Crowe

Mapping existing services provided by the voluntary sector for people living with neurological disabilities/conditions in the community

Report to Disability Federation of Ireland, Neurological Alliance of Ireland and the Health Service Executive

January 2023

This report has been commissioned by
the Neurological Alliance of Ireland,
the Health Service Executive and
Disability Federation of Ireland.

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NEUROLOGICAL ALLIANCE
of IRELAND

HSE

dfi DISABILITY FEDERATION
OF IRELAND

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 800,000 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.

Contents

Foreword

We are delighted to share the findings of this report which is the culmination of a joint partnership between the Health Service Executive (HSE), the Disability Federation of Ireland (DFI) and the Neurological Alliance of Ireland (NAI).

For many years, whilst recognizing the significant contribution that the voluntary disability sector provides to support people with neurological conditions to live independently in the community, we have been aware of challenges in capturing the breadth of provision of this work, due largely to the range and scale of voluntary organisations working in this space.

There are over 60 community-based voluntary organisations providing services to people with a neurological disability across Ireland. Some provide specialist services and others more generalized supports. In addition, there are some providing national services and others who are operating in specific geographic locations. These services have evolved and developed over the years as organisations have identified and responded innovatively, and often collaboratively, to unmet need. However, to date there has been no framework to acknowledge or collectively describe the services that exist.

The neuro-mapping project, which was funded through the HSE Strengthening Disability Services Fund, was devised to respond to this challenge. It sought to develop a mapping template that would capture the full range of service types provided by the voluntary organisations on a national basis, using the language and terminology of the service providers. It also sought to capture examples of joint service initiatives between voluntary providers and the HSE. Through both of these outputs, together with a baseline mapping of existing voluntary service provision within each CHO, the project has provided essential information on current service provision by voluntary organisations. This information will support the progression of the National Neurorehabilitation Strategy by highlighting the breadth of voluntary organisation service provision and shining a spotlight on good collaborative practice to be replicated moving forward.

As a result of significant input from the disability voluntary organisations, the neuro mapping project has been successful in developing a Service Mapping Template that captures the range of services that are provided across the country by voluntary organisations. By using a consensus approach and validation process via the national survey, the Template comprises of 10 categories and 98 service types to describe the provision of services in the community provided by DFI and NAI member organisations. Through this process there was also an opportunity for the use of consistent terminology when representing these services to service users, funders and the general public.

The five joint service initiatives outlined in this report, give an insight into the types of collaboration that are taking place between the HSE and the community and voluntary sector. They also demonstrate how these partnerships lead to integration and improvement in service options for people with neurological conditions. The findings resonate with the work of the Department of Health Dialogue Forum, in particular the production of the partnership principles for statutory and voluntary organisations.
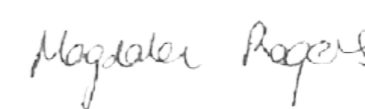
The oversight of the project is aligned with the National Neuro-Rehabilitation Strategy, and the findings will inform future work of the National Neuro-Rehabilitation Steering Group as it looks to create a Model of Care of Community Integration for those living with neurological conditions within the community.

It is important to recognise that the HSE also provide community-based services to people with neurological conditions. The development of the Service Mapping Template is the necessary first step required to undertake analysis on how services provided by voluntary organisations integrate and interact with services provided by the HSE. The Service Mapping Template can also be used to engage with people accessing and using community-based services for people with neurological conditions, as their views are sought in terms of service planning, user experience and service improvements.

We would particularly like to acknowledge the significant contribution from the DFI and NAI member organisations in this project and look forward to working together to ensure the Service Mapping Template informs the future planning and development of services for people with neurological conditions living in Ireland.

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Acknowledgements

Crowe are pleased to present DFI, NAI and HSE with this Service Mapping Report. This report concludes twelve months of research, stakeholder engagement and analysis by Crowe's project team.

We would like to thank the project partners in DFI, NAI and HSE and also the project steering group for their valued guidance and support during the project. We would also like to thank the key stakeholders consulted in relation to survey tool design for their time and insights and all of the voluntary organisations who took the time to complete the survey.

Glossary

DFI	Disability Federation Ireland
NAI	Neurological Alliance of Ireland
HSE	Health Service Executive
CHO	Community Healthcare Organisation
Project Partners	DFI, NAI and HSE
LIG	Local Implementation Group
JSI	Joint Service Initiative
JSI Partners	Voluntary organisations and the HSE that are collaborating on a project

Executive Summary

E.4 Introduction and Context

In November 2020, Disability Federation of Ireland and Neurological Alliance of Ireland successfully submitted a joint proposal to the HSE as part of the Strengthening Disability Services Fund. The project aims were to:

- Describe nationally the breadth of community services that people with neurological conditions access from voluntary organisations.

- Identify examples of good practice and collaboration, between voluntary organisations working together and / with the HSE.

E.5 Project Governance

Crowe Ireland were commissioned to complete this work following a tender process. Throughout the process, Crowe reported to the project partners. Overall project oversight included:

- Project Partners: HSE, DFI, NAI (see section 10.2).

- Steering Group: HSE, DFI, NAI, Service User representation, nominee from National Steering Committee, representation from voluntary organisations providing service to people with neurological conditions (see section 10.3).

- Neurological Alliance of Ireland are represented on the National Steering Group (NSG) supporting the implementation of the National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland and update the group as appropriate.

E.6 Methodology

A survey tool was co-designed, distributed and survey results were analysed and presented as heat maps. The co-design of the survey occurred through a number of focus groups formulating an agreed list of services under 10 different service categories.

Through a submissions process, five joint service initiatives were identified that demonstrate effective collaboration between voluntary organisations and the HSE as part of a pathway to respond to the needs of people living with neurological conditions in the community. Based on the submissions and conversations with those involved, an outline of the collaborations is included in section 6 of this report.

E.7 Key Insights

Key insights from the research and consultation process are outlined below and discussed further in section 4 under the headings below:

- Performance of the survey tool
- Mapping breadth of service provision by CHO
- Insights on Joint Service Initiatives (JSI) interviews

E.8 Key Survey Findings

Section 5 includes the survey findings presented in the form of heat maps under 10 service categories. The heat maps provide details of the services that are available within a particular CHO by a surveyed voluntary organisation under the 10 agreed service categories:

- Assessment and Planning
- Therapeutic and Clinical Supports
- Supported Living/ Accommodation Supports
- Respite
- Accessibility Supports, Activities of Daily Living and Long-term supports
- Community Integration and Participation
- Vocational/Employment/Training/Rehabilitative Supports
- Information, Advocacy and Education
- Family and Caregiver Supports
- Co-ordination and Point of Contact

E.9 Joint Service Initiatives

Each of the JSIs outline findings in the following areas:

- Rationale of the Joint Service Initiative
  - Inspiration behind the collaboration
  - Steps involved in developing the JSI
  - Roles of the JSI partners

- Positive Impacts
  - Greatest achievement noted by JSI partners in terms of collaboration
  - Successful outcomes of the JSI
  - Ingredients of a successful collaboration

- Challenges
  - Challenges encountered

- Conclusions

E.10 Conclusions and Recommendations

The recommendations come from both the survey analysis and the JSI insights and recommend actions for the future to build on the findings in this report. The recommendations include the following:

- Use the methodology and findings to support the implementation of the National Neuro-Rehabilitation Strategy
- Include additional datasets in future service mapping activity
- Use the methodology and findings to support and strengthen engagement.

1 Introduction

1.1 Context

In November 2020 Disability Federation of Ireland and Neurological Alliance of Ireland successfully submitted a joint proposal to the HSE as part of the Strengthening Disability Services Fund. The project aims were to:

- Describe nationally the breadth of community services that people with neurological conditions access from voluntary organisations

- Identify examples of good practice and collaboration, between voluntary organisations working together and in conjunction with the HSE.

The resulting Joint Project to Map Services Provided by Voluntary Organisations for People with Neurological Conditions Living in the Community has provided evidence of the breadth of existing services provided by voluntary organisations to people with neurological conditions in each Community Healthcare Organisation (CHO) in Ireland. The survey tool, for the first time, provides important aggregated data that captures thebreadth of services available through voluntary organisations. The project enables the project partners (DFI, NAI and HSE) to understand and communicate to relevant stakeholders the services and supports, both currently available and absent, to people with neurological conditions.

While this work is informed by the 2017 mapping of neurorehabilitation services carried out by the National Steering Group for the Neurorehabilitation Strategy, this exercise aims to provide a richer and more detailed insight into the community supports provided by the voluntary sector. This has been enabled by the consensus driven, user design approach in developing the service mapping tool.

Prior to the completion of this service mapping project, there was no pre-existing listing that had been agreed with providers that reflected the entire range of services and supports provided by the voluntary sector to people living with neurological conditions in the community. Furthermore, there were no agreed categories under which to group the wide range of individual services in a way that was understood and accepted by voluntary providers. This user design approach to this survey tool helped overcome the challenges previously experienced where an array of different descriptions were used to describe services which hindered comparative analysis of services at an aggregate level.

In line with user design thinking, it was considered vital that as many voluntary organisations as possible who provide services to people with neurological conditions were included in the mapping exercise. To ensure consistency and inclusivity across all CHO areas, it was necessary to generate agreement on the terms used in the survey tool, so that the full range of services available were captured and could be aggregated. As such, an extensive engagement process was developed with all community organisations and HSE representatives to develop consensus on terms used and on the survey template for the mapping.

This service mapping project should be understood in the context of the Implementation Framework for the National Neuro-Rehabilitation Strategy 2019 -2021. This three-year plan, built on a 10-step framework, encompasses clear governance structures, population planning and a mapping approach to improve the quality of life of people living with neurological conditions. The 'National Strategy and Policy for the Provision of Neuro-Rehabilitation Services in Ireland Implementation Framework 2019 - 2021' acknowledges that there is widespread variation in accessibility of community rehabilitation services across the country (p.45). See Appendix A1.1 for further information on the Neuro-Rehabilitation Implementation Framework.

By developing an agreed list of categories and service descriptors and providing a map of the existing services provided, the DFI, NAI and HSE project will support the CHO and LIGs (Local Implementation Groups) to carry out their work.

2   Project Governance

2.1   Project Management and Project Governance

Crowe Ireland (hereinafter referred to as Crowe) were appointed to the neurological service mapping project following a tender process. Crowe is an established research and consulting firm with extensive experience working in the health and social care sector and the project team has specific expertise in the disability sector in particular. Crowe had regular communications and meetings with the project partners and the steering committee throughout the various project phases.

Overall project oversight included:

- Project Partners: HSE, DFI, NAI (see section A1.2).

- Steering Group: HSE, DFI, NAI, Service User representation, nominee from National Steering Committee, representation from voluntary organisations providing service to people with neurological conditions (see section A1.3).

- Neurological Alliance of Ireland are represented on the National Steering Group (NSG) supporting the implementation of the National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland and update the group as appropriate.

The Terms of Reference of the Project Steering Group is detailed in section A1.4. The communication mechanisms undertaken to raise awareness of the Neuro-Mapping Project are detailed in section A1.5

2.2   Project Scope

The scope of the service mapping includes:

- All services that are provided by voluntary organisations to people with neurological conditions living in the community

- The scope of service provision captured was based on service to people aged 18-65 in accordance with the National Neurorehabilitation Strategy

- The mapping will include non-HSE funded organisations that support people with neurological conditions.

The service mapping does not include:

- Services provided to people living in older persons residential care settings

- Services provided directly by HSE

- Activity data on quantum of service.

2.3   Project Aims

The aims of the project included:

- Developing a survey tool to identify the breadth of existing services provided by voluntary organisations for people living with neurological disabilities in the community across each CHO. For this report, services were informed by various sources.

- Highlighting the activity of voluntary organisations providing a service to people living with neurological conditions.

- Presenting examples of good practice to demonstrate collaboration and good practice that support the continuum of care for people with neurological conditions.

2.4   Project Outputs

This project outputs include:

- A robust user-designed survey tool with consensus on language for mapping services.

- An agreed national framework which provides agreed service categories and service descriptors that have been developed in consultation with service providers and HSE.

- A service mapping report which:

  - presents aggregate national data by CHO which evidences the existing services provided by the voluntary sector for people living with neurological disabilities in the community

  - provides evidence of the breadth of community services within each CHO provided by voluntary organisations and accessed by people with neurological conditions to support them living in the community

  - describes joint service initiatives which demonstrate collaboration and good practice that support the continuum of care for people with neurological conditions.

