



**The Right Care in
the Right Place:**
*Access to Services
for People with
Neurological Conditions
Across Ireland*

Incorporating key findings
from the 2024 Neurological
Alliance of Ireland Patient
Experience Survey

June 2025



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EXECUTIVE SUMMARY

This report represents a subset of findings from the 2024 **My Neuro Survey** collaboration, focusing on access to and waiting times for a range of key neurological care services across the Republic of Ireland. This report incorporates the responses of 591 adults with neurological conditions and 83 family carers responding on behalf of an adult with a neurological condition.

KEY FINDING 1: Significant regional differences in access to neurological care services across the country

Respondents were asked about their access to a range of neurological care services over the past 12 months.

- 68% reported they could not access Neuro-Rehabilitation services in the community, rising to 92% in the West and 78% in the North West
- 68% could not access Neuropsychology, rising to 82% in the West & 80% in the North West
- 56% could not access Dietician services, rising to 67% in the West and North West
- 45% could not access Occupational Therapy, rising to 61% in the South East & West
- 31% could not access Physiotherapy, rising to 44% in the South East
- 33% could not access Speech and Language Therapy, rising to 56% in the West

KEY FINDING 2: Lengthy waiting times for services, with significant variation across the country

- 31% of respondents reported waiting times of 1-2 years to see a Neurologist, rising to 50% in West, 40% in North West
- 13% reported waiting times of 1-2 years for Speech and Language Therapy, rising to 36% in North East, 33% in South East
- 11% reported waiting times of 1-2 years for Neuropsychology, rising to 25% in the South, 17% in North West
- Reported waiting times of 1-2 years for Neuro-Rehabilitation services in the community were highest among respondents in Dublin (14%) and the North West (17%)

KEY FINDING 3: High percentages of respondents reporting they had never had access to specific services

- 25% of respondents reported never having had access to Neuro-Rehabilitation services despite needing this service, rising to 37% in the South East & 35% in the North East
- 36% of respondents reported never having had an appointment with a specialist nurse for their condition, despite needing this service, rising to 52% in the West and 43% in the North East

SUMMARY RECOMMENDATIONS

1. Findings Highlight the Critical Need for Ongoing Investment in Neurological Care

Continued prioritised year on year investment in neurological care is needed to address the lack of access to and lengthy waiting times for the ten key neurological care services highlighted in this report. The finding that **a quarter of respondents reported never having had access to neuro-rehabilitation services** despite needing this service while **over a third had never had an appointment with a specialist nurse** for their condition highlight the critical need for investment in these services. Nearly one third of respondents reporting waiting times of 1-2 years to see a Neurologist. More than one in ten respondents reported waiting times of between 1 and 2 years for speech and language therapy and neuro-psychology services.

2. Action is Needed to Address the Regional Variations in Access to Care

The findings consistently point to a pattern of significant regional variation in access to and waiting times for key neurological care services.

More needs to be done to develop regional services to ensure equitable timely access to neurological care across the country.

FOREWORD

For over twenty years, the Neurological Alliance of Ireland, working closely with its member organisations, has been at the forefront of promoting awareness of the needs of people with neurological conditions and in driving the development and implementation of policy responses in this area.

This current report presents a subset of the findings from the 2024 My Neuro Survey project, focusing on access to care and waiting times for key neurological care services. The report provides a regional breakdown of respondent's experience: providing an important insight into different patterns of access to care across the country.

As a signatory to both the WHO Intersectoral Global Action Plan for Epilepsy & Other Neurological Conditions, and the UNCRPD, Ireland has pledged to improve access to diagnosis, treatment and neuro-rehabilitation services for people with neurological conditions.

The overall findings in this report highlight that accessing basic care at every stage for those living with a neurological condition continues to be a serious challenge, while evidence of significant regional disparities support the long standing concerns of NAI around regional inequity in access to neurological care.

