area that also represents geographical spread

Consequently, CHOs 2, 3 and 6 were selected to be included in Phase 2 of the Neuro-Mapping Project.

4.3 Consultation sessions with people with neuro-rehabilitative needs

Two online briefing sessions were held in each participating CHO to increase awareness about Phase 2 of the Neuro-Mapping Project. Following these, details about the project were communicated to key stakeholders (statutory and voluntary) in each CHO and they were asked to share information leaflets with people with neuro-rehabilitative needs and invite them to participate. To maximise inclusivity and accessibility, people with neuro-rehabilitative needs were offered the opportunity to participate in the project through a variety of means including in-person, online, via email or by phone. In total, 56 people with neuro-rehabilitative needs participated across the three CHOs. For a more detailed breakdown of participants from each CHO, please see Appendices 2-4.

30 in-person

17 online

5 via email

4 via phone

27 males
29 females

The neurological diagnoses of participants included:

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

4.4 Consultation with service providers

Once the sessions with people with neuro-rehabilitative needs had been completed, two online consultation sessions with service providers were organised in each of the CHOs, one for staff providing community Neuro-Rehabilitation services to adults with acute onset neurological conditions and one for staff providing community Neuro-Rehabilitation services to adults with progressive neurological conditions. Snowball sampling techniques were used to enhance recruitment for these sessions with key stakeholders (statutory and voluntary) in each CHO contacted and asked to share information regarding the consultation sessions widely with relevant service providers. As part of the registration process for these sessions, service providers were asked to complete a precursor questionnaire. The feedback from people with neuro-rehabilitative needs and from the questionnaire were used to structure the discussion for the service-provider sessions. Participation of HSE service providers was greater than that of voluntary organisation service providers despite recruiting through relevant and appropriate communication channels. For a more detailed breakdown of participants from each CHO, please see Appendices 2-4.

Methods of service-provider participation

Precursor questionnaire from staff providing community Neuro-Rehabilitation services to adults with **acute onset** neurological conditions:

12 voluntary service providers

58 HSE service providers

Precursor questionnaire from staff providing community Neuro-Rehabilitation services to adults with **progressive** neurological conditions:

15 voluntary service providers

52 HSE service providers

Online consultation sessions with staff providing community Neuro-Rehabilitation services to adults with **acute onset** neurological conditions:

13 voluntary service providers

54 HSE service providers

Online consultation sessions with staff providing community Neuro-Rehabilitation services to adults with **progressive** neurological conditions:

12 voluntary service providers

27 HSE service providers

5. Feedback from consultation sessions (Objectives 2 and 3)

5.1 Introduction

Consultation sessions with people with neuro-rehabilitative needs and service providers across Community Health Organisations (CHOs) 2, 3 and 6 were completed between January and May 2024. This chapter provides a summary of key themes arising from these consultation sessions, in addition to suggestions from people with neuro-rehabilitative needs and service providers on how community Neuro-Rehabilitation services could be improved.

5.2 People with neuro-rehabilitative needs

This section provides an overview of the combined feedback from people with neuro-rehabilitative needs in CHOs 2,3 and 6 regarding their experiences of accessing community Neuro-Rehabilitation services. A summary of feedback specific to each of these three CHOs is available in Appendices 2-4.

5.2.1 Lack of dedicated specialist services

The overwhelming opinion of participants was that there are insufficient specialist neuro-rehabilitative services available in the community, with many individuals describing a complete absence of services in their locality. In the absence of specialist services, participants attended generalist services that did not have the knowledge to meet their needs or paid to access private services. Participants stressed that attending private services is expensive, particularly for individuals who had had a change to their financial circumstances following their neurological diagnosis. Furthermore, individuals were frustrated with the lack of expertise and were fearful that the non-specialist services could cause a regression. In particular, participants emphasised the importance of and need for increased access to specialist neuropsychology and physiotherapy. A minority of participants described some positive experiences that they had had attending specialist services; however, it was also noted that these were only provided for short durations.

> “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.”

> “I stopped walking as I was embarrassed of my gait. It looked like I was drunk. I was sent to physio that didn’t know anything about brain injury. That put me backwards.”

5.2.2 Complexity of navigating services alone

Many individuals expressed feelings of loneliness, abandonment and frustration following discharge from acute/in-patient services. The drop off in service provision left individuals concerned about the possibility of regressing and overwhelmed at the prospect of identifying relevant services themselves. Participants found it very challenging to identify relevant community services, most often because they were not aware of what services were available and what services they needed. They described an absence of a focal point where they could get person-centred information regarding services. Participants felt strongly that the burden of finding and accessing services was left to the individual or their family members and believed that if they did not identify and ask for services that they would not be offered to them.

> “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.”

> “There are no services offered. It’s only because I ask and I complain, they throw you out a little physiotherapy or something.”

5.2.3 Gaps in long-term continuity of care

Participants described an absence of long-term supports, particularly in relation to functional ability and psychological health, with individuals often stating that there was not enough emphasis on rehabilitation in their long-term management plan. When participants did get access to services, they believed that these had a short-term focus as there was no follow-up after completing the intervention block. Many participants felt that they would have benefited from additional input and highlighted current issues with long-term provision of community Neuro-Rehabilitation services given that they would be living with their disability for the rest of their lives and would need ongoing review from specialists throughout their life cycle. Participants also reflected that in their experience services work in silos. As a result of this, they felt that health care professionals are not aware of services that are available to support the long-term management of their 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.”

> “As soon as you do the course, there is never any follow-up. There is no one picking up the phone. I feel very lost in the public system. It would be great if they could follow-up and check in.”

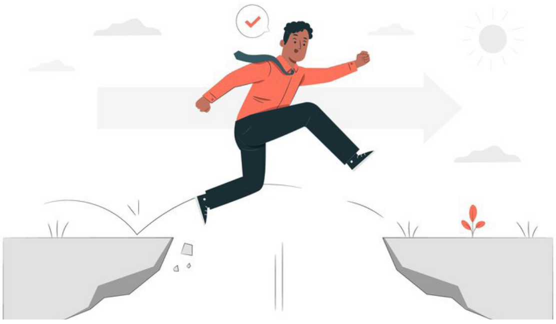
5.2.4 Obstacles to accessing services

In cases where services were available, it was highlighted how the services were very limited/stretched with large caseloads and large waiting lists. Many individuals felt that they were deteriorating while waiting for services and stressed how they would benefit from earlier and ongoing intervention. Due to these waiting lists and service capacity restrictions, participants also described how they often have to fight and battle to get access to services. Participants reported that they are made to feel helpless, like they are begging and like they should be grateful for bad services. The challenge of physically attending services was highlighted by some participants who, for reasons such as mobility impairments, lack of transport, or distance from service, were unable to attend in-person services. While some participants reported tele-rehabilitation services as being beneficial, those who were unable to attend in-person services felt that they were insufficient to fully meet their needs. Participants often emphasised that issues appeared to be at the system level rather than the individual level and reported that they could sense the frustration experienced by staff about the inadequacies of the service.

> “…you have to be your own advocate. I have to bully, push, annoy to try to prioritise my situation which I think is awful”

> “My doctor puts me into a system, onto a database, two years later you hear you are currently on a waiting list… do they think a miracle has happened? And they ask me to contact them if I still want the service. The more I have the disease the more I am regressing without this treatment. Then I get so annoyed. It’s an insult.”

> “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.”

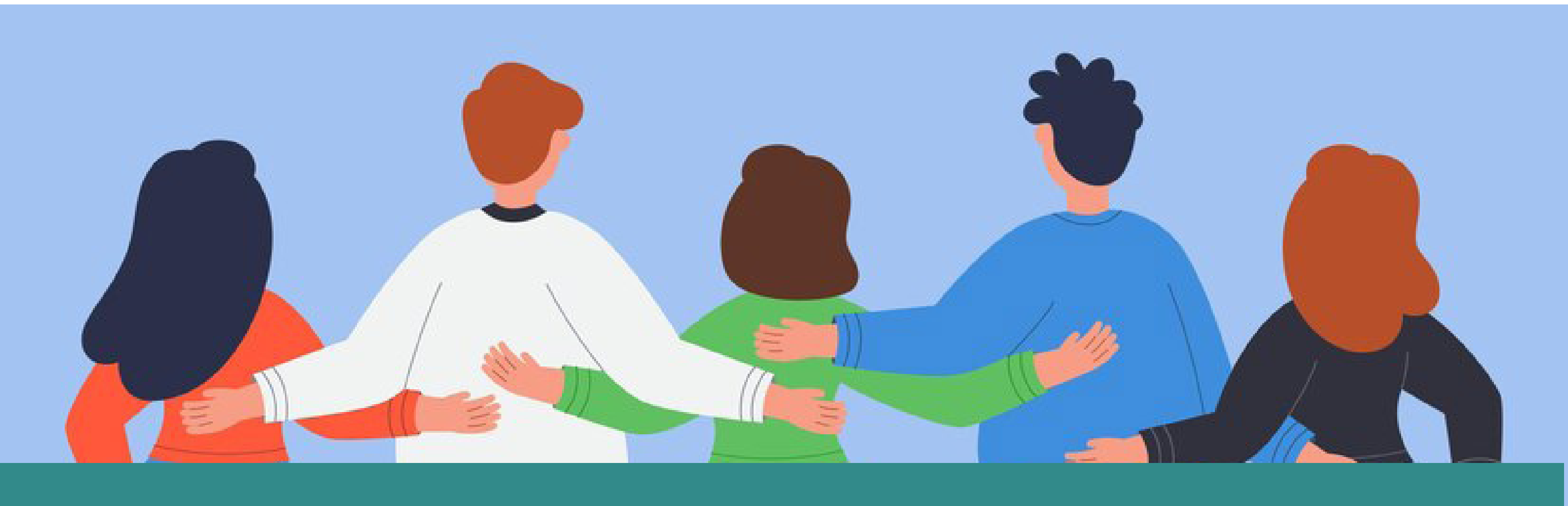


5.2.5 Value of support network and social connections

A support network was viewed as a key component in gaining access to neuro-rehabilitative services, with family members and carers often identifying potentially relevant services and advocating for the individual to gain access to them. An opportunity to meet and converse with individuals who had had a similar experience was also viewed as an important part of the service-user journey. Despite this, participants did not believe that group-based programmes were always the most appropriate, with some individuals stating that they would benefit greater from more one-to-one and person-centred intervention.