2.5 Project Limitations

Limitations noted in relation to this research are:

- The boundaries of interpretation are limited to the data gathered i.e. existing voluntary sector service provision to people with neurological conditions, aged 18-65. Therefore, the breadth of service does not reflect statutory provision or provision to people outside the ages of 18-65

- In focusing on existing provision, data cannot provide information on adequacy, quality or suitability of services, gaps in service in comparison to demand or adequacy of resources (funding or staffing)

- All data gathered is self-reported and is limited in terms of not being independently verified and cannot be compared to previous independent studies

- While the response rate was very robust, there may be organisations offering neurological services that did not complete the survey.

3 Methodology

3.1 Background

Developing a map of service provision for neurological services consisted of an iterative process of survey tool co-design, survey distribution, survey analysis and the development of heat maps. The critical path is outlined in section A1.6 of this report.

The survey tool requests data detailing the range and scope of existing community services provided to people with neurological conditions from a geographic perspective. Data has been gathered via the creation and distribution of a bespoke survey tool designed to depict the provision and location of community-based services being delivered to people with neurological conditions.

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

3.2 Development of a Survey Tool

The development of the survey tool consisted of three phases:

1. Co-design of a robust service mapping survey tool
2. Survey distribution
3. Survey analysis and reporting

3.2.1 Co-design of a robust service mapping survey tool

The purpose of the survey tool was to identify the breadth of services available across each CHO. At the outset of the project, it was agreed that the first step in the survey design process was to co-create an agreed list of service descriptors in order to effectively map existing services. Therefore, it was agreed that time needed to be invested in co-designing the survey tool through engagement with service providers and the HSE.

The starting point was that the project partners and Crowe developed an organising framework based on service categories under which related service descriptors could be grouped. The purpose of co-designing and testing the initial framework was to:

- ensure that the service descriptors have a shared meaning for all stakeholders

- understand and ideally eliminate any existing confusion in relation to services that are the same but being described in different ways

- ensure that the same service descriptors are used by all organisations so that survey data in relation to the services is comparable would /will allow for:
  - valid aggregation of data from providers across the country
  - meaningful like-for-like comparisons of survey data on services across CHOs

The phases involved from initial draft to the circulation of the final survey tool were:

1. The project partners developed an initial draft list of service descriptors, grouped under suggested categories. This draft was informed by the 2017 mapping of neurorehabilitation services and providers service listings that were available online;

2. Crowe reviewed the first draft providing feedback and recommendations which informed a second draft;

3. The second draft was reviewed by the project Steering Group for further comments and recommendations, which were incorporated into a third draft;

4. Category descriptions were developed by the Steering Group. The third draft of the survey tool was then used for testing purposes in the engagement processes below;

5. Crowe facilitated 2 focus groups with 11 service providers and 3 joint interviews with 6 HSE representatives. The purpose of the engagement was to gather feedback and insights from organisations and the HSE on the service categories and service descriptors making up the framework, language used and suggestions of additional services;

6. All feedback was collated by Crowe and sent to the project partners and project Steering Group for review and final recommendations;

7. The design of the final survey tool incorporated these recommended adaptations and the final survey tool (with 10 service categories shown below and 98 services).

For reference, category headings and definitions are shown below:

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 offer aids or assistances that enable a person to live more independently or that help sustain long term wellbeing and independence.
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/ Rehabilitative 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 exercise 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.

The importance of this phase of the process should not be underestimated as it now provides a robust framework for mapping and grouping related services under category headings defined by consensus.

3.2.2 Survey distribution

In parallel with the survey tool design phases above, the project partners were in regular communication with service providers to inform them of survey development and to invite organisations to register to receive the final survey. Over 60 voluntary organisations, from NAI and DFI membership and HSE contacts, were invited to register an interest in participating in the survey. The survey was then formulated and distributed by means of an online survey tool, LimeSurvey.

The survey was distributed to the 48 voluntary organisations who registered, nominated a representative and gave consent to be contacted by Crowe. A "personal link" or access code was issued to each participant. This method ensured that only one response was submitted from each participating voluntary organisation (in order to prevent duplication).

All those who received the survey opted-in by way of a consent form circulated and administered by the project partners which included consent to Crowe receiving their contact details and using those contacts to send the online survey. All survey respondents were assured that their data would not be reported individually i.e. that only aggregated data would be included in the report.

It is also important to note that a number of information sessions were facilitated by the project partners to clarify the purpose, parameters, process and expectations of survey participants. Both the project partners and Crowe were available for any project related or technical questions that arose.
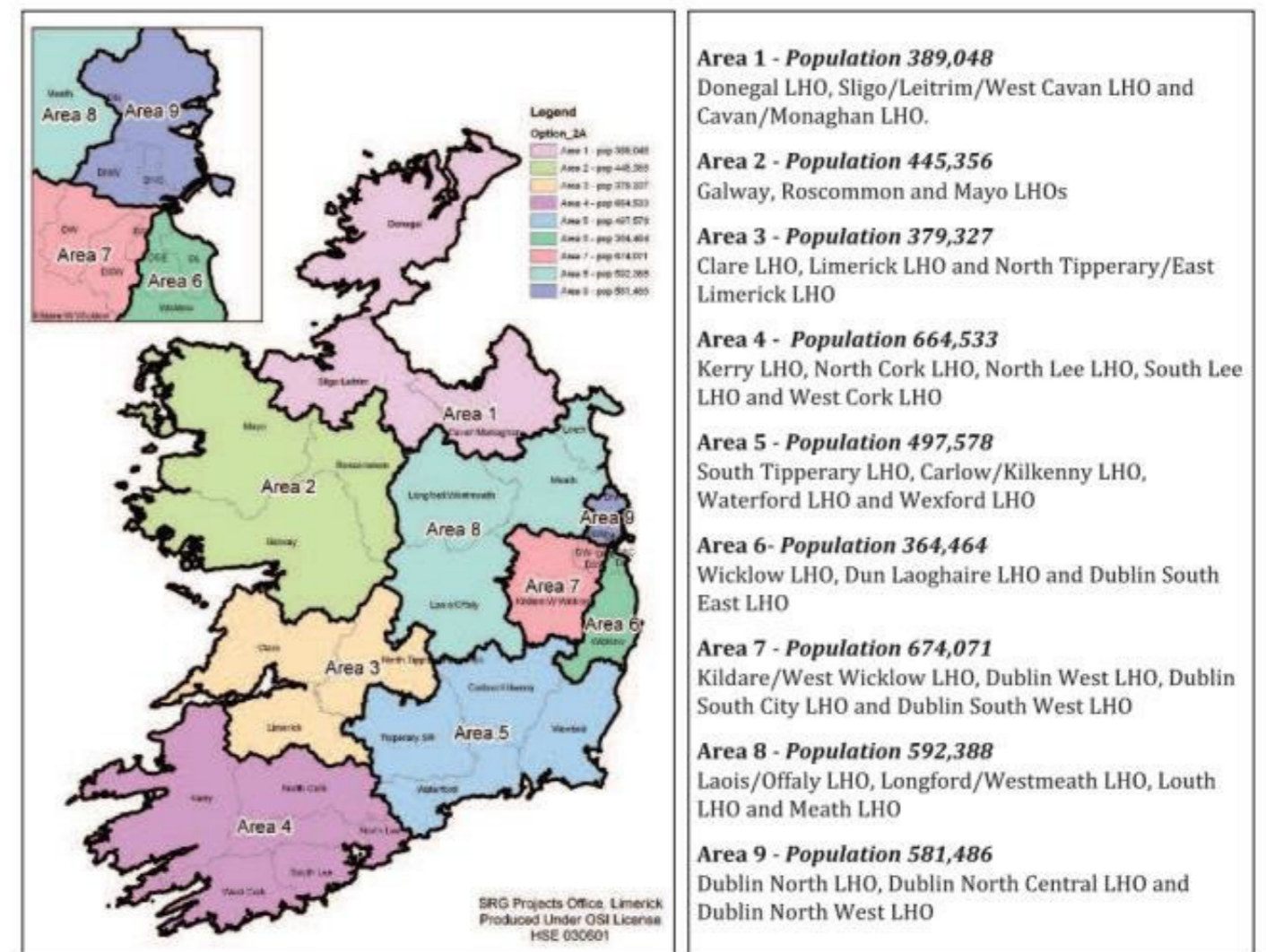
3.2.3 Survey analysis and reporting

Following the closing date of the survey, the survey was closed and all responses downloaded and collated data was analysed. Following a quality review and clean-up of the responses received, **the analysis of the survey is based on 44 out of 48 respondent voluntary organisation surveys.**

The number of responses in each category is dependent on the number of organisations that provide at least one service in one of the CHOs. Those who do not provide a service will not have answered where it was not applicable. Therefore, each question is analysed on a basis of the total number of voluntary organisations that provide at least one service within that category. This is noted under each heat map for each of the 10 categories, as is the number of organisations who do not provide any service in the same category.

As noted previously, the survey analysis is presented in 10 sections, one for each of the 10 categories. A definition of each category was provided to respondents when completing the survey. Under each category, respondents were asked to indicate whether they provide the various services listed in any of the 9 CHOs and by way of an "Other" option to indicate any services provided but not listed. Answers returned under "Other", the majority of which were only provided by 1 organisation, are included in Appendix 8.3.

For reference, the nine Community Health Organisations (CHOs) are shown below.

Area 1 - Population 389,048
Donegal LHO, Sligo/Leitrim/West Cavan LHO and Cavan/Monaghan LHO.

Area 2 - Population 445,356
Galway, Roscommon and Mayo LHOs

Area 3 - Population 379,327
Clare LHO, Limerick LHO and North Tipperary/East Limerick LHO

Area 4 - Population 664,533
Kerry LHO, North Cork LHO, North Lee LHO, South Lee LHO and West Cork LHO

Area 5 - Population 497,578
South Tipperary LHO, Carlow/Kilkenny LHO, Waterford LHO and Wexford LHO

Area 6 - Population 364,464
Wicklow LHO, Dun Laoghaire LHO and Dublin South East LHO

Area 7 - Population 674,071
Kildare/West Wicklow LHO, Dublin West LHO, Dublin South City LHO and Dublin South West LHO

Area 8 - Population 592,388
Laois/Offaly LHO, Longford/Westmeath LHO, Louth LHO and Meath LHO

Area 9 - Population 581,486
Dublin North LHO, Dublin North Central LHO and Dublin North West LHO

(HSE, 2015)

3.3 Briefing meetings

A series of briefing meetings occurred after the findings of the survey were collated. The purpose of the stakeholder briefings was to sense check project findings to date and seek input from key stakeholders on next steps. The briefing meetings occurred with voluntary organisations that were invited to participate in the survey, Disability Managers, members of the National Neuro-Rehabilitation Strategy Steering Group and service users.

3.4 Joint Service Initiatives

3.4.1 Background

This part of the project aimed to identify a set of joint service initiatives that demonstrate effective collaboration between voluntary providers and HSE services as part of a pathway to respond to the needs of people living with neurological conditions in the community.

A JSI was defined, for the purposes of the project, as involving one or more voluntary providers working in partnership with HSE statutory services to respond to the needs of people with neurological conditions in the community.

3.4.2 Key requirements

The key requirements to be selected as a representative sample:

- The JSI must involve one (or more) voluntary providers working in partnership with HSE statutory services to respond to the needs of people with a neurological condition(s) living in the community.

- Each partner in the joint initiative must be willing to take part in an interview if the collaboration is selected for the final report.

- The JSI should be in place for a minimum of six months and should continue to be in place at the time of the application.

- The JSI should demonstrate clear benefit to people living with a neurological condition(s) in the community through meeting at least one of the following criteria:

  - a JSI which leads to a more integrated approach to the delivery of services for people in the community living with a neurological condition(s).

  - a JSI in response to a specific service need among people with neurological condition(s) living in the community.

  - a sharing of resources between providers in order to deliver services to people with neurological conditions.

- The application should be able to identify aspects of the JSI that could be replicated in other regions and/or for other neurological conditions.

13 submissions were sent to the project partners, who selected a representative sample of 5 to be contacted by Crowe. Based on the submissions and conversations with those involved, an outline of the collaborations is included in section 6 of this report.

4 Key Insights

4.1 Introduction

The purpose of this project was firstly to design a robust survey tool to capture the range of existing services provided to people with neurological conditions and to generate survey data that could effectively map services provided by voluntary organisations in each of the CHOs across the country. Furthermore, examples of good practice demonstrate collaboration between voluntary organisations and the HSE. It is appropriate to discuss the findings within the language of CHO areas as this is in line with the 2019-2021 Implementation Framework National Neuro-Rehabilitation Strategy which provides the policy context for this project.