The findings of this report provide a clear impetus to deliver on the commitments within the 2025 Programme for Government to neurology and neuro-

rehabilitation services. NAI looks forward to working with all stakeholders to address the gaps in care highlighted in this report in order to provide better outcomes for all those living with a neurological condition.

We want to take this opportunity to extend our warm thanks to everyone who contributed their responses to this survey, and to our lived experience reference group who were key to ensuring that the survey represented the issues affecting people with neurological conditions and their families across Ireland.

We also wish to extend our warm thanks to our partners in the Neurological Alliances across England, Scotland, Wales and Northern Ireland, for providing us with the opportunity to become part of the existing neurological Patient Experience Survey collaboration. Our warmest thanks also to our member organisations for their support and engagement throughout this project.

NEUROLOGICAL CONDITIONS IN IRELAND

In April 2024, the Lancet Neurology¹ reported on the findings of the 2021 Global Burden of Disease, Injuries and Risk Factors Study, which showed that neurological conditions are now the leading cause of ill health and disability worldwide.

Here in Ireland, over 860,000 people are estimated to be living with a neurological condition². The ageing demographic within developed countries like Ireland

Mags Rogers
Chief Executive
Officer



means that neurological conditions associated with ageing are set to increase significantly over the coming years. Additionally, due to advances in care and treatment, including improved trauma care and perinatal and paediatric care, more and more people are living with acquired neurological conditions and require the full range of specialist supports to enable them to live to their full potential.

Successive health policy reports and strategies, together with previous NAI reports and advocacy campaigns have pointed to the deficits across neurological care services and the continued impact on people with neurological conditions and their families throughout Ireland.

Pascal Derrien
Chair of NAI



¹ Global, regional and national burden of disorders affecting the nervous system 1990-2021: a systematic analysis for the Global Burden of Diseases Study 2021 (April 2024) *The Lancet Neurology*: vol 23 Issue 4 p344-381

² Strategic Review of Neurology and Neurophysiology Services in Ireland (2007) Report Commissioned by the National Hospitals Office Health Services Executive

PREVIOUS NAI REPORTS AND PUBLICATIONS

LIVING WITH A NEUROLOGICAL CONDITION IN IRELAND: SURVEY SERIES 2011-2019

In October 2020, the NAI published the findings of its nationwide “Living with a Neurological Condition in Ireland” survey of over 400 adults and family carers living with a neurological condition. The report findings, based on a survey carried out pre-pandemic, highlighted critical challenges for people with neurological conditions in accessing services for their condition with nearly a fifth of respondents reporting they could not access counselling, physiotherapy, nurse specialist and neuropsychology services in the preceding 12 months.

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NATIONAL RESOURCE AUDIT OF NEUROLOGY SERVICES 2020

In 2020, NAI in partnership with the National Clinical Programme for Neurology, carried out an extensive survey across neurology centres throughout Ireland examining a range of areas including staffing, access dedicated inpatient beds, access to diagnostics, and access to a range of supports including neuro-rehabilitation services. The report highlighted significant gaps in staffing across neurology services, with particular issues of concern being the shortfall of specialist nursing posts across neurology services, the dearth of staffing within regional neurology centres and the lack of neuro-rehabilitation services in the community.

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ABOUT THIS REPORT

The current report incorporates a subset of findings from the **My Neuro Survey** project, a collaboration between the Neurological Alliance of Ireland and partner alliances in England, Wales Neurological Alliance, Neurological Alliance of Scotland, Northern Ireland Neurological Charities Alliance (niNCA), working with independent market research company Revealing Reality.

The My Neuro Survey project represents one of the most extensive efforts to date to gather insights from people living with neurological conditions and family carers across Ireland. The full insights from across the three surveys of adults, children and carers are available in a separate report and will be disseminated by the Neurological Alliance of Ireland through a series of factsheets and briefings throughout 2025 and beyond. Responses to the surveys were gathered through an online link over a four-month period, between 22 July and 15 November 2024. Paper copies of the surveys were also available on request through a dedicated email address.