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

> “...it is ok to an extent but it does not work for me because they have to manage the session for the group, not the individual. I need more one on one stuff.”



5.3 Service providers

This section provides an overview of the combined feedback from service providers in CHOs 2,3 and 6 regarding their experiences of the current landscape of community Neuro-Rehabilitation services. A summary of feedback specific to each of these three CHOs is available in Appendices 2-4.

As part of the registration process for sessions, service providers were asked about factors influencing the service-user journey of accessing community Neuro-Rehabilitation services and these were then discussed in greater detail during the sessions. The primary themes discussed by service providers are highlighted below.

5.3.1 Inadequate investment in development of services

Service providers were frustrated with the negative impacts of under-staffed and under-resourced services, resulting in long waiting lists and limited multi-disciplinary team working. In addition to the consequences for service-users, it was also highlighted that the strain on services and lack of support is causing high rates of burnout among service providers, leading to the loss of highly trained and experienced staff members

> “The big elephant in the room is the recruitment embargo that has been going on for the last while and seems to be never ending and how that has just decimated staff that we already had and then has certainly led to further burnout of staff that we have managed to hold on to, but really has, you know, prevented an influx of new staff and possibly maintenance of really experienced quality, like long standing staff”

> “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”

Service providers stressed that there are insufficient specialist services in the community to meet the rehabilitative needs of adults with neurological conditions. Most often, service-users are referred to primary care, but it was stated that this a generalist service with a large and varied caseload, where many clinicians do not have the, experience or training to manage the higher rehabilitative needs of people with neurological conditions. It was also noted that the approach to service delivery is not standardised across primary care networks, resulting in disparities in the service-user journey and experience.

> 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.

> You see everything and anything and you see them briefly and then they move on to whatever is next. You wouldn't expect a general practitioner to do brain surgery. It's not fair to expect, you know, your generic primary care physio to do a complex I don't know standing assessment for somebody with you know who's gone, gone off their feet. They need a sleep system. They need all the standing frames. You know, they have the psychological impact of losing that independence, that's not for primary care.

5.3.2 Challenges transitioning between services

Service providers felt strongly that the lack of knowledge of available services in the area among service providers and service-users was a barrier to individuals accessing relevant and appropriate services in a timely manner. Service providers reported that organisations are most often working in silos with a lack of joined up thinking across services, impacting on continuity of care across sectors. This is further compounded by high staff turnover and time constraints of staff to assimilate this information. In the absence of a central directory of services, service providers noted that they themselves were unsure of all the services in the area despite in some cases having worked in that area for many years. As a result, service providers were not surprised that service-users found navigating services challenging, but expressed particular concern for individuals who have communication and/or cognitive impairments trying to identify and access relevant services by themselves.

> 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.

> There are so many different people that they could benefit from. There's no kind of one stop shop where one person coordinates all of that for them. Do they have to make contact with all of these different people?

Service providers also reported that challenges with referral processes impact access to services. Issues with inefficient referral methods including multiple different forms, long-winded forms and having to identify the relevant catchment area were seen as a deterrent due to the time commitment, resulting in delayed or missed referrals. Service providers also noted that inappropriate referrals or inaccurate information increase the time spent on administrative tasks rather than therapy provision. The impact of the lack of technology was also highlighted, with service providers stating that service-user notes are stored in hard copies, and so, the physical notes are often gone from the service-provider when they are trying to collect additional information for referrals.

> “it’s just such a complicated process to make a referral for somebody within the community, you know, you could spend days chasing a phone number to find out who to send the referral form to, what’s the appropriate referral form.”

> “once you have sent that initial referral, their notes are gone and the lack of technology infrastructure is very clear there. So, their notes are gone, their physical notes are gone from you, you don’t have access to that information without quite a bit of work so that certainly makes ongoing referrals quite difficult or going and getting that extra information quite difficult.”

5.3.3 Inequitable access to services

Service providers noted the impact of availability of transport and a support network on access to services. It was reported that this holds particularly true for individuals living in more rural/isolated areas and those with more significant impairments when attending in-person services. Factors such as age and home location were also highlighted as influencing access to and availability of services. Service providers noted that the neuro-rehabilitative needs of individuals aged over 65 years are largely underserved as they do not qualify for specialist services. Moreover, it was highlighted that home location is an access criterion for some services, with individuals outside of a specific catchment area not entitled to avail of the service.

> “it’s sort of like geographic based and all that, but it continues to be a really big challenge and I suppose I have some families that just financially to actually be paying for taxis from rural areas…there’s a lot of rural isolation and a lack of access to transport to get to services.”

> “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”

Service providers also stated that access to services is often based on neurological diagnosis. Service providers reported that type of neurological diagnosis is often an access criterion for services and, resultantly, individuals are unable to avail of services despite having a rehabilitative need for it.

> "I would have patients just sitting on my caseload that you know clinically would fit the need, but they can't access it because of their diagnosis. So just that kind of disparity and being able to access these services."

> "It's not across for everybody, but it's like there's really good work happening for some clients and yeah, not for everyone yet."

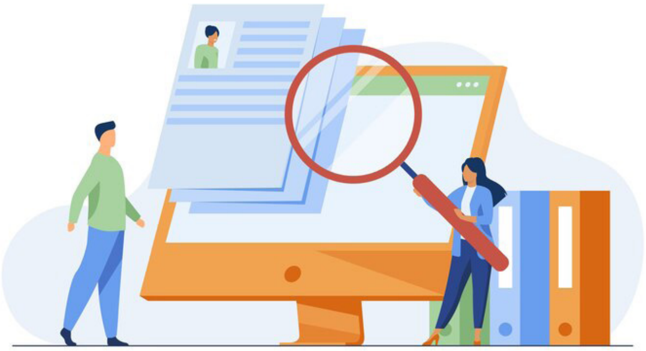
5.4 Suggestions for the future:

As part of the engagement with people with neuro-rehabilitative needs and service providers, many suggestions were made as to what would help address barriers and improve services.

The main suggestions are listed below:

- The primary point highlighted across all consultation sessions was the need for **more specialist services to be available in the community** that would respond to the specific neuro-rehabilitative needs of this population. This was furthered by strong recommendations from service providers regarding the need to **adequately resource and staff services** so that they can provide timely and high-quality interventions to people with neuro-rehabilitative needs.
- To address the current difficulties encountered by people with neuro-rehabilitative needs with regard to navigating services, it was stressed that that there is a need for **increased signposting of services** that are available within the community. It was also noted that **enhanced liaison between disciplines and services**, in addition to the **availability of a care coordinator or key worker**, would help facilitate the service-user journey along the continuum of care. **Enhanced information technology systems** such as centralised assessments, outcomes and referral methods, as well as standardised assessments were also proposed as an option to facilitate integration of community services.
- Given the chronic nature of many neurological conditions, it was suggested that services would provide a **follow-up post-discharge** and facilitate **easier re-entry options**. An additional suggestion was to consider the **introduction of maintenance groups and programmes** to provide a more long-term input option, along with opportunities for peer support.
- To ensure **equitable access to services based on neuro-rehabilitative needs**, it was proposed that restrictive access criteria such as age and neurological diagnosis should be removed.
- It was noted that individual preference and need is varied; therefore, it was suggested that services should provide a range of **home-based, clinic-based and tele-rehabilitation options**, as well as **local rehabilitation and satellite clinics**.
- It was highlighted that the current primary care model of service did not meet the needs of adults with neuro-rehabilitative needs; thus, from a structural perspective, service providers reflected on the possible value of using the learnings from the development of Children Disability Network Teams to establish a model of service structured around **adult disability network teams** or the establishment of **clinical specialist posts** in the community.