In relation to the data presented for the service mapping, it provides insights into the incidence of provision by way of two key markers:

1. Whether or not the service is provided in each of the CHOs;
2. How many voluntary organisations are providing each of the services.

As such, the conclusions that can be reached are based on the breadth of existing services across CHOs and across the number of voluntary sector providers offering each service. Insights cannot be provided or inferred on the depth and/or adequacy of services levels. It should also be noted that the services mapped are those provided by voluntary organisations so there will be cases where HSE is an additional provider.

The analysis below presents key insights in relation to the performance of the survey tool, and indicators of provision providing insights into the breadth of services by CHO. Finally, some general anonymised insights are provided on overall provision by organisations.

4.2 Performance of survey tool

■ The process of co-creating the survey tool has resulted in a robust service mapping survey framework that has the potential to be replicated in future similar service mappings. This is testament to the considered input of all involved in the engagement processes which tested the initial survey tool and the integration of feedback provided into the final version of the survey tool.

■ The validity of the survey tool is also underlined by the fact that all of the services listed under "Other" were only mentioned once, apart from three areas which should be considered for inclusion in future iterations of service listings (see Appendix 2 for expansion of other):

- Mindfulness which was added 3 times under Therapeutic and Clinical Supports and once under Family and Caregiver Supports.

- Two areas arose a number of times under the "Other" related to: support in accessing/signposting services (but not directly providing those services) e.g. respite, independent living supports, community integration and participation services; and also provision of funding advice (hardship fund applications), funding or subsidies for certain services e.g. counselling/psychotherapy for "members", family counselling and psychotherapy.

- While "Respite to relieve family and caregivers" was mentioned twice in Family and Caregiver Supports, this was included in the list of services included under Respite – Family and Caregiver and as such does not need to be considered for inclusion in any future iteration of the list of services.

■ Having co-created and tested the survey tool, this provides a gateway to the quantitative mapping by the Local Implementation Groups (LIGs) in scoping services across the continuum of care (per the requirement of the Neuro-Rehabilitation Implementation Plan). The quantitative mapping will now be possible using consistent terminology, a consensus-based framework and starting with a deeper understanding of the breadth of the voluntary sector provision.

4.3 Mapping the breadth of service provision by CHO

4.3.1 Service providers - highest and lowest number by category

■ Information, Advocacy and Education services provided by 95% of respondents has the highest incidence of service provision

■ Respite provided by 45% of respondents has the lowest incidence of provision

4.3.2 Service providers - highest and lowest number by service

■ Information Resources has the highest incidence of provision (with a range of 27-29 organisations across CHOs)

■ Step Down Care has the lowest incidence of provision (1 provider in 1 CHO)

4.3.3 Services only provided by one voluntary organisation

20 of the 98 services are only provided by one provider in some CHOs. These services are detailed in the appropriate heat maps in section 5.

4.3.4 Services with a zero survey response

Of the 44 survey respondents, there is only one incidence where a service is only provided in 1 CHO i.e. Step-Down Care.

The 5 services with the highest incidence of zero provision were:

- Step-Down Care (not available in 8 CHOs)
- Transitional Living Service (not available in 5 CHOs)
- Nursing Home Respite (not available in 7 CHOs)
- Mental Health Nurse (not available in 6 CHOs)
- Driving Assessment and Supports (not available in 5 CHOs).

4.3.5 Anonymised insights on breadth of services by organisation

The insights below come from analysis of the individual returns by organisations and are anonymously reported. While the heat maps present data on the number of providers by CHO, the analysis below uses organisation data analysed across all categories and all service lines.

- Only 4 services providers are providing a service in every category i.e. no zero responses in any category. The other 40 respondents all have one or more categories where they do not provide any service.

- There are 6 cases where a service listed in a category is provided across all CHOs by one provider.

- As outlined under each heat map, all categories show a pattern where a fraction of the respondents provide the various services listed i.e. no category shows provision by all 44 survey respondents.

- The above indicates that services are sometimes only being provided in one or a few CHOs and/or that often organisations only provide specific services within a category but do not provide all services. This is validated above in relation to Service providers - highest and lowest number by category and by service.

- In order to ensure the anonymity of individual organisations, no heat map depicts provision by organisation as this could lead to organisations being identifiable.

4.4 Insights into Joint Service Initiatives interviews

Voluntary organisations and the HSE were invited to submit an example of an effective collaborative relationship with the HSE. Using predetermined criteria, a sample were then selected by the project partners who Crowe contacted to be interviewed. The insights gathered from these interviews included:

- Have a stakeholder consultation prior to commencement.
- Ensure roles of each partner are clarified.
- Use service users in design and ongoing feedback.
- Establish solid governance and communication arrangements to support trusting relationships.
- Seek to capture deliverables and Key Performance Indicators (KPI's) that reflect the added value of collaboration as well as impact.

5   Survey Findings

5.1   Presentation of analysis

The findings from this survey are visualised through a series of heat maps. A heat map reflects the intensity or level of service provided along a spectrum from the highest to the lowest incidence of provision. The heat map uses red to white to blue as the spectrum of colour to reflect lowest to highest incidence of provision.

- Red - a service at the lower end of the number of organisations providing the service within a particular category: the deeper the red, the lower the number of providers;
- White - a service that is the median number of organisations providing the service within a particular category;
- Blue - a service that is at the higher end of number of organisations providing the service within a particular category: the deeper the blue, the higher the number of providers.

The **illustrative** example below provides a visual demonstration of how the colours and the depth of the colour reflect the "heat"/breadth of the numbers of organisations providing Service X.

	CHO	CHO	CHO	CHO	CHO	CHO	CHO	CHO	CHO
Service X	1	2	3	4	5	6	7	8	9

The number of organisations that provide Service X within this category is lowest in CHO 1

The median number of organisations that provide Service X within this category is the midpoint of the frequency of values in CHO 5.

The number of organisations that provide Service X within this category is highest in CHO 9

Three points need to be considered when reading the findings of the service mapping survey:

1. Differences in numbers of providers per category verses number of survey respondents.

2. Services included under more than one category.

3. "Other" services listed.

1. There is a difference between the highest number of providers in each of the categories and the overall number of respondent organisations for the reasons outlined below:

   a. An organisation does not provide all of the listed services;
   b. One organisation can provide the service in one or across multiple CHOs;
   c. The organisation(s) that provide(s) a service in one CHO may not offer the service in a different CHO.

For example, using Assessment and Planning overleaf to illustrate the point, the difference between the highest number of providers (15) and the overall number of respondent organisations (29) in Assessment and Planning category because:

   a. An organisation does not provide Person centred plan as a service but does provide other Assessment and Planning services;
   b. One organisation can provide the service in one or across multiple CHOs;
   c. The organisation(s) that provide(s) Person centred plan in CHO 5,7 and 9

2. There are services that are included under more than one category in the survey tool. This is to reflect the appropriate context for that service. Where a service is provided in more than one category e.g. Day Service Employment under Vocation/Employment/ Training/Rehabilitative Supports and Therapeutic Day Services under Therapies/ Therapeutic Services, repetition is noted with an asterisk (*).

3. For each category, an "Other" option was available where respondents were asked to indicate any services that are provided by their organisation that they believed were not included in the list of services. Respondents were asked to ensure that any services they listed under "Other" were not already included in the category or in another category. The answers provided are included verbatim in Appendix 2, including where services were listed in another category.

The analysis will describe the variation in the type of services provided within each CHO, the opportunities for collaboration potential for replication of good practice, and whether more detailed analysis is required.

5.2   Organisations who participated in the survey

A total of 44 respondents completed the survey out of a potential 48. This is a very robust response rate and testament to the interest of the voluntary sector in contributing to the understanding of provision of services to people with neurological conditions in Ireland and to the work of the project partners in ensuring awareness of the project within the sector, understanding of what was involved and encouragement to complete the survey.

The number of responses in each category is dependent on the number of organisations that provide at least one service in one of the CHOs. Therefore, each question is analysed on an individual basis.

In order to ensure the anonymity of individual organisations, no heat map depicts provision by organisation as this could lead to organisations being identifiable. The heat maps follow with further detail provided on the responses under "Other" in Appendix 2.

5.3 Assessment and Planning

A service which includes formal and informal assessments, or the development of individual service or person-centred plans.

Service Types	CHO1	CHO2	CHO3	CHO4	CHO5	CHO6	CHO7	CHO8	CHO9
Neuropsychological - assessment	2	3	3	2	4	3	4	2	4
Neuropsychological - plan	2	2	3	2	4	3	4	2	4
Community rehabilitation team - assessment	3	2	4	3	4	3	3	3	4
Community rehabilitation team - plan	3	2	4	4	4	3	3	3	4
Multi-disciplinary assessment	2	2	5	3	3	3	4	2	4
Multi-disciplinary plan	3	2	4	3	3	3	4	2	4
Person-centred plan - assessment	6	5	9	8	9	8	10	6	10
Person-centred plan - plan	12	13	13	14	15	14	15	12	15
Vocational - assessment	3	3	5	4	4	5	5	3	5
Vocational - plan	5	5	6	6	6	7	7	5	7
Other	7	8	7	8	8	7	7	7	7

29 organisations provide at least one service

Highest number of providers:
Person-centred plan – 15 organisations in CHO 5,7&9
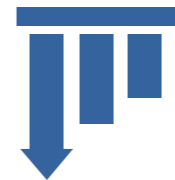
Lowest number of providers is 2
6 out of 10 services are only provided by 2 organisations

0 No services had a zero response

5.4   Therapeutic and Clinical Supports

Service interventions to improve health or reduce disability, whether from a healthcare professional, allied health professional or other qualified professional.
(The * represents services that are also included in other categories).

Service Types	CHO1	CHO2	CHO3	CHO4	CHO5	CHO6	CHO7	CHO8	CHO9
Specialist Nurse (condition specific)	2	3	2	2	2	2	4	2	2
Specialist Nurse - Led Helpline	2	3	3	2	2	2	2	2	2
Palliative Care Nursing	1	1	2	1	2	1	1	1	1
Menatl Health Nurse	0	0	1	1	1	0	0	0	0
Nurse (other than listed above)	2	1	2	1	2	1	3	0	2
Physiotherapy	5	4	6	4	7	4	5	4	6
Speech and Laguage Therapy	1	2	2	1	3	1	2	1	3
Occupational Therapy	2	2	4	3	4	2	3	3	4
Dietician Services	1	2	2	1	2	1	1	1	1
Neuropsychological Therapy	1	2	4	2	2	3	3	1	3
*Social Work	2	2	4	4	4	3	4	3	4
Counselling and Psychotherapy	11	9	10	10	11	9	10	8	10
Cognitive Rehabilitation	1	3	4	4	3	3	4	2	5
Specialist Excercise Programmes	5	5	5	5	6	6	6	4	7
Community Rehabilitation	4	3	6	5	5	5	5	4	6
Continence Service	1	1	1	1	3	1	2	1	2
Group-Exercise Programmes in the Community	6	6	6	6	5	6	7	5	7
Provision of Complementary therapies	9	5	5	5	7	6	7	7	7
Music Therapy, Art Therapy, Horticultural Therapy, Drama Therapy	10	10	11	10	9	9	10	8	11
Other	4	3	5	4	4	5	4	3	4

33 organisations provide at least one service
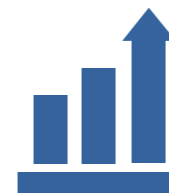
Highest number of providers:
Provision of Complementary Therapies – 11 organisations in CHO 3 & 9
Counselling and Psychotherapy - 11 organisations in CHO 1 & 5

Lowest number of providers is 1 for:
Palliative Care Nursing in CHO 1,2,4,6,8 & 9
Mental Health Nurse in CHO 3,4 & 5
Nurse other than listed above in CHO 2,4 & 6
Speech and Language Therapy in CHO 1,4 6 & 8
Dietician Service in CHO 1,4,6,7,8&9
Cognitive Rehabilitation in CHO 1
Continence Service in CHO 1,2,3,4,6 & 8

0 Mental Health Nurse is not available in CHO 1,2,6,7,8 & 9 from the surveyed voluntary organisations

5.5 Supported Living/Accommodation Support

Service interventions to improve health or reduce disability, whether from a healthcare professional, allied health professional or other qualified professional. (The * represents services that are also included in other categories).