The current report focuses on respondent's answers to a subset of questions from the adult (over 18 years) survey, focusing on access to and waiting times for a range of key neurological care services. The responses are broken down across eight geographic regions below*. This report incorporates the responses of 591 adults with neurological conditions and 83 family carers responding on behalf of an adult with a neurological condition.

LIMITATIONS

While every effort was made to reach a wide and diverse range of individuals living with neurological conditions, it is not possible to confirm that the sample is fully representative of the broader population of people living with neurological conditions in Ireland. All findings are based on self report/report of family carer on behalf of a person with a neurological condition. Findings should be interpreted with this context in mind.

AREA FOR REGIONAL ANALYSIS	COUNTIES
SOUTH EAST	Carlow, Kilkenny, Wexford, Waterford
MIDLANDS	Laois, Offaly, Westmeath, Longford, Kildare, Wicklow
NORTH EAST	Cavan, Monaghan, Louth, Meath
SOUTH	Cork, Kerry
WEST	Galway, Mayo, Roscommon,
MID WEST	Clare, Limerick, Tipperary
NORTH WEST	Sligo, Leitrim, Donegal
DUBLIN	Dublin County

**Note that the regional breakdown for the purposes of analysis in this report does not correspond with the 6 regions under which the Health Service Executive delivers health and social care services.*

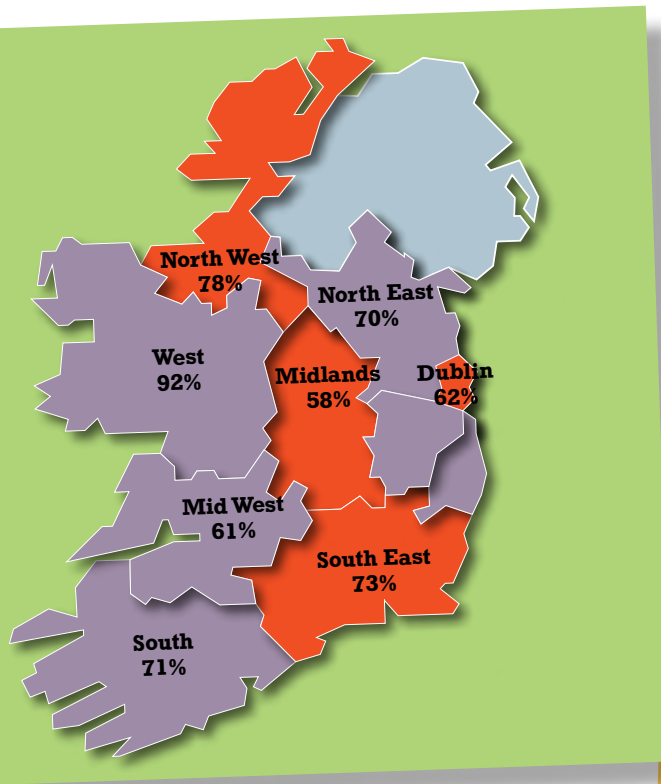
KEY FINDINGS: Access To Key Neurological Care services

Table 1: Respondents Self Reported Access To Key Neurological Care Services Over The Past 12 months