6. Discussion of findings



As previously described, Community Health Organisations (CHOs) 2,3 and 6 were selected for this project as they were considered to be broadly representative of the national picture. While some points were raised more frequently in certain CHO areas, for example, given the geographic spread of CHO 2, barriers to accessing services such as transport and living location were cited more frequently; overall, this project identified relatively consistent findings across the selected CHOs. As the analysis of the data collected from people with neuro-rehabilitative needs and service providers did not result in the identification of any themes that were specific to individual CHOs, this suggests that the findings and recommendations arising from this project are likely to be applicable to all nine CHO areas.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)[3] and the World Health Organisation (WHO) Rehabilitation 2030 Initiative[4] highlight both the right to and importance of access to rehabilitation as an essential health service. However, the primary issue highlighted by both people with neuro-rehabilitative needs and service providers across all engagement sessions is the dearth of Neuro-Rehabilitation services currently available in the community. This finding is consistent with those of other research projects, such as a survey undertaken among people with MS[8] and interviews conducted with stroke survivors and carers[9], that also highlighted that existing services do not meet the physical and psychosocial rehabilitative needs of adults with neurological conditions. The HSE National Service Plan 2024[10] and Sláintecare Action Plan 2023[11] both outline the importance of reducing reliance on a hospital-centric model of care and instead increasing capacity in the community. Furthermore, an integral element of the National Neuro-Rehabilitation Strategy Implementation Framework[2] is the development of appropriately resourced inter-disciplinary community-based specialist rehabilitation teams across Ireland. Despite this, the findings of this project demonstrate that the landscape of community Neuro-Rehabilitation remains underdeveloped and underfunded, supporting the need for the ongoing advocacy work of NAI and DFI calling for further investment in Neuro-Rehabilitation services and community health and social care services to support people with neurological conditions to live well in the community.

The current siloed nature of the Neuro-Rehabilitation landscape is apparent from the feedback collated as part of this project. People with neuro-rehabilitative needs and service providers alike noted the current difficulties with trying to navigate access to community Neuro-Rehabilitation services, an issue that is augmented by the lack of a focal point of contact for information, lack of knowledge of what services are available and lack of clarity surrounding referral and discharge processes. A critical component of the Managed Clinical Rehabilitation Networks (MCRN) model is the seamless transition of service-users along the continuum of care, facilitated by appropriate communication and sharing of information between services[2]. This project clearly shows the need for enhanced integration of neuro-rehabilitative services in the community to optimise the progression of individuals along their rehabilitation journey.

This project demonstrates the lack of emphasis on a lifetime approach to disability, with an absence of forward planning for changes in individuals' needs due to ageing and/or progression of neurological conditions. Engagement sessions with people with neuro-rehabilitative needs and service providers have highlighted the predominantly episodic nature of current community Neuro-Rehabilitation services. With the exception of a minority of services, most often provided by voluntary organisations, typically people with neuro-rehabilitative needs were only able to access a service for a set time period before being discharged with no further follow-up. Further consideration of the capability of the current model of service provision to support individuals with chronic neurological conditions to self-manage and optimise health and social outcomes is warranted.

The feedback from people with neuro-rehabilitative needs and service providers shows the lack of standardisation of service provision for adults with neuro-rehabilitative needs across Ireland. A myriad of factors, such as age, living location, neurological diagnosis, availability of services in the area, and knowledge and experience of service providers, have been identified as impacting access to services. This lack of a standardised approach to access and quality of community neuro-rehabilitative services is leading to disparate service-user journeys and experiences. One of the primary principles underpinning the Sláintecare Action Plan[11] and the National Neuro-Rehabilitation Strategy Implementation Framework[2], in addition to the advocacy work of NAI and DFI, is equitable access to services based on need. The findings of this project suggest that changes to access criteria for services are required to achieve the shared vision of the HSE, NAI and DFI.

6.1 Strengths and limitations

This project is the first of its kind to undertake engagment sessions with people with neuro-rehabilitative needs and service providers regarding their experiences of community Neuro-Rehabilitation services in Ireland. This research provides new insights into the current picture of the community Neuro-Rehabilitation in landscape and, importantly, into what improvements could be made to optimise the experiences of those accessing and providing the services. Another clear strength of this research is the application of principles of participatory health research with substantial stakeholder involvement, including individuals with lived experience, throughout all key stages of this project.

In addition to its strengths, some limitations with respect to this project are also acknowledged. While the three included CHOs were selected to provide a broadly representative picture of community Neuro-Rehabilitation across Ireland, it is recognised that the experiences of people with neuro-rehabilitative needs and service providers may be different in other CHOs. A wide range of communication channels were used to recruit people with neuro-rehabilitative needs across the three CHO areas. Despite this, participation levels varied across the three areas. In addition to this, it is also noted that fewer people with neuro-rehabilitative needs opted to participate in the engagement sessions than service providers. Further reflection on how to increase participation of people with neuro-rehabilitative needs across any future similar undertakings is required to ensure that the voice of people with neuro-rehabilitative needs is adequately represented.

7. Conclusion

The purpose of Phase 2 of the Neuro-Mapping Project was to increase understanding of current service and support pathways that occur between existing and developing community services for people with neuro-rehabilitative needs. This was achieved through the delivery of the following outputs: a Service Mapping Template that is representative of statutory and voluntary service provision for people with neurological conditions, a report on the findings from engagement sessions with people with neuro-rehabilitative needs and service providers, and an overview of the feasibility of using a common set of terminology across community services.

Through engagement with key stakeholders, the findings of this project highlight the critical under-investment and under-development of community Neuro-Rehabilitation across Ireland. This has led to worse physical and psychological outcomes for people with neuro-rehabilitative needs, in addition to high-levels of burnout and staff turnover among service providers. The focus of the National Neuro-Rehabilitation Strategy is to achieve the best outcomes for people with neuro-rehabilitative needs by providing safe, high-quality, person-centred care at the lowest appropriate level of complexity. In this respect, the community Neuro-Rehabilitation sector has reached a critical juncture where urgent investment and advancements are required to achieve this vision. Throughout this project, five key areas for improvement have been identified that would enhance the experiences of those accessing and providing these services.

Firstly, it was stressed that there is currently a lack of knowledge among people accessing and providing services alike regarding what community Neuro-Rehabilitation services are available. This was viewed as a major barrier to individuals availing of relevant and appropriate services in a timely manner. It was noted that increased signposting of available services would assist people with neuro-rehabilitative needs, their families and service providers in navigating services. Further development of the Service Mapping Template would facilitate signposting and mapping of services.

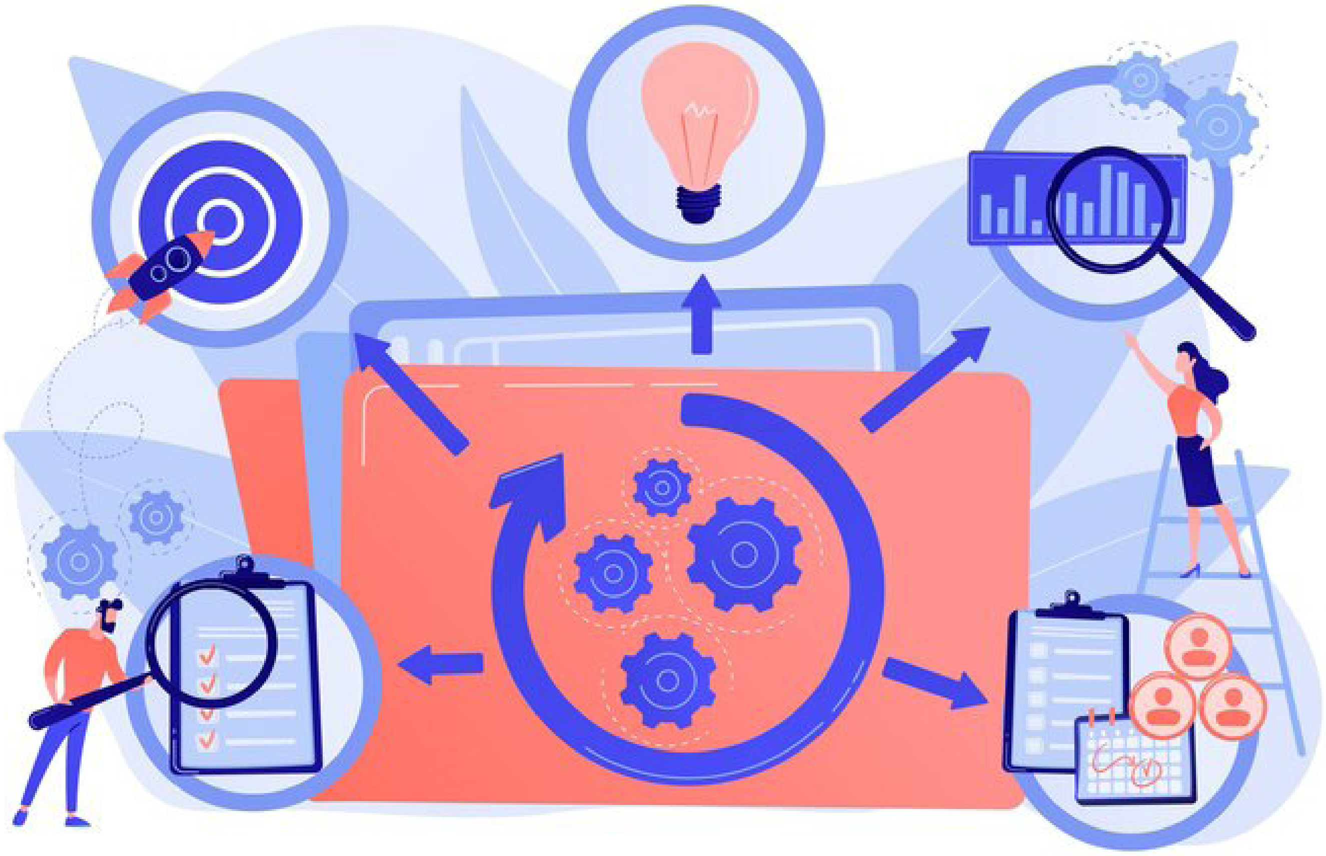
Second, the siloed nature of community Neuro-Rehabilitation service provision was highlighted throughout this project, with many individuals expressing frustration over the lack of infrastructure to support integration of services. It was suggested that enhancements to methods of information sharing between services would facilitate a more seamless transition along the rehabilitation continuum of care.