Service Types	CHO1	CHO2	CHO3	CHO4	CHO5	CHO6	CHO7	CHO8	CHO9
Independent Living Suupport	8	7	9	9	7	9	8	7	7
*Home Care Services - supported living	7	6	7	7	7	6	6	6	6
*Personal Assistant Services - supported living	4	3	5	5	3	3	2	3	2
Provision of Short-Term Accommodation in the Community	2	1	1	1	1	1	1	1	1
Provision of Long-Term Accommodation in the Community	2	2	3	2	3	2	1	2	1
Long Term Supported Living Services	4	4	5	4	5	3	4	4	3
Step Down Care	0	1	0	0	0	0	0	0	0
Residential Rehabilitation	2	2	2	2	2	2	2	2	2
Transitional Living Services	1	1	1	0	1	0	0	0	0
Other	5	4	4	5	5	5	5	5	6

23 organisations provide at least one service
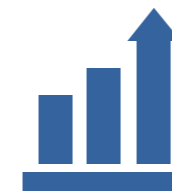
Highest number of providers:
Independent Living Support – 9 organisations in CHO 3,4,6

Lowest number of providers is 1 for:
Short-Term Accommodation in the Community CHO 2,3,4,5,6,7,8 & 9
Long-Term Accommodation in the Community CHO 7
Step Down Care CHO 2

0 Step Down Care is not available in CHO 1, 3, 4,5,6,7,8 & 9 and Transitional Living Services is not available in CHO 4,6,7,8 & 9 from the surveyed voluntary organisations
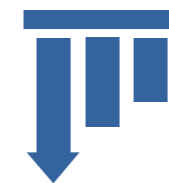
5.6 Respite

Services which provide a break from normal routine to reduce stress for the person or family member. (The * represents services that are also included in other categories).

Service Types	CHO1	CHO2	CHO3	CHO4	CHO5	CHO6	CHO7	CHO8	CHO9
Provision of Short Breaks	5	4	6	3	4	3	4	3	3
*Personal Assistant Services - Respite	4	2	3	3	3	2	2	2	2
*Home Care Services - Respite	3	2	2	1	2	2	2	1	2
Respite Hours	2	2	3	2	2	1	1	1	1
Emergency Respite	3	2	3	3	3	2	2	2	2
Residential Respite	3	2	4	2	3	3	3	2	1
Alternative Respite (Holiday Breaks)	5	5	5	4	5	3	3	3	4
In-Home Respite	3	3	3	2	2	3	2	2	2
Out-of-Home Respite	3	2	3	2	1	1	1	2	2
Nursing Home Respite	0	0	0	1	1	0	0	0	0
Dedicated Respite	2	1	2	2	1	1	3	1	1
Other	5	3	6	4	3	4	4	5	3

20 organisations provide at least one service, which is the lowest of all categories
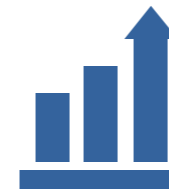
Highest number of providers:
Provision for short breaks – 6 organisations in CHO 3

Lowest number of providers is 1 for:
Home Care Services CHO 4
Respite Hours CHO 6,7,8 & 9
Out-of-Home CHO 5,6,7
Nursing Home Respite CHO 4 & 5
Dedicated Respite CHO 2,5,6,8 & 9

0 Nursing Home Respite is not available in CHO 1,2,3,6,7,8 & 9 from the surveyed voluntary organisations

5.7 Accessibility Supports, Activities of Daily Living and Long-term supports

Services which offer aids or assistances that enable a person to live more independently or that help sustain long term wellbeing and independence. (The * represents services that are also included in other categories).

| Service Types	CHO1	CHO2	CHO3	CHO4	CHO5	CHO6	CHO7	CHO8	CHO9
Provision of General Aids, Appliances and Equipment (walking aid, shower chair)	3	2	3	3	4	3	4	2	4
General Communication Aids or Devices	6	6	6	6	7	5	6	6	7
Provision of Specialist or Bespoke Equipment (eg. wheelchair, provision of voice messaging/message banking/ voice repair)	4	5	4	4	5	4	4	5	4
Custom Posture/Seating Service	1	1	1	1	2	1	1	1	1
Equipment Loan Services	4	3	4	4	4	3	3	3	3
Assistive Technology	6	6	7	7	7	6	6	6	7
Computer Apps/Software	5	5	5	5	6	5	5	5	6
Driving Assessment and Supports	0	1	1	1	0	0	0	1	0
Provision of Dedicated Transport Services	4	3	3	3	3	4	5	3	5
*Personal Assistant Services - accessibility supports	3	2	4	3	2	1	1	2	1
Alarms	6	6	6	6	6	6	6	6	5
Day Rehabilitation Programme(s)	3	4	5	5	5	5	5	3	6
*Day services - accessibility supports	3	3	5	4	4	4	5	3	6
Other	5	5	5	5	5	6	5	5	6

27 organisations provide at least one service

Highest number of providers:
Assistive Technology - 7 organisations in CHO 3, 4, 5 & 9
General Communication Aids and Devices - 7 organisations in CHO 5 & 9
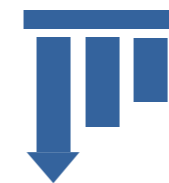
Lowest number of providers is 1 for:
Custom Posture/Seating Service in CHO 1,2,3,4,6,7,8 &9
Driving Assessments and Supports in CHO 2,3,4 & 8
Personal Assistant Service – accessibility supports in CHO 6,7 & 9

0 Driving Assessments and Supports is not available in CHO 1, 5,6,7 & 9 from the surveyed voluntary organisations

## 5.8 Community Integration and Participation

Services which reduce the barriers to participating in a person's local community or maximise involvement in local community life.

Service Types	CHO1	CHO2	CHO3	CHO4	CHO5	CHO6	CHO7	CHO8	CHO9
Rehabilitative Training Services	4	4	5	5	4	5	5	4	7
Individual Community Rehabilitation	5	4	6	6	5	5	5	5	6
Social Prescribing	4	4	5	5	3	3	3	4	3
Self-Management/Symptom Management Programmes & Resourses	12	12	13	14	11	12	12	12	12
Leisure Activities/ Programmes	13	11	13	14	11	12	14	11	14
Peer Support Programmes	19	18	19	20	18	19	19	18	20
Other	4	5	2	3	4	6	5	4	5

35 organisations provide at least one service

Highest number of providers:
Peer Support Programmes - 20 organisations in CHO 4 & 9
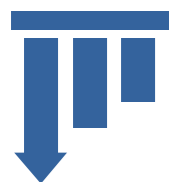
The lowest number of providers was 3 for:
Social Prescribing in CHO 5, 6, 7, and 9

0 No services had a zero response

5.9 Vocational/Employment/Training/Rehabilitative Supports

Services which help a person access, or retain employment, further education or training or other meaningful occupation e.g. volunteering (The * represents services that are also included in other categories).

Service Types	CHO1	CHO2	CHO3	CHO4	CHO5	CHO6	CHO7	CHO8	CHO9
Support to Retain Employment	7	7	8	8	8	8	8	7	9
Return to Work Programmes	6	6	7	7	7	7	7	6	7
Vocational Rehabilitation Programmes	4	4	4	4	4	5	5	4	7
*Rehabilitative Training - vocational	3	3	4	4	3	4	4	3	6
Vocational Training	4	4	6	5	5	5	5	4	6
Information Talks to Employers	7	7	9	8	8	8	8	7	9
*Day Services - vocational	1	1	3	2	2	2	2	1	4
Other	3	3	3	3	3	4	4	3	4

22 organisations provide at least one service

Highest number of providers:
Information Talks to Employers – 9 organisations in CHO 9
Support to Retain Employment – 9 organisations in CHO 3 & 9

The lowest number of providers is 1 for:
Day Services – vocational in CHO 1, 2 & 8

0 No services had a zero response

5.10 Information, Advocacy and Education

Formal or informal provision of relevant information, education, or representation to assist a person exercise their rights.

Service Types	CHO1	CHO2	CHO3	CHO4	CHO5	CHO6	CHO7	CHO8	CHO9
Information and Support in all grants and entitlements, e.g., Social Protection Entitlements, medical card, dug payment scheme, housing adaption grants	20	20	21	20	21	21	22	20	21
Information and Guidance on Legal Matters	7	6	7	6	7	6	6	6	7
Information Helplines(s)	19	19	18	18	19	18	18	18	18
Personal Advocacy Support	21	21	22	21	21	21	23	21	23
Support Groups / Information Talks for people with the condition / Peer Support Service / Peer Support Groups	29	28	27	27	26	27	26	27	27
Access to Social Events	19	18	20	20	17	20	21	17	21
Online Forums/Webinars	25	24	24	24	25	24	24	23	25
Online Learning Resources	14	15	15	14	15	15	15	14	15
Information Resources: Websites, Newsletters, Leaflets, Publications	28	28	28	27	27	28	28	27	29
Access to Hardship Funds	12	12	11	12	12	11	12	11	12
Palliative care and End of Life Information and Support	6	7	7	7	7	7	7	6	7
Other	9	8	8	8	9	8	8	8	8

42 organisations provide at least one service, the highest for any category
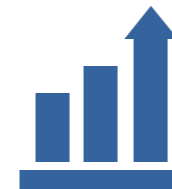
Highest number of providers:
Support Groups/Information Talks – 29 organisations in CHO 1
Information Resource – 29 organisations in CHO 9
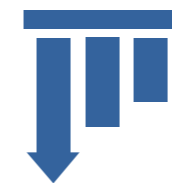
The lowest number of providers is 6 for:
Information and Guidance on Legal Matters in CHO 2,4,6,7 & 8
Palliative care and End of Life Information and Support in CHO 1 & 8

0 No services had a zero response

## 5.11 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. (The * represents services that are also included in other categories).

Service Types	CHO1	CHO2	CHO3	CHO4	CHO5	CHO6	CHO7	CHO8	CHO9
Support Groups / Fora for family Carers	16	15	15	15	18	17	17	15	17
Family Carer Information & Training Sessions/ Programmes	14	15	15	15	16	15	15	14	15
Support Worker(s) with Specific Family / Carer Support Remit	8	8	10	9	11	9	10	8	10
*Social Work	3	3	4	5	5	4	5	4	5
Psychological Supports for Families	10	10	11	12	12	11	12	10	12
Family Training e.g., around equipment use, excercise	7	8	7	7	9	7	8	7	8
*Respite - Family and Caregiver	6	4	5	5	4	5	5	5	4
Family and Care Giver Peer Support	14	14	15	14	15	15	14	13	14
Holistic Services	8	5	6	5	5	5	5	5	5
Other	7	6	7	8	6	7	7	6	6

34 organisations provide at least one service, the highest for any category
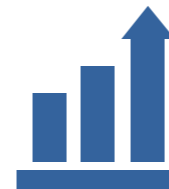
Highest number of providers:
Support Groups/Fora for Family Carers – 18 organisations in CHO 5
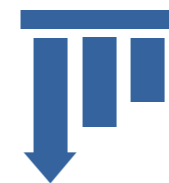
Lowest number of providers is 3 for:
Social Work in CHO 1 & 2

0 No services had a zero response

5.12 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

Service Types	CHO1	CHO2	CHO3	CHO4	CHO5	CHO6	CHO7	CHO8	CHO9
Individual Case Work Services(s): supporting engagement with health/ disability/community services	16	15	17	17	17	16	17	15	17
Community Worker or Key Worker Service(s)	10	9	11	10	11	11	12	9	11
Case Management	6	5	7	7	7	7	8	6	8
Other	5	4	4	5	5	4	4	4	4

30 organisations provide at least one service

Highest number of providers:
Peer Support Programmes - 20 organisations in CHO 4 & 9

Lowest number of providers is 5 for:
Case Management in CHO 2

0 No services had a zero response

6   Joint Service Initiatives

6.1   Introduction

The HSE and all the voluntary organisations who gave their consent to participate in the survey were invited to provide a submission on a Joint Service Initiative (JSI) where they collaborated with another voluntary organisation and/or with the HSE. 13 submissions were sent to the project partners, who selected a representative sample of 5 to be contacted by Crowe. Crowe interviewed the JSI partners who had jointly sent the submission. All interviews, apart from one, were attended by voluntary organisation(s) and the HSE and in the one case where only the voluntary organisation was available, they communicated with their HSE partner in advance of the interview.

This section tells the story of 5 JSIs:

- Cognitive Rehabilitation
- Active Neuro
- Kerry Stroke Day Service
- Physiotherapy Assistant Programme and
- Galway Acquired Brain Injury.

The JSIs provide a project overview (taken from the submission) and interviewees views on:

- rationale for the project
- positive impacts
- challenges encountered, and
- recommendations for other collaborative projects.

6.2   Synthesis of Joint Service Initiative

The purpose of the JSI is to draw insights from existing collaborations between the voluntary and statutory services, as to the merits of a partnership approach to delivering services for people with neurological conditions and guidance to support sustainability. Although the JSIs that are presented represent a range of different types of service collaboration, the following themes emerge, that when applied underpin a partnership that will benefit service users:

- There should be a thorough stakeholder consultation on commencement, as this helps to build foundations to support sustainable collaboration and establishing a shared vision for the project.