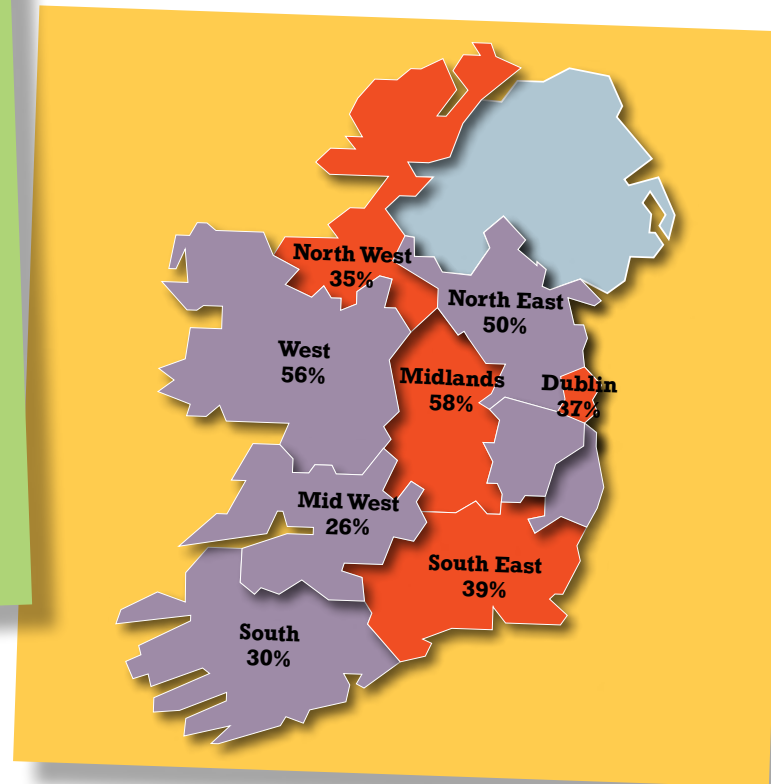
RESPONSE	Neurologist	Specialist Nurse	Dietician	Inpatient Neuro-Rehabilitation	Community Neuro-Rehabilitation	Neuro-psychology	Occupational Therapy	Physiotherapy	Speech & Language Therapy	Respite Care
I had it and it met my needs	55%	47%	32%	12%	20%	20%	38%	44%	52%	20%
I had it and it did not meet my needs	28%	15%	10%	11%	10%	9%	15%	24%	14%	8%
I have not been able to access it	15%	38%	56%	76%	68%	68%	45%	31%	33%	62%
Prefer not to say	2%	1%	2%	2%	3%	2%	2%	1%	2%	9%