People with neuro-rehabilitative needs and service providers stated that many services have restrictive access criteria, such as age and diagnosis, that result in inequitable access to services. It was also noted that the preference and needs of individuals vary and, subsequently, services should have rehabilitation options that reflect this.

The critical lack of specialist community Neuro-Rehabilitation services was emphasised by participants across all engagement sessions for this project. This resulted in strong recommendations from service providers regarding the need to adequately resource and staff services so that they can provide timely and high-quality interventions to people with neuro-rehabilitative needs.

Lastly, the ability of the current structure of the community Neuro-Rehabilitation sector to meet the rehabilitative needs of people with neurological conditions was questioned by participants. Some redesign and restructuring of community Neuro-Rehabilitation services was proposed to optimise service delivery and improve outcomes for people with neuro-rehabilitative needs.

Specific recommendations in relation to the above five themes are outlined in the next chapter.



8. Recommendations

8.1 Introduction

The findings from this project resulted in the generation of recommendations for how the community Neuro-Rehabilitation journey can be optimised and streamlined for people with neuro-rehabilitative needs. These recommendations are based on the feedback and suggestions provided by people with neuro-rehabilitative needs and service providers. These recommendations are detailed by theme in the below sections.

8.2 Knowledge of services

One of the key findings of this project was lack of knowledge of services and information on neurological conditions. The following recommendations respond to this gap:

1. A directory of services should be established. This should be an online live/interactive document that can be updated with relevant information so that it does not become out of date and should align with other relevant service directories.
2. Education and information about neurological conditions and services that are available to support rehabilitation should be readily available to people with neurological conditions and their families.
3. People with neuro-rehabilitative needs may not be aware or be in a position to consider the community-based services that they require or would benefit from prior to discharge from an acute admission. An information resource of potentially relevant services, e.g., an information pack, should be sent to individuals a short time after discharge to address this.
4. Engagement with key stakeholders has highlighted that the Service Mapping Template established during Phase 1 of the Neuro-Mapping Project represents a comprehensive list of community-based services available to individuals with neurological conditions living across Ireland. Further development of the Service Mapping Template is required to facilitate signposting and mapping of services, e.g., linking to the first recommendation in the form of a service directory.

8.3 Services working together

It was highlighted by service providers that there is potential for improvements in how information is gathered and shared between services. Recommendations relating to this are as follows:

1. A standardised referral process across Neuro-Rehabilitation services should be developed to reduce time spent on administrative tasks.
2. Standardised and centralised assessments should be introduced so that service providers can track an individual's progress as they transition between services (e.g., inpatient to Community Neuro-Rehabilitation Teams).
3. Increased investment in information technology infrastructure is required to maximise the cross flow of information between services and support the seamless transition of individuals along the continuum of care.

8.4 Access to services based on need

Given the chronic nature of many neurological conditions, it is likely that an individual will require different services at different points in time across their lifespan. The following recommendations relate to this:

1. The delivery of community-based services should be person-centred based on the individual's circumstances, a range of home-based, clinic-based and tele-rehabilitation options, along with satellite rehabilitation clinics should be available.
2. Maintenance groups should be offered to individuals following an intervention block as a more long-term input option to maximise input from specialist services and provide peer-support opportunities.
3. As part of the discharge plan from a service, individuals should receive timely follow-up contact, for example within two months.
4. Access criteria such as age/diagnosis should be removed to ensure equitable access to services.
5. Re-entry pathways for individuals should be part of discharge planning and should not require a new referral.

8.5 Need for specialist services

It was noted that if the current service model was fully resourced and staffed that a more comprehensive and high-quality service would be available. The recommendations in relation to this are as follows:

1. All community services that respond to the rehabilitative needs of people with neurological conditions should be fully staffed and resourced.
2. There should be a full complement of Community Neuro-Rehabilitation Teams in each region and these teams should be fully staffed and resourced as per the recommendations of the National Neuro-Rehabilitation Strategy and model of care for rehabilitation medicine.
3. Each Community Neuro-Rehabilitation Team should have a consultant in Neuro-Rehabilitation medicine as a member of the team.
4. Each region should provide the same standard and range of services.

8.6 Service design to support continuum of care

Planning of future services in the community need to consider the continuum of care for people living with neurological conditions. The following recommendations relate to the design of future services:

1. Establish the role of community rehabilitation coordinator, which would be a focal point of contact for people with neuro-rehabilitative needs/their families to help them navigate and identify relevant services in a defined geographical area. This role could also support complex case management in the community.
2. Clinical specialist posts should be developed in primary care to maximise the benefit of input from specialist teams.
3. Provide comprehensive and integrated access to disability services to adults with neuro-rehabilitative needs, using the learnings from the development of Children Disability Network Teams, e.g., adult disability network teams.
4. A comprehensive accessible transport service should be resourced to support access to services.
5. Provision of Personal Assistance services should be resourced to support access to services and maximise benefit from specialist services.

8.7 Next steps

The recommendations of this report will be developed into actionable objectives in the workplan of the National Neuro-Rehabilitation Steering Group and the Community Workstream under the National Neuro-Rehabilitation Strategy. A similar project, engaging with people with neuro-rehabilitative needs and service providers, will be undertaken in three years' time to examine what progress has been made in the field of community Neuro-Rehabilitation service provision.

9. References

1. National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011-2015, Department of Health and Health Service Executive.

2. National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland Implementation Framework 2019-2021, Health Service Executive.

3. Convention On The Rights Of Persons With Disabilities, United Nations.

4. Rehabilitation 2030 Initiative, World Health Organisation.

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7. Gilfoyle M, MacFarlane A, Hannigan A, Niranjan V, Hughes Z, Salsberg J. (2022) The public and patient involvement imperative in Ireland: Building on policy drivers, Frontiers in Public Health.

8. My MS My Needs Comprehensive survey of the needs of people with MS, MS Ireland.

9. Sexton E, Fowler K, Hickey A, Williams DJ, Horgan F, Byrne E, et al. (2024) Priorities for developing stroke care in Ireland from the perspectives of stroke survivors, family carers and professionals involved in stroke care: A mixed methods study, PLoS ONE.National Service Plan 2024, Health Service Executive.

10. National Service Plan 2024, Health Service Executive

11. Sláintecare Action Plan 2023, Department of Health.

Appendix 1.

A1.1 Neuro-Mapping Project Steering Group

Project Partners	
Ciara Lynch (Chairperson) **Deirdre Murphy (resigned Dec 2024)** **Marie Lynch** **Magdalen Rogers**	**Health Service Executive (HSE)** **Disability Federation of Ireland (DFI)** **Neurological Alliance of Ireland (NAI)**
Steering Group Members	
Caitriona Coen HSE CHO 2 **Fearghal Gray HSE CHO 3** **Jenny Neary HSE CHO 6**	**HSE Primary Care and Disability Services representation from CHO areas 2,3 & 6**
Elaine Whelan HSE	**Community Neuro-Rehabilitation Team (CNRT) Representation**
Richard Stables Headway **Dr Susan Coote MS Ireland**	**Voluntary Organisation Representation from CHO areas 2,3 & 6**
Joe Condon EOPD **Dr Rosie Mangan Uni of Stirling**	**Service-User Representation from CHO areas 2,3 & 6**
Dr Nicola O’Malley	**Research Project Officer**

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.

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.

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

A1.2 Neuro-Mapping Project Steering Group Terms of Reference

1. Review and input into project plan and milestones, including methodology.
2. Support identification of project stakeholders including identification of service users for delivery of project objectives 2 & 3.
3. Advice regarding communication strategy.
4. Advise and input into project outputs and support synergies with other relevant work.
5. Support and participate in briefings to relevant stakeholders.
6. Support and advise where challenges relating to project methodology and delivery of outputs have been identified.
7. Steering Group Meetings will be held at least quarterly online.

Appendix 2. Summary of feedback CHO 2

Approach to getting input from people with neuro-rehabilitative needs and service providers in CHO 2

Two online briefing sessions were held to inform service providers in CHO 2 about the Neuro-Mapping Project. Following these, information leaflets were sent to service providers and they were asked to share them with people with neuro-rehabilitative needs. To maximise inclusivity and accessibility, people with neuro-rehabilitative needs were offered the opportunity to participate in the project through a variety of means including in-person, online, via email or by phone. Once the sessions with people with neuro-rehabilitative needs had been completed, two online consultation sessions with service providers in CHO 2 were organised, one for staff providing community Neuro-Rehabilitation services to adults with acute onset neurological conditions and one for staff providing community Neuro-Rehabilitation services to adults with progressive neurological conditions. As part of the registration process for these sessions, service providers were asked to complete a precursor questionnaire. The feedback from people with neuro-rehabilitative needs and from the questionnaire were used to structure the discussion for the service-provider sessions.