- The project will benefit where roles of each partner/service are clarified and the work is divided out appropriately with all stakeholders, ensuring the involvement of service users in design and ongoing feedback.

- Solid governance, protocols and communication arrangements need to be put in place to build trusting and open relationships between partners.

- It can be beneficial to start with a pilot to road test services before formalizing services.

- It is important to keep relevant stakeholders informed and to have accessible information for service users, being careful to set out realistic expectations, and clarify access routes.

- Finally, as part of the management and oversight, it is important to agree deliverables and KPIs which reflect the added value of collaboration. In addition, a system should be in place to track referrals, activity, outcomes (both qualitative and quantitative). These systems will enable objective evaluation that will capture outcomes and outputs, to ensure robustness of the project and support sustainability.

At the time of the interviews, four out of five of the JSIs were still collaborating. The JSI that was no longer collaborating had concluded the specified project period for which they were funded and had applied for further funding to continue the project into a second phase. Since this interview, we have received confirmation that the JSI in question has been granted funding to restart the programme.

The majority of JSI partners said they did not face any major challenges when they first started their JSI. They also said there were no challenges that could not be overcome. When JSI partners were asked if they would consider collaborating with other state agencies or voluntary organisations, all said they would and emphasised the importance of ensuring the benefit of collaborating for their service users and for all JSIs partners.

The write up that follows is based on the contribution by the JSI partners at the time of the interview. All interviewees have been sent the notes that follows and have signed-off on the content.

6.3 Cognitive Rehabilitation

6.3.1 JSI partners

JSI partners	Title
Aidan Larkin	MS Ireland - National Service Development Manager
Pauline O'Dwyer	HSE – Case Manager Galway East

6.3.2 Project overview (Extract from the JSI submission)

MS Ireland highlighted the lack of support for people with MS experiencing cognitive deficit to the HSE. A project was established with RehabCare to deliver a cognitive rehabilitation project using the expertise within RehabCare and developing a tailor-made programme for people with MS in Galway. Cognitive deficit is a very silent symptom which can have a significant impact on the person with MS and also on their wider family system. Management of cognitive difficulties may focus on either remedial strategies or on the development of compensatory strategies.

An assessment is carried out at the beginning of the service to identify the specific areas of difficulty, and a therapeutic plan agreed with the person with MS and family members as appropriate. The service takes a client centred approach, and where possible the client will work with the team to identify the therapeutic goals that are most important to them.

Areas that are addressed are as follows: memory using external aids for improving memory, attention, concentration, planning, visual special information, fatigue management, gaining awareness/education about MS itself. Cognitive deficit is also addressed in relation to its effect on the individual's life.

As a project it demonstrates that expertise within one agency can be utilised to the benefit of other groups. The benefits to the MS cohort have been immense. Developing strategies to compensate for some areas of cognitive deficit has had a great impact both on the participants within this project but also on the wider family unit and extends into the employment space. This project receives referrals from MS Ireland, HSE Primary Care and UHG. In the absence of a comprehensive neuropsychological service in CHO2 this project is critical in both responding to cognitive deficit in a MS population and in developing evidence based compensatory strategies to address same.

6.3.3 Rationale of the Joint Service Initiative

- **Inspiration behind the Joint Service Initiative**

MS Ireland had identified there was a lack of services available for people with cognitive issues. If the client is not at a P1 level, they may spend significant time on a waiting list and cognitive deficit can accrue in the meantime. MS Ireland highlighted this issue to the HSE, which led to the collaboration. Services are provided in CHO 2, Galway. This collaboration project aims to address cognitive deficit issues as they are recognised by the person with MS and/or other health care providers in conjunction with the person with MS. This intervention then seeks to develop strategies to manage these issues.

- **Steps involved in developing the Joint Services Initiative**

As MS Ireland and the HSE have collaborated on previous projects, they were "natural partners" to resolve the gap of the service. Furthermore, people with a particular skill set are required to provide this service. There were regular meetings with disability managers and case managers for the set up.

- **Roles of the JSI partners**

MS Ireland are described as the "caseware service" and the HSE are the "case management service". MS Ireland act as the referral agent. Applications are sent to the HSE Disability Services Case Managers for review which are generally discussed prior to receiving the application. Applications are then forwarded to RehabCare. MS Ireland, HSE Case managers and RehabCare meet every 6 weeks to review the progress of applicants and potential new applicants.

The HSE acts as a funder of the service. The referrals are tracked and sent to RehabCare. Relationships are then built through the tracking phase. The HSE Physical and Sensory services have a more generalist approach to supporting clients as they work with individuals from all physical and sensory disability backgrounds one of which is MS. However MS Ireland solely support individuals with an MS diagnosis and specialise in supporting this client group only. "The collaboration works as there is a generalist and specialist working together" and this leads to a more "seamless service" which incorporates support for both the physical and cognitive aspects of MS support.

6.3.4 Positive impacts

Greatest achievement noted by JSI partners in terms of the collaboration

- The **long-term relationship** built around the programme (which has been running for 10 years).
- Building a **relationship with University of Galway** and sustaining a relationship with the main point of contact. "Building the academic relationship with NUIG **allows academic research to marry with service practice**".
- The **growth of the individuals themselves**.

Successful outcomes

- The **progress and growth of the service users** themselves. Service users are provided the cognitive support and information to be able to process and work through strategies / routines to keep improving.
- Service users are availing of a **more seamless service pathway**.
- **Creating awareness of MS** and cognitive rehabilitation services.

Ingredients of successful collaboration

- The key ingredient for a successful relationship building **a sustainable relationship** that is **mutually beneficial** to all parties. People being involved for a long-time means **building long-term relationships, trust and a reputation**.
- MS Ireland works with the HSE regularly, they view each other as **natural partners** and **can lean on one another** and work **as equals**.
- The JSI partners are capable of **freely discussing thoughts** and insights and **communicate on regular basis** maintaining their relationship.

6.3.5 Challenges

Challenges encountered during the collaboration were:

- Challenges currently faced is **resource availability**.

  - The service is currently only available in one CHO (CHO 2, Galway).
  - MS is a progressive disease and interventions are provided at a moment in time but repeat interventions are required as client's status changes. There are staffing issues to fulfil this need.

- There is no specific tracking system for outcomes, number of referrals, number of applications etc. A client management cloud-based system would provide better reporting and data that the current use of Excel. MS Ireland, therefore, find it **difficult to "sell" rehabilitation care and the experience benefits to the primary occupational therapist and neurological services in hospitals**. This **requires both qualitative and quantitative data**.

6.3.6 Conclusions

Lessons learned
The lessons learned on this collaboration include:

- Set up a **robust system to measure KPI's**.
- Have an **evaluation system** that looks at data and trends.

Recommendations for others completing a similar project

The recommendations provided to other organisations that intend to set-up a similar project include:

- **Set up a robust system to measure outcomes**, this helps **build a business case and identify any opportunities**.
- **Seek introductions to academic contacts** to develop research and outcome measurement data.
- **Position and promote your service and include success stories** e.g. on the HSE website.
- Have **a steering committee with a variety of stakeholders that reports regularly**.
- **Design and agree clear deliverable actions**.

6.4 Active Neuro

6.4.1 JSI partners

JSI partners	Title
Dr. Susan Coote	Clinical Specialist Physiotherapist / Exercise Coordinator
Marian Mullaney/ Louise Crowley	Limerick Primary Care Physiotherapy Manager in Charge III
Phelim Macken	Limerick Sports Partnership

6.4.2 Project overview (Extract from the JSI submission)

Active Neuro provides health promoting physical activity programmes for people living with neurological conditions in the community. Funded by the SláinteCare Integration Fund and hosted by MS Ireland, this pilot project in the Mid-West increased the availability of and access to a range of exercise programmes for people with static and progressive neurological conditions such as stroke, Parkinson disease, Multiple Sclerosis, brain injury and hereditary ataxias. Using a cross sectoral, integrated care approach, this project brought together a range of stakeholders from the HSE, University, charity and community sectors to collaborate to share knowledge and skills, optimise efficiency of service delivery, avoid duplication of services and importantly to develop pathways from acute, through Primary Care for each on each use and on to charity and community services.

6.4.3 Rationale of the Joint Service Initiative

Inspiration behind the Joint Service Initiative

MS Ireland partner, Dr. Susan Coote, was working as an academic researcher in University of Limerick, researching evidence-based physiotherapy programmes and identified challenges in implementing this research into practises. Additionally, people with MS consistently searched for a service that focused on physical activity, as they felt they required it the most, but were unable to access it. As people with MS are a minority group, health promoting exercise interventions for people with MS were, for the most part, absent. As a result, Active Neuro was born of void in service provision and a need for funding. The programmes provided by Active Neuro aimed to enable people to live well at home, reducing demands on the overstretched Primary Care services, acute hospital and A&E usage.

- **Steps involved in developing the Joint Service Initiative**

    In developing Active Neuro, one of the main tasks involved was applying for funding for the programme. A proposal was developed by the JSI partners, MS Ireland and the HSE Primary Care Manager, and sent to the Department of Health. The application was successful in receiving funding from the SláinteCare Integration Fund.

    Once funding was approved, a mapping and gapping evaluation took place to establish what services were currently available to people with neurological conditions. The evaluation involved a consultation process with 24 different organisations (which were identified through word of mouth) across acute, early discharge, neurorehabilitation, community-based organisations, sports partnerships, private physios and gyms.

There was an open competition for project posts including for people with specific neurological skills.

- **Roles of the JSI partners**

The core JSI partners were MS Ireland and the HSE and there were links to other organisations in other relevant sectors, for example, Parkinson's Society MW, Sports Partnerships in Limerick, Clare, and North Tipperary and University of Limerick, Physiotherapy Programme. In this JSI, groundwork completed by JSI partners included identifying organisations willing to collaborate.

The wider links allowed the programme to have the ability to be flexible and incorporate various sectors views and insights in developing a programme for people living with neurological conditions.

Referrals came from a range of sources including the participants themselves and outwards referrals were to the Sports Partnerships through their Sports Inclusion Disability Officers and to community gyms and activities.

6.4.4 Positive impacts

Greatest achievement(s) noted by the JSI partners in terms of the collaboration were:

- **The public consultation at the start and setting up the stakeholder forum**, bringing all stakeholders together in one place as a group "so everyone knew what everyone else was doing and they realised there was an awful lot happening they didn't know about before".

- The ability to **adjust to the pressures of Covid-19**. The impact of Covid-19 meant service users were unable to access the programme for 4 weeks. The **JSI partners were flexible and adapted by providing the programmes online** to service users. JSI partners were **concerned that the transition to online would impact the social aspect for service users, but the opposite was true**, they thoroughly enjoyed the online programmes. There was still the "banter" and "craic" online that was in the in-person groups.

- Generating qualitative and quantitative data and having the structure to do it and show that there are positive outcomes for the service users that are valued.

Successful outcomes mentioned were:

- The positive impacts of this JSI was **the value of filling the post-rehabilitation void** which was a success for all stakeholders and particularly the service users themselves.

- The service users **improved their physical and mental health**. Physiotherapy led programmes combined **exercise and education to reduce symptom severity, increase exercise confidence and promote self-management.**

- Through the **online transition, participation and completion levels increased** due to the breadth of people with neurological conditions who could now access the programme. Having the classes online **eliminated travel time, fatigue, finance expenses and finding babysitters for children.**

- The "Unique Selling Point (USP) was **how cross-sectoral the Active Neuro project was**".

- Previously, groups tended to be mixed but **online made groups more homogenous-stick**, wheelchair, rollator users - so **peers could talk about specific needs**.

- The shift to online allowed service users **to maintain a social connection** with members of the groups outside of programme hours as the zoom links were left open to maintain social connection. This **also allows** the legacy of the "Active Neuro" **programme to live on**.

- **Experience surveys revealed high levels of satisfaction with the programmes** that was supported by excellent attendance and completion rates. The age range of participants varied from 20-92 years old. Most participants had progressive conditions (PD and MS) and for them maintaining status is positive. Participants reported that the group intervention allowed them **to reside in a community of social support** whilst **accessing the specialist physiotherapy** they required. Through the statistics and data below the JSI developed a business case for a second phase.

- Project data showed that of the participants involved in this project that:
  - 71% improved their leg strength;
  - 56% had an improvement in fatigue;
  - the number of fallers reduced by 49% from 39 to 20 fallers;
  - the number of falls reduced from 276 to 192 (30% reduction) and
  - 43% (66/153 people) reduced their usage of healthcare services.