PERCENTAGE OF RESPONDENTS REPORTING THEY COULD NOT ACCESS THIS SERVICE OVER THE PAST 12 MONTHS

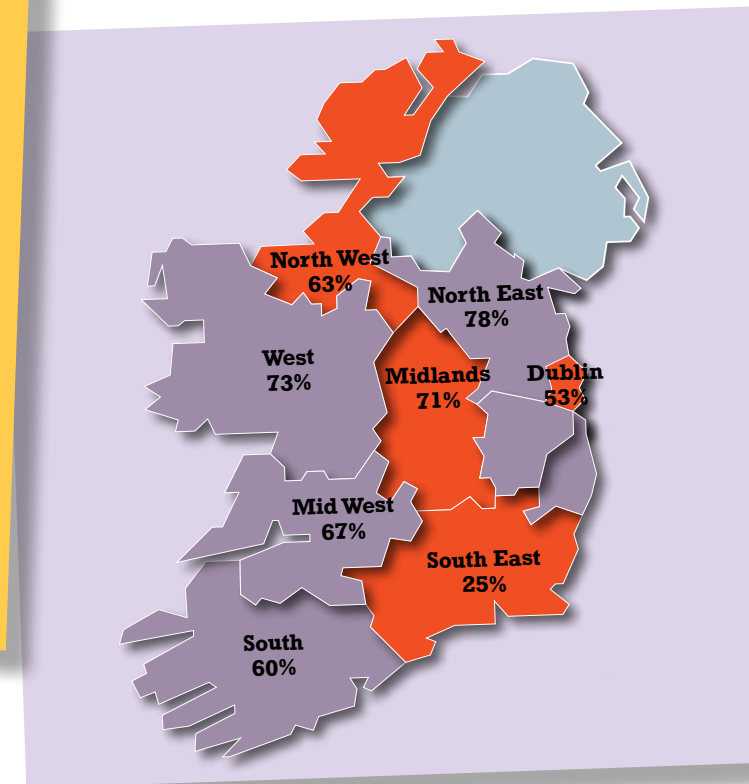
Community Neuro-Rehabilitation Services



Specialist Nurse



Respite Care

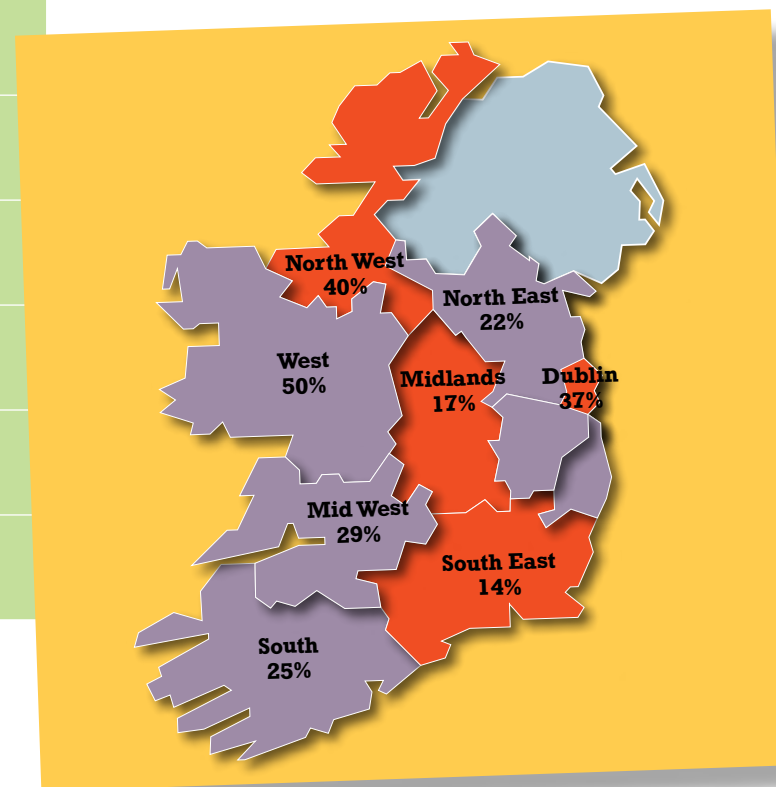


KEY FINDINGS: WAITING TIMES: Waiting times For Key Neurological Care Services

Table 2: Respondents Self Reported Waiting Times For Key Neurological Care Services

	Neurologist	Specialist Nurse	Dietician	Inpatient Neuro-Rehabilitation	Community Neuro-Rehabilitation	Neuropsychology	Occupational Therapy	Physiotherapy	Speech & Language Therapy	Respite care
Less than 3 mths	0%	4%	6%	4%	0%	2%	4%	4%	7%	3%
3-6 months	3%	1%	1%	1%	1%	2%	5%	6%	4%	3%
7-11 months	11%	9%	3%	3%	1%	5%	10%	12%	7%	6%
1-2 yrs	31%	4%	2%	1%	7%	11%	7%	8%	13%	3%
More than 2 yrs	17%	9%	7%	10%	12%	12%	8%	13%	7%	6%
Still waiting	27%	58%	52%	52%	70%	58%	53%	51%	47%	58%
Don't know	10%	15%	21%	19%	9%	10%	10%	6%	13%	18%
Prefer not to say	1%	1%	8%	7%	0%	1%	3%	1%	2%	3%

Percentage reporting waiting times of 1-2 years to see a Neurologist



KEY FINDINGS: Access To Neuro-rehabilitation/Specialist Nurse Services

Table 3: Percentage Of Respondents Reporting If They Have Ever Had Access To Neuro-Rehabilitation Services For Their Condition