People with neuro-rehabilitative needs

- **18 people with neuro-rehabilitative needs from CHO 2** participated

5 in-person

10 online

2 via email

1 via phone

7 males
11 females

- The neurological diagnoses of participants included:
    - traumatic brain injury (n=8)
    - multiple sclerosis (n=6)
    - stroke (n=3)
    - functional neurological disorder (n=2)
    - epilepsy (n=1)
    - rare neurological condition (n=1)
    - spinal cord injury (n=1)

Methods of service-provider participation

Precursor questionnaire from staff providing community neuro-rehabilitation services to adults with **acute onset** neurological conditions:

6 voluntary service providers

27 HSE service providers

Precursor questionnaire from staff providing community neuro-rehabilitation services to adults with **progressive** neurological conditions:

6 voluntary service providers

25 HSE service providers

Online consultation session with staff providing community neuro-rehabilitation services to adults with **acute onset** neurological conditions:

7 voluntary service providers

24 HSE service providers

Online consultation session with staff providing community neuro-rehabilitation services to adults with **progressive** neurological conditions:

3 voluntary service providers

9 HSE service providers

Summary of feedback

Experiences of people with neuro-rehabilitative needs

Lack of dedicated specialist services:

A minority of participants described a positive journey of accessing community Neuro-Rehabilitative services in CHO 2. However, the majority stressed that there was a complete absence of specialist Neuro-Rehabilitation services in their area and did not believe that the general services that they were attending were sufficient to meet their needs. In particular, participants across nearly all sessions emphasised the importance of and need for increased access to specialist neuropsychology and physiotherapy.

> “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.”

> “I was trying to get vestibular physiotherapy; I had two sessions in Galway but the person did not know what to do. I was lost at sea.”

> “I need a neuropsychologist but there is none so I have to get on with it.”

Navigating services alone:

Upon discharge from acute/in-patient services, many participants described a drop off in service provision, leaving individuals feeling concerned about the possibility of regressing and overwhelmed at the prospect of identifying relevant services themselves. Across all sessions, participants described their experiences of the lack of information sharing and the absence of a focal point of contact that they could turn to for guidance.

> “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.”

> “…more communication and joined up thinking to say what is going on. I would like to know what else is going on.”

> “There is a lot of googling…. There is a lack of information sharing.”

Value of support network and social connections:

A support network was viewed as a key component in gaining access to Neuro-Rehabilitation services, with family members and carers often identifying potentially relevant services and advocating for the individual to gain access to them. An opportunity to meet and converse with individuals who had had a similar experience was also viewed as an important part of the service-user journey. Despite this, participants did not believe that group-based programmes were always the most appropriate, with individuals stating that they would benefit greater from more one-to-one and person-centred intervention.

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

> …it is ok to an extent but it does not work for me because they have to manage the session for the group, not the individual. I need more one on one stuff.

> It's a constant battle, only for my wife. There are new things happening me all the time but where do you go, what do you do?

Obstacles to accessing services:

Participants across CHO 2 reported having to travel great distances to attend in-person sessions. When participants were referred for services, they were often faced with long waiting times, with many individuals having to access private services due to this. However, it was stressed that attending private services is expensive, particularly for individuals who had had a change to their financial circumstances following their neurological diagnosis. Due to these waiting lists and service capacity restrictions, participants also described how they often have to fight and battle to get access to services.

> …you have to be your own advocate. I have to bully, push, annoy to try to prioritise my situation which I think is awful

> I think once you have been referred to physiotherapy, occupational therapy and you have a long-term illness, that should be it, you should only need one referral, why do I have to constantly re-establish that I am sick. They are creating bottlenecks in the system because I am not able to re-refer, I have to go back to my doctor and take up their services. Why do we have to go through this continual start, access, stop, reset and so then we don't get that continuity of access to services and so it is detrimental to our condition.

> Me as the service-user, I just need the service, I don't care where the money comes from. If I need a service, I have to be lucky that the budget is there for the service in my locality. You have this postcode lottery, if you happen to be in the right area you get access to services/ devices, if you are not then you don't.

Service-provider experiences

As part of the registration process for sessions, service providers were asked about factors influencing the journey of people accessing community Neuro-Rehabilitation services in CHO 2 and these were then discussed in greater detail during the sessions. The primary factors discussed by service providers are highlighted below:

- Service providers emphasised the negative impact of **under-staffed** and **under-resourced** services in CHO 2, resulting in long **waiting lists** and limited multi-disciplinary team working. In addition to the consequences for service-users, it was also highlighted that the strain on services and lack of support is leading to high rate of burnout among service providers.

> I'm new in post for the last three months and the I suppose the wait, the waiting lists and the wait for patients prior because there was no one necessarily in the post

> if it's only staffed with one therapist in a particular discipline, and that therapist goes off and there's no replacement there and takes nine months to replace, you get this really difficult situation where you will have teams formed with parts of the team and other members not there and I think that's what's making it very difficult for a lot of teams

- Given the geographic spread of CHO 2, service providers noted the impact of availability of **transport** and a **support network** on access to services. It was reported that this holds particularly true for individuals living in more rural/isolated areas and those with more significant impairments when attending in-person services.

> A lot depends on the person in question, what support they have available at home, because what's at home has to make up for what's lacking in the public service. So, if the patient has a really good family support and they tend to do better in terms of because there's some there reinforcing nearly the gaps in service

> it's sort of like geographic based and all that, but it continues to be a really big challenge and I suppose I have some families that just financially to actually be paying for taxis from rural areas…there's a lot of rural isolation and a lack of access to transport to get to services.

- Service providers stressed that there are **insufficient specialist services** in CHO 2 to meet the needs of those accessing services. Service providers stated that there is an absence of dedicated specialist multi-disciplinary teams in the community to meet the rehabilitative needs of people with neurological conditions. It was also noted that the approach to service delivery is not standardised across primary care networks, which was most often influenced by the particular background and experience of the primary care staff, resulting in disparities in the service-user journey and experience.

> “they need that follow-up in terms of return to driving, cognitive rehabilitation, vocational rehabilitation, those real specialist sort of acquired neurological pieces around the occupational therapy process that just unfortunately our community colleagues they just don’t have capacity for, and I suppose there is that element where that sort of specialist training might be lacking as well.”

> “We need more neuro specialist physiotherapists in the community, they are generalised services as of now. There are no diverse neuro-specialist posts and training.”

- Service providers stated that given the volume of organisations and services in the area, there was a **lack of knowledge of services** among service providers and people with neuro-rehabilitative needs preventing timely access to services. It was noted that many services are working in isolation and, resultantly, it was challenging to find links with other services in the area. This is further compounded by high staff turnover and time constraints of staff to assimilate this information.

> “the challenge there is I suppose maybe working in isolation and working in silos, even having your own set of notes and not being able to visually see what physiotherapist, what occupational therapist, what wider team members are working with the same clients, you’re working with and in terms of having to then the admin that creates to try and find those links, especially as a new staff.”

> “it’s an ongoing question being asked of our staff of where to go or who can we go to and I suppose we would be trying to put together a list of all the different resources that are out there that might be available to them, but a lot of the time there’s always kind of that wall of being able to afford it and getting themselves on the waiting list, putting in the referrals”

- Service providers noted that there is inequitable access to services based on neurological diagnosis. Service providers reported that type of **neurological diagnosis** is often an access criterion for services and, resultantly, individuals are unable to avail of services despite having a rehabilitative need for it.

> I would have patients just sitting on my caseload that you know clinically would fit the need, but they can't access it because of their diagnosis. So just that kind of disparity and being able to access these services.

> It's not across for everybody, but it's like there's really good work happening for some clients and yeah, not for everyone yet.

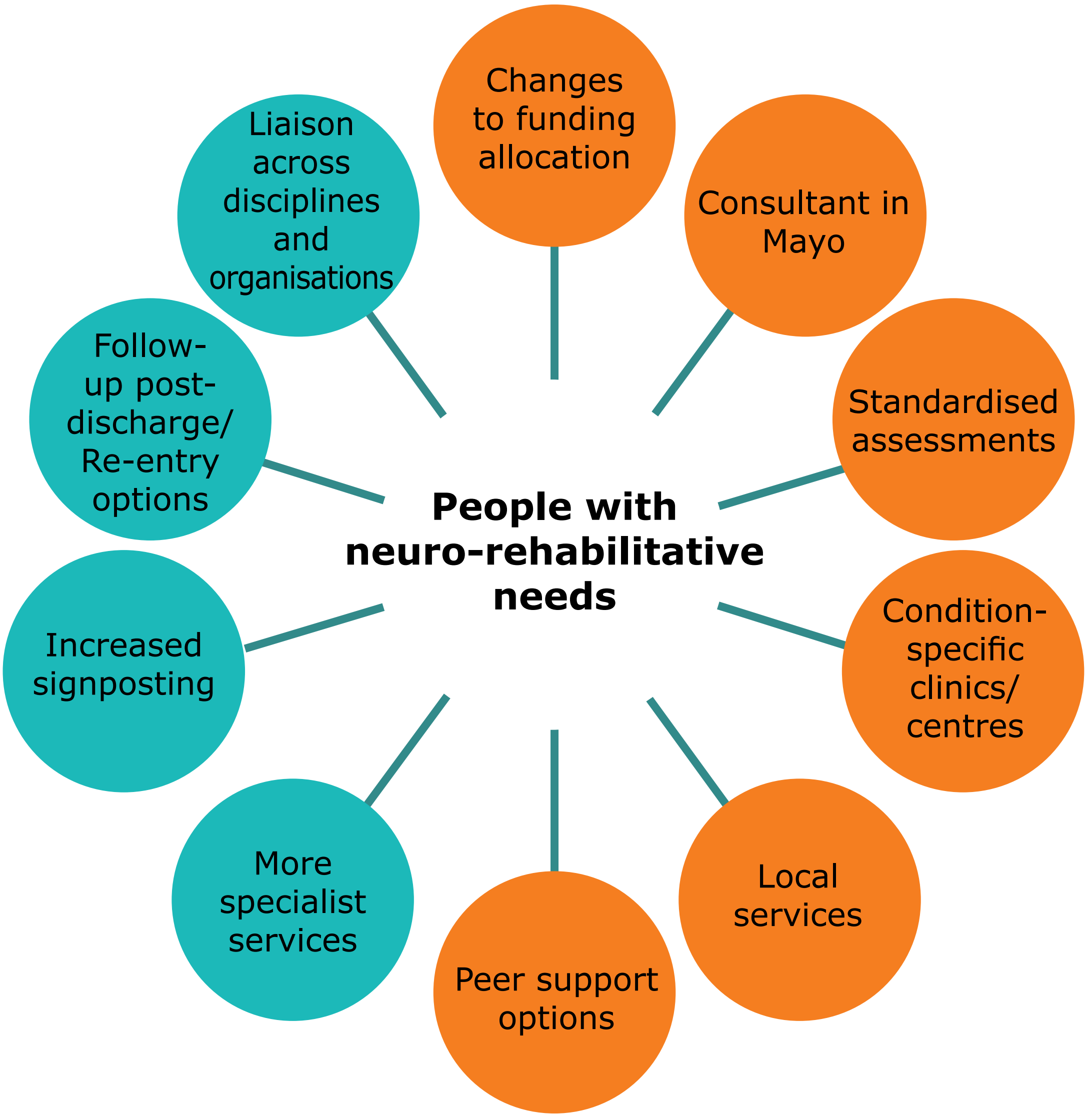
- Service providers also reported that challenges with **referral processes** within CHO 2 impact access to services. Firstly, it was noted that there are multiple different referral forms and processes across different services, making it a time-consuming endeavour to identify the correct one. Second, it was highlighted that the quality of referrals is highly variable and oftentimes service providers have to chase additional information. As notes are stored in hard copies, the notes are often gone from the service-provider when they are trying to collect this information.