Ingredients of a successful collaboration noted during the interview were:

- Being **open to finding new connections** with people who you think are not within the project remit.

- **Creating personal relationships with the people you are working with and understanding their needs**.

- **Having regular meetings** with all stakeholders involved, giving updates and opportunities to highlight issues that may be arising.

- **Communicating with the service users** themselves and **identifying areas of improvements**.

- **Understanding that service users are one of the key partners**. During this joint service initiative, service users were contacted at the end of every block of treatment to gather their views, insights and progress. "**Engaging with them and really listening is key**".

6.4.5 Challenges

Challenges encountered during the collaboration were:

- **As a consequence of Covid-19**, resources from all sectors of the HSE focused on the implications and consequences of Covid-19, leading to a **lack of availability of some the project stakeholders**.

- **Managing numbers due to oversubscription**.

- Another challenge involved finding a clinical partway through the service as some participants felt that they needed physiotherapy all the time so a change of mindset was needed. Therefore, the programme took an **exercise and education approach aimed at giving participants the skills and knowledge to continue exercise after the programme concluded**. This led to the classes becoming a motivator and confidence-builder for service users as they learned the skills for self-management.

6.4.6 Conclusions

Lessons Learned on this collaboration include:

- The importance of completing the mapping exercise as a first phase, to ensure services are being augmented and not duplicated.

- Effectiveness is improved with a specialist team.

- There is a need to bring people together to learn what is being done. Pay attention to models of care being provided.

- Online can be an opportunity to increase access and age is not a barrier.

- Attendance statistics were not impacted due to the classes being free.

Suggested **recommendations for other collaborative projects were**:

- Where relevant, apply for the SláinteCare integration fund as a kick-starter. It was very important to the success of this project.

- Be open to communicating with a wide remit of stakeholders from a variety of sectors.

- As a charity, you are best placed as the link point between acute, primary care, disability services and other partners (sports partnerships in this case) in terms of community integration.

- Create a stakeholder forum from the start, including JSI partners, wider links and service users.

6.5   Kerry Stroke Day Services

6.5.1 JSI Partners

JSI partners	Title
Paddy Garvey	Baile Mhuire Day Services – Board of Directors
Eibhlis Cahalane	HSE - Physiotherapist Lead
Finbarr Mawe	Ard Chúram Day Centre - Chairperson

6.5   Kerry Stroke Day Services

6.5.1 JSI Partners

6.5.2 Project Overview (Extract from the JSI submission)

The Stroke Day Service was set up in 2018 in response to a need identified by the Kerry Stroke Support Group and is as a result of a unique partnership between the HSE, the two voluntary agencies (Baile Mhuire Day Care Centre for Older People and Ard Chúram Day Care Centre) and the Kerry Stroke Support Group. The service is delivered in Baile Mhuire Day Care Centre for Older Persons in Tralee and in Ard

Chúram Day Care Centre in Listowel. The aim of the Stroke Day Service is to provide a much needed community service for people post stroke by providing a programme that offers a mixture of physical activity, socialisation and mental stimulation in the existing day centre setting. A multidisciplinary team in each of the two centres consists of a physiotherapist, nurse manager, exercise facilitator, health care attendants and an occupational therapist who manage the programmes that run one day a week for 8-10 weeks at a time. The team is a mixture of HSE and voluntary agency staff allowing a flexible approach to the service which has adapted in response to client's needs.

An evaluation of the programme, which was facilitated by the Munster Technological University in Tralee in 2019, demonstrated the many physical and quality of life benefits for both the participant and their family members/carers. The Stroke Day Service is attempting to address the gap in community services in Kerry through the provision of a community-based service and is a direct example of the shift from acute care to the community as recommended in many policies including the Sláintecare Report. The incorporation of physical activity with opportunities for socialisation and mental stimulation is a unique attribute of this Stroke Day Service and the evaluation has demonstrated both physical and psychological benefits as a direct result of the programme.

6.5.3 Rationale of the Joint Services Initiative

- **Inspiration behind the Joint Service Initiative**

The Kerry Stroke Support Group advocate for people post stroke and meet on a monthly basis. In a series of these meetings, it was highlighted there was a gap in physical activity services, socialisation and mental stimulation for people post-stroke in the area and in the existing day centre setting. The Kerry Stroke Support Group highlighted this to the HSE, Baile Mhuire Day Care Centre and Ard Chúram Day Care Centre who now provide the service in Tralee and Listowel respectively.

- **Steps involved in developing the Joint Service Initiative**

The steps involved in setting up this collaboration involved:

1. Establishing a committee with stakeholders from all parties involved. This committee included representatives from the HSE, Baile Mhuire Day Service, Ard Chúram Day Centre and members from Kerry Stroke Support Group.
2. The committee discussed the need, set-up, model and aim of this collaboration.

1. Kerry Stroke Group submitted a business plan for development and as a result funding was allocated to Balie Mhuire Day services and Ard Chúram Day centre.
2. Setting up pilots, allowing for evaluation and understanding the practicalities of the collaboration.
3. Kerry Stroke Group submitted a business plan for development and as a result funding was allocated to Balie Mhuire Day services and Ard Chúram Day centre.
4. Setting up pilots, allowing for evaluation and understanding the practicalities of the collaboration.

- **Roles of JSI partners**

Both JSI partners, Baile Mhuire Day Service and Ard Churam, have an excellent relationship with the HSE as they both have collaborated on previous projects with the HSE. This pre-existing relationship and the good governance structures in both agencies facilitated the establishment of the stroke day centres.

A vital stakeholder involved in this collaboration and contributor to the success of this project was the presence of the community workers. Community workers play a key role in linking voluntary agencies with the HSE. They assist community based voluntary groups in funding applications and establishing correct governance and policy/procedures in establishing services for the people living in the community.

6.5.4 Positive impacts

Greatest achievements noted by JSI partners in terms of the collaboration

- **Positive impact of the Stroke Day service for service users**.

- Having a **great team relationship across the team. Learnings were shared** amongst team members and **together they reviewed, resolved and communicated issues**.

- With each new stakeholder, the team learned something new. There was a **fluent and efficient communication process**.

- "**The collaboration is a unique clinical input in a community setting**", allowing for **easier collaboration with other local organisations services** (e.g. local gyms, yoga classes, mindfulness etc) and **flexibility** in conjunction with the HSE, **while still having a set structure**.

- Pilot **outreach project to the south of the county has meant that people who could not travel could access the service**.

Successful outcomes mentioned were:

- Service users grew in **confidence based on personal achievements and experienced improved physical and mental health** by participating on the programme.
- The programme was **also beneficial to carers by providing an element of respite for carers/family members**.
- After the 8-week programme was completed, **participants saw the benefits** and did not want to leave the programme.
- The service users had increased opportunities for **social interactions**.
- **Re-purposing and adapting the programme during Covid-19**.

Ingredients of a successful collaboration noted during the interview were:

- The key for this collaboration is **eagerness, trust, communication, and having a pre-existing relationship between the HSE and the voluntary agencies which was fostered through effective HSE Community workers**.
- **Continuously linking** up with voluntary organisation and **advocating for the members of the community**.
- Having a **shared interest, vision and wanting to improve the services available, fill the gaps, reach out** and **learn from the experience**.

6.5.5 Challenges

Challenges encountered during the collaboration

The JSI partners did not face challenges they could not overcome as the willingness was there. The relationship was built already due to previous collaborations; therefore the JSI partners knew the protocols and routines. COVID-19 proved a challenge as it did for many services, however the virtual services continue to be offered and provide new ways of working.

6.5.6 Conclusions

Lessons learned on this collaboration include:

- The **importance of effective team working**.
- Have a **process to evaluate your outcomes and achievements**. The Stroke Day service collaborated with the Munster University college to produce an evaluation document which has been very beneficial.

Suggested **recommendations for others completing a similar project** were:

The JSI partners have provided advice to other centres who hope to collaborate with the HSE in providing this service in different CHO's. The recommendation and advice they provided was:

- Have an effective steering **committee with good representation from all relevant stakeholders**.
- Choosing a suitable community-based venue for the programme.
- **Maximise the community-based resources to** foster and develop the collaborative working relationship.
- **Have a sustainable funding model**.
- **Adapt and change with your learnings**.
- **Get the foundations and governance right at the start**.

6.6 Physiotherapy Assistant Programme

6.6.1 JSI Partners

JSI partners	Title
Aidan Larkin	MS Ireland – National Services Development Manager
Olwyn Hanley	HSE - Physiotherapy Manager

6.6.2 Project overview (Extract from JSI submission)

MS Ireland has a Department of Social Protection sponsored community employment project (CEP) which focuses on delivering FETAC/QQI training to its participants. The JSI partners focus on delivering physiotherapy assistant (FETAC/QQI Level 5) training to the majority of participants through the in-house senior physiotherapist. In addition to the CE participants, inclusion of staff from the HSE, PA support agencies, Enable Ireland, RehabCare and nursing homes avail of an opportunity to increase their skill mix amongst their teams.

6.6.3 Rationale of the Joint Service Initiative

■ **Inspiration behind the Joint Service Initiative**

The JSI partners in this collaboration, MS Ireland and the HSE, had previously collaborated on a programme called 'Getting the Balance Right'. This programme from MS Ireland aimed to augment what the HSE were doing. Therefore, the physiotherapy assistant programme already fitted in to what the HSE and MS Ireland were collaborating on. MS Ireland is in a position to make the physiotherapy assistant available to the HSE physiotherapist and work with the HSE in delivering a programme.

■ **Steps involved in developing the Joint services initiative**

MS Ireland and HSE physiotherapy department have an established long-term relationship and meet regularly. The collaboration started casually - the realisation of a need for a training programme was identified as "it was very difficult to have people deliver the service". From here, the collaboration naturally progressed. MS Ireland were providing supports under their own programme or the HSE Primary Care Physiotherapist would, on occasion, contact MS Ireland for support.

■ **Roles of the JSI partners**

The physiotherapy assistants (PTA) are funded by the Department of Social Protection sponsored Community Employment Scheme. MS Ireland has a service level agreement with the HSE which includes governance responsibilities e.g. the PTA has to have completed FETAC Level 5, so the skill level of professional requirement is met. MS Ireland provides the training programmes, as they have developed the expertise and enhanced communication and insights into the role, and among other agencies, send people to MS Ireland to complete the training programme.

The PTAs work under the supervision of the MS Ireland Senior Chartered Physiotherapist in delivering a range of physiotherapy interventions to people with MS both in person and online. Within primary care services in CHO2, the physiotherapy team often assess people with MS, and other neurological conditions, as requiring additional input and MS Ireland have matched PTAs with the person. In this scenario, the Primary Care Physiotherapist prescribes the treatment, instructs the PTA and supervises the PTA for the duration of the treatment. As PTAs are trained, MS Ireland then inform the HSE of PTAs availability.

6.6.4 Positive impacts

Greatest achievement(s) noted by JSI partners in terms of the collaboration

■ Primary Care offer an **enhanced service to clients who otherwise would not be able to avail of such a service due to the constraints** on their own service resulting in positive therapeutic outcomes.

■ Through the FETAC/QQI training that MS Ireland offer other agencies, e.g. PA support agencies, nursing homes, Enable Ireland, RehabCare, an **increased skill mix** results thus offering a greater client experience for those in need of supervised therapeutic intervention.

■ This **model is a very relocatable** one in this scenario with MS Ireland as the lead agency partnering with the DSP, delivering accredited training to CE participants and other agencies.

■ The collaboration **created awareness of the dearth and lack of focus on the neurological cohort in primary care services** and **increased understanding of what better services can look like**.

■ **Working together in a more collaborative way**, "the sum is better than the parts" and provides **enhanced provision and enhanced outcomes**.

■ **Listening to people with neurological conditions**.

Successful outcomes mentioned were:

- One successful outcome is that a **physiotherapy post is now embedded** as part of the MS Ireland service arrangement so it is a service "we can rely on".
- "MS Ireland and the HSE have a **collaborative and productive relationship**".
- **Programme delivery online resulting in**:

  - 60% of participants would now prefer to stay online because it **reduces the need to travel and maximises their energy**.
  - 70% completion rate at active neuro classes, in excess of in-person classes. "Getting the balance right" highlighted that when services are frequent and increase over time, improvements occur.

Ingredients of successful collaboration noted in the interview were:

- Sharing **common goals and vision**.
- **Keeping service users central**, reminding JSI partners of the needs of people with MS.
- **Willingness and openness to listen and capture key stakeholders' thoughts and insights** through using a collaborative approach including people with neurological conditions.