	Overall (NET COLUMN)	Dublin	Mid West	Mid-lands	North East	North West	South East	South	West
Yes and it was sufficient for my needs	6%	10%	7%	5%	6%	6%	6%	2%	2%
Yes but it was not sufficient for my needs	7%	8%	7%	4%	10%	3%	6%	6%	4%
No but I need this	25%	20%	38%	18%	35%	26%	37%	17%	31%
No I do not need this	40%	41%	31%	41%	30%	55%	40%	46%	33%
Don't Know	20%	19%	17%	31%	17%	10%	12%	23%	25%
Prefer not to say	2%	1%	0%	1%	1%	0%	0%	5%	4%

Percentage of respondents reporting never having had access to neuro-rehabilitation services

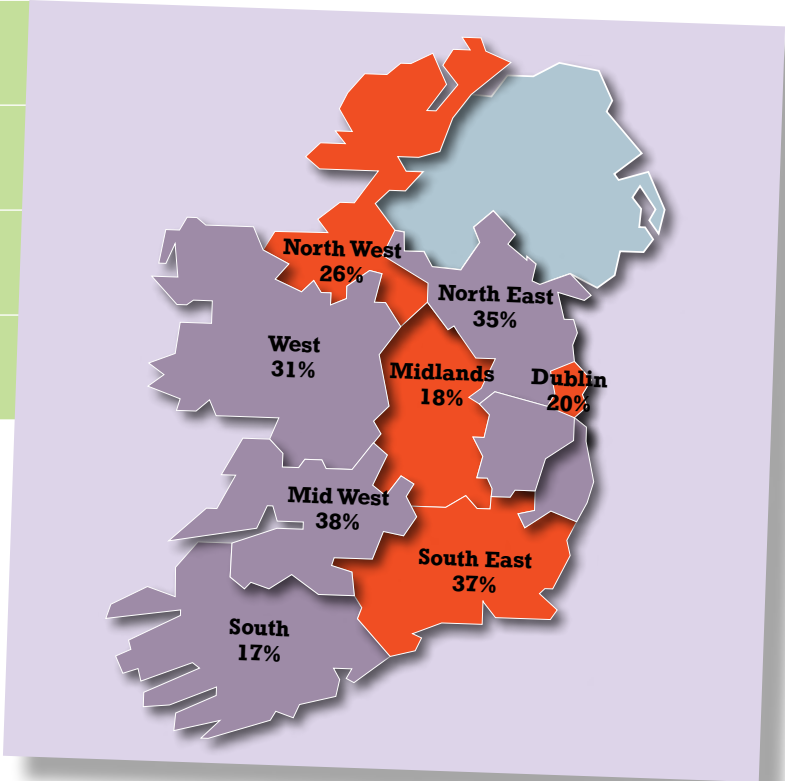
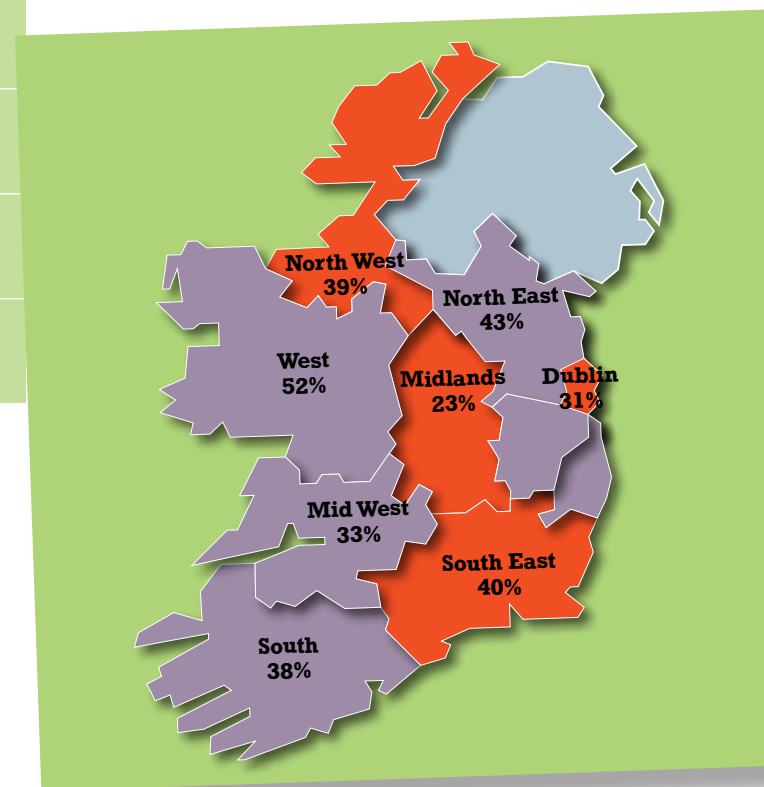