> once you have sent that initial referral, their notes are gone and the lack of information technology infrastructure is very clear there. So, their notes are gone, their physical notes are gone from you, you don't have access to that information without quite a bit of work so that certainly makes ongoing referrals quite difficult

> we would find referrals that come on the standardised primary care form, there's a very limited space so people can only fill in whatever they can, whereas any referral that comes as part of a discharge report, so say referrals that would come as part of the National Rehabilitation Hospital discharge, would have far more detailed, far more complex information. It would have the different therapists that had been involved in the care so that's way more beneficial.

Suggestions for the future

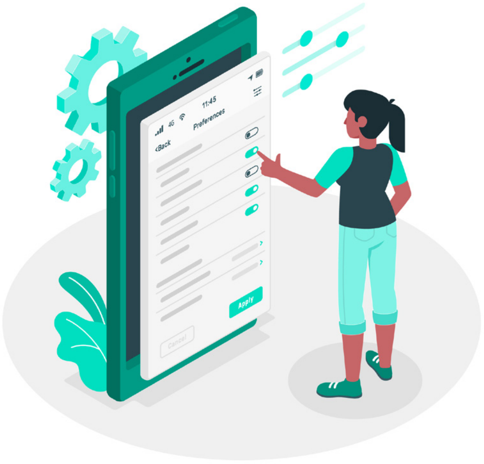
As part of the engagement with people with neuro-rehabilitative needs and service providers, many suggestions were made as to what would help address barriers and improve services. Input from people with neuro-rehabilitative needs and service providers are shown below. There were some common themes put forward and these are highlighted in the blue circles.




Fully staffed and resourced services
Maintenance groups
Needs-based access to services
Case worker
Home-based, clinic-based and tele-rehabilitation options
Care pathways
Adult disability network teams
Improved information technology systems/ infrastructure
More specialist services
Increased signposting
Re-entry options
Liaison across disciplines and organisations
Service providers

Appendix 3. Summary of feedback CHO 3

Approach to getting input from people with neuro-rehabilitative needs and service providers in CHO 3



Two online briefing sessions were held to inform service providers in CHO 3 about the Neuro-Mapping Project. Following these, information leaflets were sent to service providers and they were asked to share them with people with neuro-rehabilitative needs. To maximise inclusivity and accessibility, people with neuro-rehabilitative needs were offered the opportunity to participate in the project through a variety of means including in-person, online, via email or by phone. Once the sessions with people with neuro-rehabilitative needs had been completed, two online consultation sessions with service providers in CHO 3 were organised, one for staff providing community Neuro-Rehabilitation services to adults with acute onset neurological conditions and one for staff providing community Neuro-Rehabilitation services to adults with progressive neurological conditions. As part of the registration process for these sessions, service providers were asked to complete a precursor questionnaire. The feedback from people with neuro-rehabilitative needs and from the questionnaire were used to structure the discussion for the service-provider sessions.

People with neuro-rehabilitative needs

- **25 people with neuro-rehabilitative needs from CHO 3** participated

19 in-person

3 online

3 via email

16 males
9 females

- The neurological diagnoses of participants included:

  - stroke (n=13)
  - traumatic brain injury (n=4)
  - multiple sclerosis (n=3)
  - rare neurological condition (n=1)
  - progressive supranuclear palsy (n=1)
  - epilepsy (n=1)
  - brain aneurysm (n=1)
  - brain tumour (n=1)

Methods of service-provider participation

Precursor questionnaire from staff providing community neuro-rehabilitation services to adults with **acute onset** neurological conditions:

3 voluntary service providers

8 HSE service providers

Precursor questionnaire from staff providing community neuro-rehabilitation services to adults with **progressive** neurological conditions:

6 voluntary service providers

8 HSE service providers

Online consultation session with staff providing community neuro-rehabilitation services to adults with **acute onset** neurological conditions:

2 voluntary service providers

7 HSE service providers

Online consultation session with staff providing community neuro-rehabilitation services to adults with **progressive** neurological conditions:

5 voluntary service providers

8 HSE service providers

Summary of feedback

Experiences of people with neuro-rehabilitative needs

Services are beneficial but there is an absence of long-term continuity of care:

Many participants felt that they would have benefited from additional input and highlighted current issues with long-term provision of community neuro-rehabilitative services given that they would be living with their disability for the rest of their lives and would need ongoing review from specialists throughout their life cycle.

> “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.”

> “Even when you are getting a service the fear is there about what will happen when it stops. It’s not nice being on a limited service. There is uncertainty about what will happen, the time frame for the service there is an anxiety for the future and a fear of deterioration. It’s like a plug being pulled out.”

> “…this progress has sadly regressed due to the lack of services available.”

Expertise is needed but there is an absence of specialised services:

The lack of specialist community neuro-rehabilitative services was a common theme across all sessions. In the absence of specialist services, participants attended service providers who did not have the knowledge to meet their needs. People were frustrated with lack of expertise and were fearful that the non-specialist services could cause a regression.

> “I am not aware of any specialist physiotherapy services in this area.”

> “I stopped walking as I was embarrassed of my gait. It looked like I was drunk. I was sent to physio that didn’t know anything about brain injury. That put me backwards.”

> “Primary care outpatient physio does not treat neuro or long-term patients and it’s hard to find private neuro physiotherapy locally.”

Burden of responsibility of finding services:

Individuals reported feeling isolated as they did not know what services they should/could avail of. Many individuals believed that service providers were not aware of the services that an individual could avail of, with some also reporting a lack of empathy/support/help from service providers. Participants strongly felt that the burden of finding/accessing services was left to the individual/family members.

> “I wouldn’t know where to reach out. There is a disconnect there.”

> “There’s a pattern there between lack of proactivity and care in terms of follow-up. You are left to yourself but don’t know what you need and if you need it.”

> “People are made to feel helpless and like they are begging, like they should be grateful for bad services.”

Financial burden of accessing services:

In the absence of available HSE services, individuals reported accessing private services, particularly physiotherapy. However, individuals reported difficulties in finding private neuro-rehabilitative services and stressed the financial strain associated with paying for these services. Moreover, individuals reported being unable to work while awaiting services, placing additional financial burden on them.

> "I have paid €1700 for private physiotherapy."

> "I have to go to privately. The Health Service Executive gives only 12 sessions, and they are very spaced out."

Accessibility limitations of services:

The challenge of physically attending services was highlighted by some. While some participants reported tele-rehabilitation services as being beneficial, those who were unable to attend in-person services felt that they were insufficient to fully meet their needs.

> "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."

> "…unable to physically attend at services. Video calls are useful but are not adequate."