6.6.5 Challenges

Challenges encountered during the collaboration were:

- **Resource availability**: For example, MS Ireland having enough PTAs available: CE scheme turnover (If a CE participant is aiming to achieve an award, they have three years to do so, otherwise the CE participant is only eligible for the scheme for one year). During Covid-19, community employment was extended. There is no additional funding provided for non-pay costs, this is a challenge as people are matched based on their geography.
- It is difficult to **manage expectations i.e. level of demand v. service**.

6.6.6 Conclusions

Lessons learned on this collaboration include:

- Have **robust governance and protocols**.
- **Create efficiencies**.
- **Capacity: there is one physio per primary care team and there needs to be two: one for neuro and one for musculoskeletal**. This will not change unless there is an increase in resourcing.
- There is **huge gap in service provision in terms of CHOs and even within counties**.
- **HSE broader organisation is not fully aware of the services needed / provided**.

Suggested **recommendations for others completing a similar project** were:

- Have a **structured arrangement with clear governance and protocols to work effectively and efficiently**.
- **Evidence outcomes**.
- **Look at the pathway of conditions**.
- **Cross neurological groups are the future**.

6.7   Galway Acquired Brain Injury

6.7.1 JSI Partners

JSI Partners	Title
Patrick Hannon	Quest – Area Manager
Simon Murray	Abi Outreach – Community service manager
Pauline O'Dwyer	HSE – Case Manager Galway
Ciara Hennigan	Rehabilitation Instructor

6.7.2 Project overview (extract from submission)

Galway Acquired Brain Injury Services (GABI) are delivered by Quest Brain Injury Services, together with RehabCare's Outreach Team. Together, GABI offers services which are free to survivors of brain injury within the community setting. Referrals come through the HSE, and initial assessments with the person and a family member then identify the most appropriate rehabilitative supports. This is based on the person's individual need and then streamed to appropriate services.

Quest's centre-based day rehabilitation service aims to help people with an ABI achieve greater independence and integration into their local community. As well as brain injury awareness, the programme places emphasis on improving quality of life, developing skills, and identifying opportunities for further education, training, employment and care. The rehabilitative model incorporates a combination of individual training, small group work, community-based activities, workplace activities as well as counselling and therapeutic supports. The GABI outreach service provides people with flexible specialist support and rehabilitation, tailored to each person's own needs and goals. Programmes vary and are designed with each individual in mind. Examples include learning to adapt to the brain injury, personal and behavioural development, life skills management and cognitive rehabilitation. GABI services are provided by a team of skilled instructors and support workers, and are underpinned by Neuropsychology, Behaviour therapy and Neuro OT supports.

Links are maintained through regular meetings and reviews of client progress through either service. Recommendations for follow-on by either team and with HSE stakeholders are also made. The team at Quest, which are Rehab Group based, includes a Life Skills Instructor, IT Instructors, Vocational and Learning Supports, Outreach Support, a Counsellor, OT, Chartered Psychologist and a shared Neuropsychologist. RehabCare Outreach services compromise Neuro OT and Neuropsychology and team members who work one to one with clients in home and the community.

6.7.3 Rationale behind the joint service initiative

- **Inspiration behind the joint service initiative**

The inspiration came from the HSE originally. The JSI partners were two departments within Rehab Group and both had separate meetings with the HSE. The HSE identified duplication, as occasionally, the JSI partners crossed over between individuals and clients. The HSE wanted and needed a streamlined referrals process, moving clients from one phase of services to the next phase of services. The services provided by each organisation are slightly different: in one the remit is higher needs and 1:1 service requirement and in the other, services are provided in a group setting.

Previously, the referral system was not streamlined. There were multiple methods of applying for the services through different platforms and occasionally applicants applied to both JSI partners. There was a lack of knowledge on the work of the different organisations, with applicants assuming you had to complete one phase before moving to the next phase. Now, the JSI applications go to a nominated person within the HSE to capture types of needs and variations. This has stopped duplication of applications and facilitated people getting the correct service for their needs through a streamlined process.

- **Steps involved in the development of the collaboration**

In the early stage of the collaboration, JSI partners clarified the type of brain injury that their services could support, and protocols were developed to ensure that people are referred into the right service at the right time so benefits can be maximised.

The application process was revised to make it more effective and efficient. Referrals are now sent to the HSE and then the applications are filtered down to the appropriate JSI partner e.g. brain injury of certain types might not fit under QUEST. This can also involve referring individual to other services if they are required before being referred into GABI service e.g. addiction services.

HSE are a referral pathway and would consider the two organisations as colleagues. All JSI partners work together and communicate regularly to ensure everyone is up-to-date on referrals, progression, new applications and waitlists.

6.7.4 Positive impacts

Greatest achievement(s) noted by the JSI partners in terms of this collaboration

- **Establishing clarity** on the services provided by the JSI partners (QUEST and RehabCare Outreach). This clarity leads to **effective management and a more streamlined referral process** as the HSE are aware of the exact services and benefits provided by each of the JSI partners.

- Clarification in the differentiation in services has **filtered through to the first point of contact**, the social worker who provides information to the service users and their families. This has meant **fewer unsuitable applications are received**.

- **Service users have a better understanding of the services available to them and the importance of receiving the correct service for them at the right time**.
- The **structure currently in place is sustainable as it has held in place even as people move on**.

Ingredients of successful collaboration noted during the interview were:

- The key ingredients of **collaboration are communication, openness and learning from other JSI partners and key stakeholders** to ensure all JSI partners are on the "same page" making the process streamlined, efficient and effective.
- The **process identifies the stages the clients are at which enables effective workforce planning and management**. Through understanding progression of current service users, plans can be made for new clients entering a programme.
- By having an oversight of the stages, it enhances **effective risk management**.

6.7.5 Challenges

Challenges encountered during the collaboration were;

- Prior to the collaboration, **people worked in "silos". It was difficult to formulate a structure and gather information from all areas**.
- **Ensuring that all stakeholders understand the best interventions for an individual at the right point in time**.
- **Ensure the suitability of services– "it's not one size fits all"**.
- **IT inefficiencies can be a barrier in working in collaboration effectively** which could be overcome with a shared client management system rather than working on two different systems.

6.7.6 Conclusions

Lessons learned on this collaboration include:

- **Maximise value by having a clear definition of who is suitable for the services you provide**. This will reduce people getting "false hope" and causing stress to people applying for the service when it is not suitable / appropriate.

- **Inform and update key stakeholders / referrals regularly of the services provided and outcomes for the individual.**
- Review the application and **revert for additional information if necessary (particularly on whether other services are required)**, before having assessment.

Suggested **recommendations for others completing a similar project were:**

- **Commit to shared communication and honesty.**
- **Divide up the work appropriately and understand everyone is in a learning process.**
- **Have an IT system that allows you to work effectively.**
- Create written material e.g. brochure to **clearly explain services provided, outcomes to be expected and when the intervention(s) are going to provide most benefit**.

7 Conclusions and Recommendations

7.1 Conclusions

Conclusions that can be reached from this assignment include:

- The value of using design thinking to develop the survey is demonstrated in the resulting co-created and comprehensive survey tool that uses terminology that is understood and ensures that service data in the heat maps compares like with like;

- It can be assumed that the high response rate can be attributed to the level of communication with and involvement of services providers from the outset of the project. The project partners were exemplary in terms of the level of communication with the sector and this can only have contributed positively to the high response rate and in turn the level of confidence in the survey findings;

- As a result of the above, the survey results can be said to depict an accurate picture of services currently provided by voluntary organisations to people with neurological services in the community which was one of the two main aims of this project;

- The five JSI have outlined the positive impact of collaboration between voluntary organisations and the HSE, as well as lessons for others who are interested in progressing collaboratve projects;

- Finally, while the origin of this project is in the implementation plan for the National Neuro-Rehabilitation Strategy, there may well be wider application for the processes used, resulting survey tool and supporting sustainable collaboration and positive impacts for service users. In this regard, the project partners, steering group and service providers who attended briefings, completed the surveys and shared information on their JSIs should be commended for their contribution to the body of work that represents significant process in terms of mapping neurological services provided in the community by voluntary organisations.

7.2 Recommendations

On the basis of these conclusions and informed by the insights detailed in previous sections, the following is recommended:

7.2.1 Use the methodology and findings to support the implementation of the National Neuro-Rehabilitation Strategy

a. Based on the survey tool, a comprehensive process mapping exercise is now required, to understand the extent to which services provided by the voluntary and statutory sector are incorporated and integrated in the current pathways and experiences for people with neurological conditions in the community. This should be undertaken at CHO level, using user experience to inform the methodology.

b. Use the survey tool (service descriptors and categories) to progress the individual mapping of neurorehabilitation services and supports within each CHO as outlined in the Implementation Framework for National Neuro-Rehabilitation Strategy 2019-2021. This project provides an important baseline and methodology (survey tool) for this work.

7.2.2 Include additional datasets in future service mapping

a. Having created a proven service mapping framework and shared terminology that can be effectively aggregated, it is suggested that further mapping exercises could include data on quantum of resources (funding and staffing) and demand which would allow for analysis of resource utilisation and return and service gaps.

b. Using the categories and list of service types, and following the process recommended under 7.2.1., a quantitative mapping is required to ascertain the level of service provision within each CHO, to include the statutory (and voluntary) sector.

c. Explore, within the context of the Neuro-Rehabilitation Strategy, how the 10 categories and 98 service descriptors can be integrated into existing planning tools and templates to ensure an effective capture of service need and development of service provision among adults with neurological conditions.

7.2.3 Use the methodology and findings to support and strengthen collaboration

a. Create opportunities to carry out capacity building workshops/network meetings to support organisations to represent their work to key stakeholders using the categories and list service types.

b. A consultation and engagement process with service users and families is required to establish their experience of navigating the wide range of services provided and the pathway of care, and what would help improve access.

c. To optimise further collaboration, guidance for partnership models should be developed, informed by insights from joint service initiatives.

d. Incentives to promote partnerships should continue, informed by the outcome of the process mapping exercise.

e. Promote and enable the 'design thinking' methodology being replicated as a mechanism for involving all stakeholders and maximising engagement.

Appendix 1

A1.1 National Neuro-Rehabilitation Implementation Framework

The Neuro-Rehabilitation Implementation Plan requires local leaders to work with voluntary organisations in developing a range of community supports that enable people with neurological conditions to live well with their condition (p 60) and asks that each CHO Local Implementation Group (LIGs) scope out each service across the continuum of care and carry out an audit of practice (p 47).

A1.2 Project Partners

- Magdalen Rogers – Neurological Alliance of Ireland
- Annette Fitzgibbon – HSE
- Deirdre Murphy - HSE
- Marie Lynch – Disability Federation of Ireland

A1.3 Steering Group members

- Magdelen Rogers NAI (Chair)
- Annette Fitzgibbon HSE
- Deirdre Murphy HSE
- Marie Lynch DFI
- Richard Stables Headway
- Tracy Hutchin IMNDA
- Cathy McGrath DFI
- Emma Rogan service user
- Joe Condon service user

A1.4 Steering Group Terms of Reference

The Steering Group will meet every two months:

- They will review and monitor the progress of the project against the project plan, with specific regard for the outputs
- They will consider and advise project methodology that is undertaken
- They will seek to ensure mechanisms are in place to maximise Stakeholder engagement and participation
- They will monitor and support Communication Project Plan
- They will support and advise where challenges relating to project methodology and delivery of outputs have been identified.

A1.5 Communication mechanisms

A thorough communication and engagement strategy to relevant stakeholders was implemented by the Project Partners. This included regular communication notes, information webinars, briefing meetings and newsletter updates.