Table 4: Percentage Of Respondents Reporting If They have Ever Had An Appointment With A Specialist Nurse For Their Condition

	Overall (NET COLUMN)	Dublin	Mid West	Mid-lands	North East	North West	South East	South	West
Yes and it was sufficient for my needs	27%	35%	21%	34%	25%	29%	21%	16%	25%
Yes but it was not sufficient for my needs	7%	5%	12%	5%	7%	13%	8%	6%	6%
No but I need this	36%	31%	33%	23%	43%	39%	40%	38%	52%
No I do not need this	21%	22%	14%	21%	14%	19%	21%	30%	15%
Don't Know	9%	7%	19%	15%	10%	0%	10%	10%	2%
Prefer not to say	1%	1%	0%	3%	0%	0%	0%	0%	0%

Percentage of respondents reporting never having had an appointment with a specialist nurse



CONCLUSIONS AND RECOMMENDATIONS

The findings of this report highlight serious challenges for people with neurological conditions in relation to access to, and waiting times for, key neurological care services. The issues identified are consistent with previous NAI surveys and the ongoing concerns highlighted by individual advocates and NAI member organisations throughout the country. While NAI recognises that there has been welcome investment in recent years in neurology and neuro-rehabilitation services, the findings in this report highlight that there are considerable challenges to overcome in order to ensure timely and appropriate care for all those in Ireland living with a neurological condition.

ACCESS TO KEY SERVICES

A clear pattern emerges in relation to the consistency of the current findings with previous NAI surveys and reports, where a high percentage of respondents reporting that despite needing it, they cannot access basic key services such as neurology, specialist nursing and neuro-rehabilitation services. Of particular concern are the high percentages reporting they have never had to access neuro-rehabilitation and specialist nursing services.

NEURO-REHABILITATION

The Neurological Alliance of Ireland has consistently highlighted the lack of progress and delays in implementing the 2019 Framework for the National Neuro-Rehabilitation Strategy³, and the impact of this delay is clearly evident in the findings of the current survey. One quarter of respondents reported that they have never had access to neuro-rehabilitation services, the question careful to exclude respondents for whom this question was not relevant or were unsure what was meant by neuro-rehabilitation services. The high percentage of respondents reporting that they could not access community neuro-rehabilitation, and individual services such as physiotherapy, neuropsychology and speech and language therapy over the past 12 months, provides further evidence of the urgent need to implement the Neuro-Rehabilitation Strategy in order to improve access to these services.

SPECIALIST NURSING

Findings from the 2020 Neurological Alliance of Ireland audit of adult neurology services showed a shortage of up to one hundred nurse specialists across adult neurology services. Following a dedicated advocacy campaign by the Neurological

Alliance of Ireland 2021/2022 there has been significant investment in neurology nursing but much more needs to be done to ensure greater access to a nurse specialist for everyone with a neurological condition. The findings from the current report, where over a third of respondents reported they had never had an appointment with a specialist nurse, match the findings from a 2024 report⁴ which found that one third of Parkinson's patients seen in clinics did not have access to a Parkinson's disease specialist nurse. Similarly, a national survey of people with MS found that only 38% of the sample reported attending an MS specialist nurse⁵.

Over two thirds of respondents highlighted that they could not access respite care, a finding that NAI will take on board in considering the implications of the survey for its future advocacy programme.