Service-provider experiences

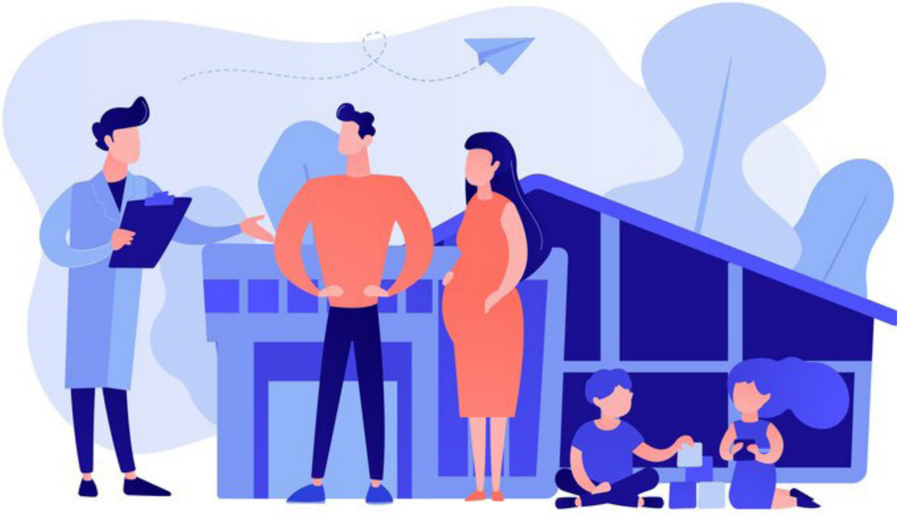
As part of the registration process for sessions, service providers were asked about factors influencing the journey of people accessing community Neuro-Rehabilitation services in CHO 3 and these were then discussed in greater detail during the sessions. The primary factors discussed by service providers are highlighted below:

- Service providers emphasised that there are **insufficient specialist services** in CHO 3 and noted that the current primary care model did not meet the needs of people with neurological conditions. Service providers stated that there is an unrealistic expectation on primary care staff to fill the current gap in specialist services, despite in many cases not having the requisite resources, experience or training.

> “primary care is episodic in nature, so you deal with the problem that’s on the referral form, you know the reason for the referral and then people are discharged after that so there isn’t that long-term continuity, it’s episodic.”

> “it’s not fair on primary care staff, physiotherapists, to land that expectation on them that we do. Some of them won’t have that experience. It’s really hard in each area to build that experience and build it up with them. I do think we do need more local specialisms.”

> “You see everything and anything and you see them briefly and then they move on to whatever is next. You wouldn’t expect a General Practitioner to do brain surgery. It’s not fair to expect, you know, your generic primary care physiotherapist to do a complex I don’t know standing assessment for somebody with you know who’s gone, gone off their feet. They need a sleep system. They need all the standing frames. You know, they have the psychological impact of losing that independence, that’s not for primary care.”



- Service providers felt strongly that the **lack of knowledge of available services** in the area among service providers and people with neuro-rehabilitative needs was a barrier to individuals accessing relevant and appropriate services in a timely manner. Service providers reported that organisations are most often working in silos with a lack of joined up thinking across services, impacting on continuity of care across sectors.

> “There are so many different people that they could benefit from. There’s no kind of one stop shop where one person coordinates all of that for them. Do they have to make contact with all of these different people?”

> “I suppose you know that, as patient said, you know the plug being pulled out and we’re not you know really sure, we’re sending them off into the community and I suppose we’re often not sure what services are available to them when we send them off.”

- Service providers were frustrated with the **under-staffing** and **under-resourcing** of services in CHO 3 which are resulting in long waiting lists and preventing timely and responsive services in the area. Service providers stressed that the lack of fully staffed teams, an issue that has worsened since the start of the recruitment embargo, prevented the provision of a multi-disciplinary approach to assessment and intervention.

> “you know a lot of it comes back to resources, which is being echoed I know from across the board by people here today, the resources to be able to take people on for maybe longer periods. So that is a challenge.”

> “one of the biggest things impacting on our capacity to continually deliver services is our inability to fill posts and be that obviously, we’ve a recruitment embargo adding to that it it’s an impossibility to even be approved for back full of maternity leaves and I think the impact that has on the continuity of sustaining our services, it’s like we can never catch up then you know there’s always gaps. I think it has a huge effect on the people that in terms of burden.”

> “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”

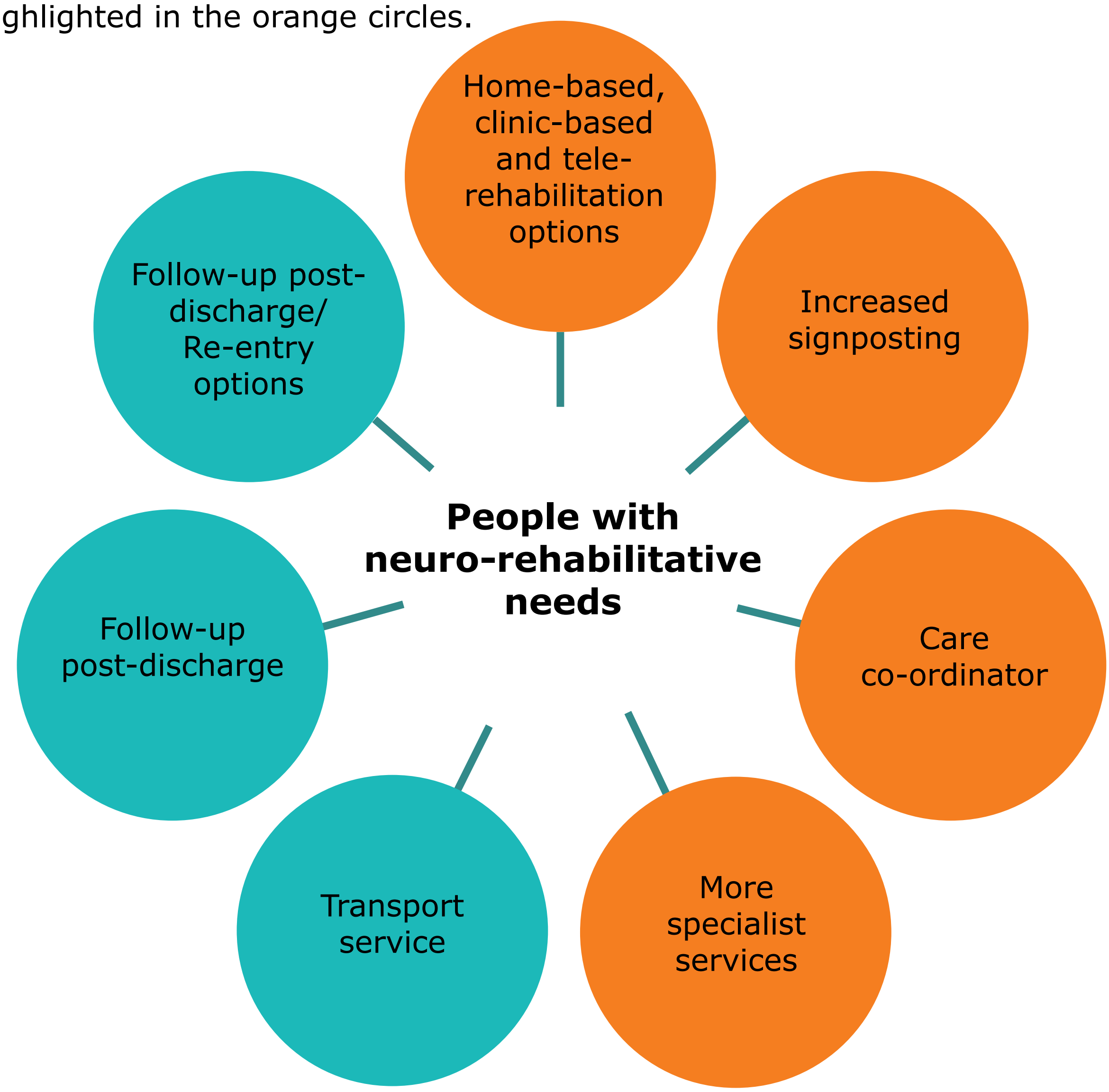
- Service providers also reported that factors such as **age, location and transport** impact access to and availability of services. Service providers noted that the rehabilitation needs of individuals aged over 65 years are largely underserved as they do not qualify for specialist services. Moreover, it was highlighted that location is an access criterion for some services, with individuals outside of a specific catchment area not entitled to avail of the service.

> “if a person is over 65 living in Clare, Limerick or North Tipperary diagnosed with a sudden onset neurological condition, there is no specialised Neuro-Rehabilitation services available to my knowledge.”

> “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”

Suggestions for the future

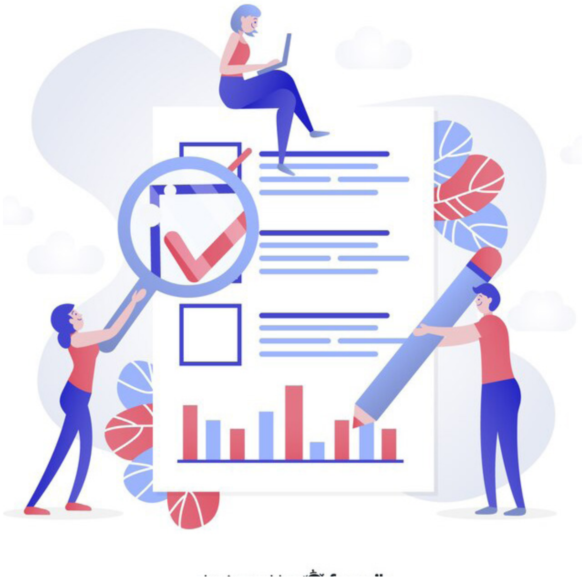
As part of the engagement with people with neuro-rehabilitative needs and service providers, many suggestions were made as to what would help address barriers and improve services. Input from people with neuro-rehabilitative needs and service providers are shown below. There were some common themes put forward and these are highlighted in the orange circles.