A1.6 Critical Path

The table below outlines the critical path for the project.
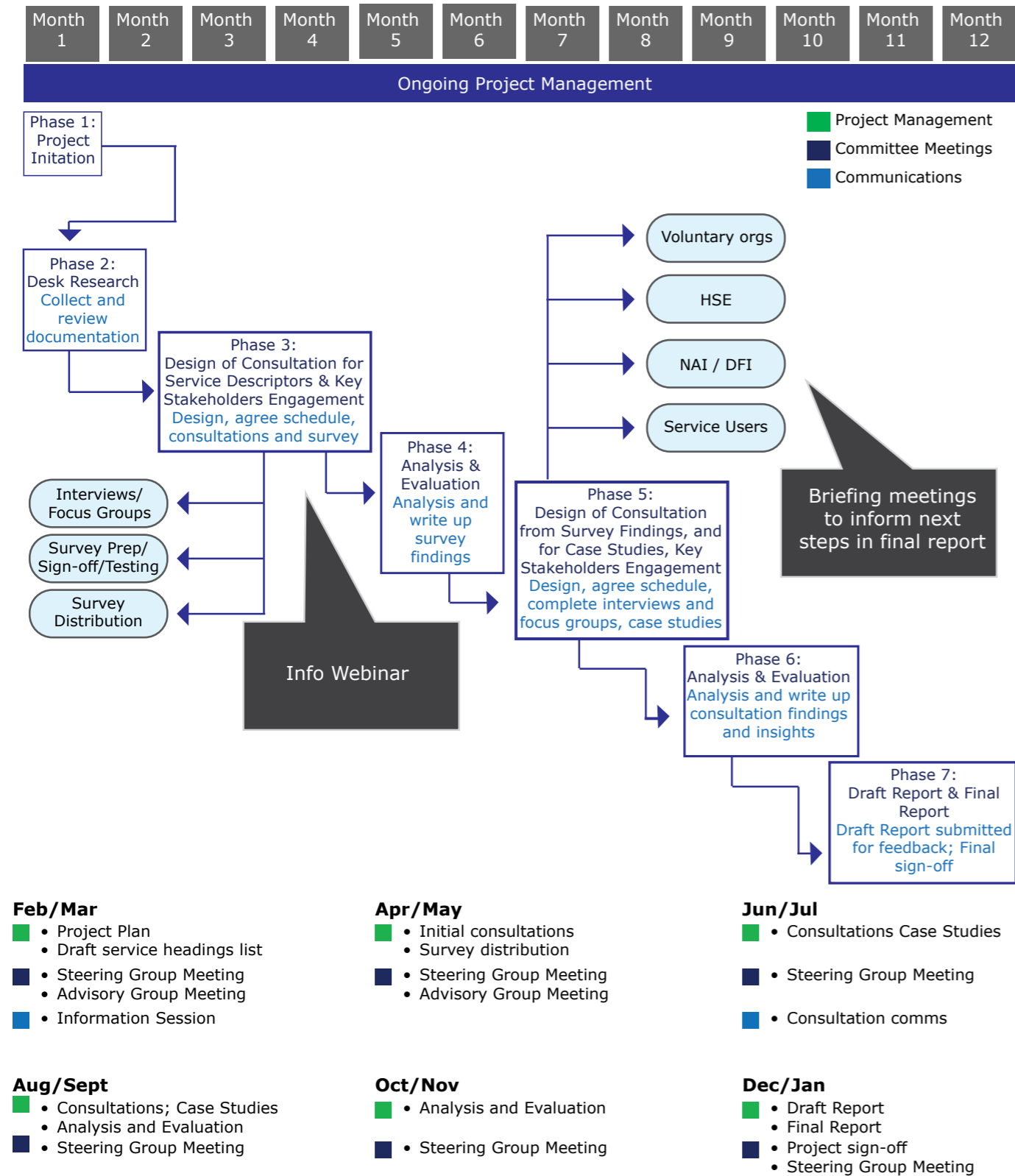
Appendix 2

A2.1 Answers provided under the "Other" category

Respondents that selected "Other" under **Assessment and Planning** listed the services shown below (verbatim text used):

- Risk Assessments to support access to services
- Delivery of a rehab plan devised by another community professional e.g. PT
- Educational programs (webinars) Self-Management Course, CME
- Assessment of need (note: type not specified)
- Holistic assessment of need
- Assessment of a person's functional vision
- Plan for independent living PA service
- Person centred plans are covered under our Day Care, Day Care at Home and Home Care
- Functional assessment for exercise class placement with an exercise specialist

Respondents that selected "Other" under **Therapeutic and Clinical Support** listed the services shown below (verbatim text used):

- Personal Support
- Men's Sheds
- Transport
- Mindfulness sessions (x 3)
- Short term interventions in self-management post stroke in vocational, fatigue and aphasia
- Choirs, Set Dancing, Yoga, Pilates
- Support Groups
- Self-care, Self-compassion courses; we fund counselling/psychotherapy for members.
- Art Therapy practice is delivered in the hands of a Psychotherapist who is also trained as an Art Therapist
- Materials on different types of grief
- Advanced care planning
- Bereavement support

Respondents that selected "Other" under **Supported Living / Accommodation Support** listed the services shown below (verbatim text used):

- (Semi - Independent) People with PWS require support with food access at all times
- Community Rehabilitation Service: 1:1 Rehab supports with persons at home
- Support with completing housing applications and housing adaptations grants
- Day Care at Home services
- Palliative night nursing care at home, Compassionate End of Life/Final Journeys trainings for staff
- Supporting non-congregated living arrangements and independence

Respondents that selected "Other" under **Respite** listed the services shown below (verbatim text used):

- We provide support to access appropriate respite but no direct services
- Contribution towards the cost of emergency respite for a person living with Huntington's disease
- Community respite
- Letting family member have few hours from house PA will support client at home
- Support group for people who take care for people with aphasia
- Personal Assistant Services- Respite when required for individual and with HSE approval and budget
- In Home respite was offered during Covid and may not continue in the future

Respondents that selected "Other" under **Accessibility Supports, Activities of Daily Living and Long-term Supports** listed the services shown below (verbatim text used):

- Fridge locks to parents supporting a child with PWS
- Personal Assistant Services accessibility supports as identified by individual approved HSE budget
- SBHI signpost services users to the appropriate supports required in the area of independent living
- Wheelchair car rental service for all of Ireland
- Integrated rehabilitation therapy to people living with Chronic Illnesses, and neurological conditions
- Provision of special glasses for visual impairment.
- Stress release balls

Respondents that selected "Other" under **Community Integration and Participation** listed the services shown below (verbatim text used):

- Provision of support meetings
- Carer workshops
- Seminars and webinars for people impacted by HD
- Social Role Valorisation supporting individuals self-directing their community inclusion choices
- Signpost service users to the appropriate community integration and participation services
- Minibuses that can be used outside core hours for group travel/activities
- Monthly face to face information and social meetings
- Online carer / in-person support groups
- Alzheimer/Dementia Cafes
- Social clubs
- Facilitator led support groups for people who have experienced stroke and carers

Respondents that selected "Other" under **Vocational/Employment/Training/ Rehabilitative Supports** listed the services below (verbatim text used):

- Provision of information to employer
- Vocational rehabilitation providers on request
- Individualised support through supported employment to gain volunteer and employment roles
- Speech and Language Therapy
- Community partner training
- Music Therapy
- Volunteering with this organisation
- Rehabilitative Support to prevent secondary injuries and support
- Life and living with a SABI

Respondents that selected "Other" under **Information, Advocacy and Education** listed the services shown below (verbatim text used):

- [We are] a national organisation with 1.5WTE staff so provision is on a national basis open to all
- Access to information on educational supports including assistive technology and grants
- Advocate on behalf of Leader for their PA service and supports budget
- National and International Conferences & Ask The Experts in Dublin Cork

Galway subsidised by us
- Facebook Support Groups
- Dedicated information service - information/emotional support re end of life not palliative care
- We support people with their application for hardship funds, but do not provide funding directly
- Informal provision of useful/relevant information and support to assist and empower people to advocate and maximise their quality of life
- Information and education on driving
- Transport options and alternatives
- In-person family carer training also supported

Respondents that selected "Other" under **Family and Caregiver Supports** listed the services shown below (verbatim text used):

- Provision of counselling
- Psychotherapy for carers and family members
- Support and advocacy on named service basis
- Respite services that relieve family members and caregivers for time to themselves (x 2)
- Family Carer Needs Assessment - Carer Outcome Star
- Family & family carers can attend our conferences and meetings to support the person with condition
- Facebook group for carers
- Self-care
- Mindfulness
- Self-compassion courses
- Funded counselling/psychotherapy for family
- Family forums
- Telephone support for in and out of hours
- Emotional support

Respondents that selected "Other" under **Co-ordination and Point of Contact** listed the services shown below (verbatim text used):

- Case work limited by capacity - support provision of information / advice regarding referrals needed
- We will take role of case facilitator
- Members Support Team Manager
- Support Officer who works with individual Leaders PA services
- 8 weeks of phone support called "Stroke Connect" signposting people and some limited case management
- Informal liaising with other primary care services and community-based organisations supporting people who attend [our] service to communicate with other services
- Info & advice to healthcare professionals, NH and GP
- Disease specialist
- Explanatory ID card

Appendix 3

A3.1 List of services under each of the 10 categories

The 98 service types are listed below under each of the 10 categories.
The * represents services that are included in more than one category.

1. Assessment and Planning
- Neuropsychological - assessment
- Neuropsychological - plan
- Community rehabilitation team – assessment
- Community rehabilitation team –plan
- Multi-disciplinary - assessment
- Multi-disciplinary - plan
- Person centred plan - assessment
- Person centred plan - plan
- Vocational - assessment
- Vocational – plan

2. Therapeutic and Clinical Supports
- Specialist Nurse (condition specific)
- Specialist Nurse-Led Helpline
- Palliative Care Nursing
- Mental Health Nurse
- Nurse (other than listed above)
- Physiotherapy
- Speech and Language Therapy
- Occupational Therapy
- Dietician Services
- Neuropsychological Therapy
- *Social Work
- Counselling and Psychotherapy
- Cognitive Rehabilitation
- Specialist Exercise Programmes
- Community Rehabilitation
- Continence Service
- Group-Exercise Programmes in the Community
- Provision of Complementary therapies
- Music Therapy, Art Therapy, Horticultural Therapy, Drama Therapy

3. Supported Living/Accommodation Support
- Independent Living Support
- *Home Care Services – supported living
- *Personal Assistant Services – supported living
- Provision of Short-Term Accommodation in the Community
- Provision of Long-term Accommodation in the Community
- Long Term Supported Living Services
- Step Down Care
- Residential Rehabilitation
- Transitional Living Services

4. Respite
- Provision of Short Breaks
- *Personal Assistant Services- Respite
- *Home Care Services - Respite
- Respite Hours
- Emergency Respite
- Residential Respite
- Alternative Respite (Holiday Breaks)
- In-Home Respite
- Out-of-Home Respite
- Nursing Home Respite
- Dedicated Respite

5. Accessibility Supports, Activities of Daily Living and Long-term supports
- Provision of General Aids, Appliances and Equipment (walking aid, shower chair)
- General Communication Aids or Devices
- Provision of Specialist or Bespoke Equipment (e.g., wheelchair, provision of voice messaging/message banking/voice repair)
- Custom Posture/Seating Service
- Equipment Loan Services
- Assistive Technology
- Computer Apps/ Software
- Driving Assessment and Supports
- Provision of Dedicated Transport Services
- *Personal Assistant Services – accessibility supports
- Alarms
- Day Rehabilitation Programme(s)
- *Day services – accessibility supports

6. Community Integration and Participation

- Rehabilitative Training Services
- Individual Community Rehabilitation
- Social Prescribing
- Self-Management/Symptom Management/Programmes & Resources
- Leisure Activities/Programmes
- Peer Support Programmes

7. Vocational/Employment/Training/Rehabilitative Supports

- Support to Retain Employment
- Return to Work Programmes
- Vocational Rehabilitation Programmes
- *Rehabilitative Training - vocational
- Vocational Training
- Information Talks to Employers
- *Day Services – vocational

8. Information, Advocacy, Education

- Information and Support in all grants and entitlements, e.g., Social Protection Entitlements, medical card, drug payment scheme, housing adaptation grants
- Information and Guidance on Legal Matters
- Information Helpline(s)
- Personal Advocacy Support
- Support Groups/ Information Talks for people with the condition / Peer Support Service /Peer Support Groups
- Access to Social Events
- Online Forums/Webinars
- Online Learning Resources
- Information Resources: Websites, Newsletters, Leaflets, Publications
- Access to Hardship Funds
- Palliative care and End of Life Information and Support

9. Family and Caregiver Supports

- Support Groups/Fora for Family Carers
- Family Carer Information & Training Sessions/Programmes
- Support Worker (s) with Specific Family/Carer Support Remit
- *Social Work
- Psychological Supports for Families
- Family Training e.g., around equipment use, exercises
- *Respite – Family and Caregiver
- Family and Care Giver Peer Support
- Holistic Services

10. Co-ordination and Point of Contact

- Individual Case Work Service(s): supporting engagement with health/ disability/ community services
- Community Worker or Key Worker Service(s)
- Case Management

Notes:

FULL REPORT

SERVICE MAPPING TEMPLATE

EMAIL

AUDIO VERSION

The full report can be accessed by scanning this QR code.

The Project Partners would like to acknowledge Crowe Ireland for their work on this project.

NEUROLOGICAL ALLIANCE of IRELAND

HSE

DISABILITY FEDERATION OF IRELAND

Voluntary Sector Neurological Service Mapping Report