REGIONAL VARIATIONS IN ACCESS TO SERVICES

The findings support a key concern of the Neurological Alliance of Ireland that there is a variation across the country in access to neurological care services. While no one region was singled out overall, there was a clear pattern of differences for individual services across regions. For example 50% of respondents in the Mid West reported that they

³ *From Theory to Action: Implementation Framework for the National Policy & Strategy for Neurorehabilitation Services 2019-2021* (2019) Health Services Executive

⁴ *Audit of Movement Disorder Services in the Republic of Ireland* (April 2024) Centre for Gerontology and Rehabilitation University College Cork in collaboration with Parkinson's Ireland and the National Clinical Programmes for Neurology, Older People.

⁵ *My MS my Needs: 2023 Summary Report* (2024) The Multiple Sclerosis Society of Ireland

could not access neuropsychology compared to 80% in the North West, 31% of Dublin respondents who had never had access to a specialist nurse compared to 52% in the West. While care is needed in drawing conclusions from the findings of a self-report survey across a wide range of neurological conditions, there is a need to ensure that development of neurological care services takes into account the need to ensure equitable access across the country.

It is important to note that the findings of this report represent a small subset of the findings from across the My Neuro Survey project in the Republic of Ireland. The overall findings from across the project are the subject of continued careful consideration and analysis by the Neurological Alliance of Ireland and will inform the advocacy priorities and ongoing work of the Alliance going forward.

PROGRAMME FOR GOVERNMENT COMMITMENTS TO NEUROLOGICAL CARE

The current Programme for Government outlines a series of commitments to increase the number of neurologists and neurology nurse specialists and deliver neuro-rehabilitation services across both hospital and community.

The finding that over one third of respondents had never had access to a specialist nurse should support and strengthen the commitment within the Programme for Government to increase the number of nurse specialists within neurology services. The significant number of respondents reporting waiting times of 1-2 years to see a neurologist point to the need to deliver on the commitment to increase the number of neurologists including in regional hospitals.

The findings of this survey are particularly stark in relation to neuro-rehabilitation services. The finding that one in four people who need to cannot access neuro-rehabilitation services highlights the importance of delivering on the Programme for Government commitment to rolling out the remaining community neuro-rehabilitation teams, increasing inpatient neuro-rehabilitation beds and investing in multidisciplinary neuro-rehabilitation services in the community.

ABOUT THE NEUROLOGICAL ALLIANCE OF IRELAND

The Neurological Alliance of Ireland (NAI) brings together nearly forty non-profit organisations to advocate for the rights of the over 860,000 people in Ireland living with a neurological condition.

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.

FURTHER INFORMATION

For further information on any aspect of this report contact NAI Chief Executive Officer Magdalen Rogers at mrogers@nai.ie

ACKNOWLEDGEMENTS

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MEMBER ORGANISATIONS of the Neurological Alliance Ireland

Acquired Brain injury Ireland

Alzheimer Society of Ireland

An Saol

Aphasia Ireland

Ataxia Foundation Ireland

Bloomfield Health Services

Brain Tumor Ireland

Cheshire Ireland

Chronic Pain Ireland

Crann Centre

Croí

Dublin Neurological Institute

Dystonia Ireland

Early Onset Parkinson's Disease Ireland
(EOPD)

Enable Ireland

Epilepsy Ireland

FND Ireland

Headway

Huntington's Disease Association of Ireland

Irish Heart Foundation

Irish Hospice Foundation

Irish Motor Neurone Disease Association

Migraine Association of Ireland

Move4Parkinsons

Multiple Sclerosis Society of Ireland

Muscular Dystrophy Ireland

Neurofibromatosis Association of Ireland

Neurology Support Centre

North West MS Therapy Centre

Parkinson's Ireland

Peamount Healthcare

Polio Survivors Ireland

PSPA Ireland

Spinal Injuries Ireland

Spina Bifida Hydrocephalus Ireland

The Rehab Group

Vision Ireland



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