Service providers
Liaison across disciplines and organisations
Home-based, clinic-based and tele-rehabilitation options
Increased signposting
Care co-ordinator
More specialist services
Fully staffed and resourced services
Satellite clinics
Centralised assessments and outcomes
Removing age restrictions
Adult disability network teams
Integrated care pathways

Appendix 4. Summary of feedback CHO 6

Approach to getting input from people with neuro-rehabilitative needs and service providers in CHO 6



Two online briefing sessions were held to inform service providers in CHO 6 about the Neuro-Mapping Project. Following these, information leaflets were sent to service providers and they were asked to share them with people with neuro-rehabilitative needs. To maximise inclusivity and accessibility, people with neuro-rehabilitative needs were offered the opportunity to participate in the project through a variety of means including in-person, online, via email or by phone. Once the sessions with people with neuro-rehabilitative needs had been completed, two online consultation sessions with service providers in CHO 6 were organised, one for staff providing community Neuro-Rehabilitation services to adults with acute onset neurological conditions and one for staff providing community Neuro-Rehabilitation services to adults with progressive neurological conditions. As part of the registration process for these sessions, service providers were asked to complete a precursor questionnaire. The feedback from people with neuro-rehabilitative needs and from the questionnaire were used to structure the discussion for the service-provider sessions.

People with neuro-rehabilitative needs

- **13 people with neuro-rehabilitative needs from CHO 6** participated

6 in-person

4 online

3 via phone

4 males
9 females

- The **neurological diagnoses** of participants included:
  - multiple sclerosis (n=9)
  - spinal cord injury (n=2)
  - Parkinson’s disease (n=1)
  - stroke (n=1)

Methods of service-provider participation

Precursor questionnaire from staff providing community neuro-rehabilitation services to adults with **acute onset** neurological conditions:

3 voluntary service providers

23 HSE service providers

Precursor questionnaire from staff providing community neuro-rehabilitation services to adults with **progressive** neurological conditions:

3 voluntary service providers

19 HSE service providers

Online consultation session with staff providing community neuro-rehabilitation services to adults with **acute onset** neurological conditions:

4 voluntary service providers

23 HSE service providers

Online consultation session with staff providing community neuro-rehabilitation services to adults with **progressive** neurological conditions:

4 voluntary service providers

10 HSE service providers

Summary of feedback

Experiences of people with neuro-rehabilitative needs

Complexity of navigating services:

Many individuals expressed feelings of loneliness, abandonment and frustration following discharge from acute/in-patient services. Participants found it very challenging to identify relevant community services, most often because they were not aware of what services were available and what services they needed. They described an absence of a focal point where they could get person-centred information regarding services and many felt that the onus of finding services was left solely on the individual and believed that if they did not identify and ask for services that they would not be offered to them.

> “I don’t think we should go looking for things ourselves. We need advice as to what would be good for us.”

> “There are no services offered. It’s only because I ask and I complain, they throw you out a little physio or something.”

> “I could be going to anyone; I could be going to a witch for all I know.”

Inconsistent services:

A minority of participants described some positive experiences that they had had attending specialist services; however, it was also noted that these were only provided for short durations. The overwhelming opinion of participants was that there are insufficient specialised neuro-rehabilitative services available in the community, with many individuals describing a complete absence of services in their locality. Furthermore, participants discussed how availability and accessibility of services was compounded by living location and transport availability. As a result of this, individuals most frequently attended non-specialist services that they did not believe met their needs.

> “…it's very awkward for me to get to because buses are difficult for me to navigate by myself.”

> “…more availability of services, it is non-existent at the moment, they don't care in Ireland, they really don't care. It's really bad in Ireland.”

> “I wanted to work on my walking, but all she did was give me some exercises for my arms but did nothing for my walking. After services are very poor.”

Gaps in long-term supports:

Participants described an absence of long-term supports, particularly in relation to functional ability and psychological health, with individuals often stating that there was not enough emphasis/focus on rehabilitation in their long-term management plan. When participants did get access to services, they believed that these had a short-term focus as there was no follow-up after completing the intervention block. Participants also highlighted that services work in silos. As a result of this, they felt that health care professionals are not aware of services that are available to support the long-term management of their neurological condition.

> “For the rehabilitation side, I had to direct the discussion towards it – if I hadn't asked, they wouldn't have offered.”

> “As soon as you do the course, there is never follow up. There is no one picking up the phone. I feel very lost in the public system. It would be great if they could follow-up and check in.”

> “Don't save us then leave us. It feels like they can't wait to get you out the door and get someone else in.”

> “I would like the General Practitioner to be a bit better informed. They don't know who to refer to.”

Systemic issues resulting in fragmented service delivery:

Participants often expressed sympathy for service providers, emphasising that issues appeared to be at the system level rather than the individual level. Primary issues highlighted by participants included the absence of services, the high staff turnover and the long waiting lists to attend the limited number of services that are available. Many individuals felt that they were deteriorating while waiting for services and stressed how they would benefit from earlier and ongoing intervention. Resultantly, many participants had accessed private services; however, due to the high cost of attending these services, most individuals stated that they were unable to afford these services on an ongoing basis.

> “I had to pay for myself, it was 100 euro a session, I got it twice, I can’t afford that.”

> “All the people that I have dealt with are excellent, I couldn’t fault them in any way, but they are restricted in what they can offer.”

> “My doctor puts me into a system, onto a database, two years later you hear you are currently on a waiting list... do they think a miracle has happened and they ask me to contact them if I still want the service. The more I have the disease the more I am regressing without this treatment. Then I get so annoyed. It’s an insult.”

> “If I had been able to contact them when I needed them, I might not have deteriorated to this point. I bought the stick myself as I needed it last week and couldn’t wait for the appointment.”

Service-provider experiences

As part of the registration process for sessions, service providers were asked about factors influencing the journey of people accessing community Neuro-Rehabilitation services in CHO 6 and these were then discussed in greater detail during the sessions. The primary factors discussed by service providers are highlighted below:

- Service providers viewed challenges with **referral processes** in CHO 6 as a main barrier to accessing services. Issues with inefficient referral methods including multiple different forms, long-winded forms and having to identify the relevant catchment area were seen as a deterrent due to the time commitment, resulting in delayed or missed referrals. Service providers also noted that inappropriate referrals or inaccurate information increase the time spent on administrative tasks rather than therapy provision.

> “The actual referral process can be so challenging in terms of trying to find when you’re busy trying to find the right form, the right updated form and even like knowing the area that the person you know the catchment areas is really complicated.”

> “it’s just such a complicated process to make a referral for somebody within the community, you know, you could spend days chasing a phone number to find out who to send the referral form to, what’s the appropriate referral form.”

- Service providers expressed frustration with the **under-staffed** and **under-resourced** services in CHO 6, resulting in long waiting lists for service-users. However, service providers stated that the impact of under-staffing did not end there, as it is also causing a high rate of burnout among service providers, leading to losses of highly trained and experienced staff members.

> “The big elephant in the room is the recruitment embargo that has been going on for the last while and seems to be never ending and how that has just decimated staff that we already had and then has certainly led to further burnout of staff that we have managed to hold on to, but really has, you know, prevented an influx of new staff and possibly maintenance of really experienced quality, like long standing staff”

> “for me there just seems to be a myth, a mismatch, there always seems to be an expectation that when you get more staff it’s to provide more services, but actually sometimes you’re struggling providing the service you’re supposed to be providing in the first place.”

- Service providers highlighted that there are **insufficient specialist services** in CHO 6 to meet the needs of people with neuro-rehabilitative needs. It was noted that there is an absence of specialist services available in the community upon discharge from in-patient services. Most often, individuals are referred to primary care, but it was stated that this a generalist service with a large and varied caseload and, resultantly, many clinicians do not have the required skillset to manage the higher rehabilitative needs of people with neurological conditions.

> “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, 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.”

> “it’s about the skillsets that clinicians would have as well in terms of managing what might be a service-user group that would have a higher level of need in the community. So if somebody is coming out or moving out of a more specialised rehab facility or service, it’s not just identifying where you can access physiotherapy or occupational therapy or speech and language therapy services in the community, but sometimes it’s actually particular clinicians that would have particular skillsets, so that’s in terms of that integration, in terms of that flow of the patient or the client flow and for people being able to get the right care in the right place.”

- Service providers viewed the **lack of knowledge of services** among people with neuro-rehabilitative needs and service providers as a barrier to accessing services. In the absence of a central directory of services, service providers noted that they themselves were unsure of all the services in the area despite in some cases having worked in that area for many years. As a result, service providers were not surprised that people with neuro-rehabilitative needs found navigating services challenging, but expressed particular concern for individuals who have communication and/or cognitive impairments trying to identify and access relevant services by themselves.

> “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.”

> “because someone with a communication impairment may not be able to advocate for themselves in the way that someone who doesn’t have communication impairment could and also you know, I think we all would agree here that that’s not ideal that they would have to advocate for services themselves.”

Suggestions for the future

As part of the engagement with people with neuro-rehabilitative needs and service providers, many suggestions were made as to what would help address barriers and improve services. Input from people with neuro-rehabilitative needs and service providers are shown below. There were some common themes put forward and these are highlighted in the blue circles.


Service providers
Liaison across disciplines and organisations
Care pathways
Improved information technology systems/ infrastructure
Removing age restrictions
Fully staffed and resourced services
Early intervention model
Case worker
Group work/ maintenance groups
Standardised outcome measures
Complex case manager
Centralised referral process
More specialist services
Local rehabilitation clinics

Notes

Report on the Neuro-Mapping Project Phase 2

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

NEUROLOGICAL ALLIANCE of IRELAND

DISABILITY FEDERATION OF IRELAND

October 2024