



NEUROLOGICAL ALLIANCE  
of IRELAND

# **“Living with a Neurological Condition in Ireland”**

***Report on the findings of a  
National Survey 2014***

# LIVING WITH A NEUROLOGICAL CONDITION IN IRELAND: REPORT ON NAI NATIONAL SURVEY 2014

## Executive Summary

An online survey examined the responses of six hundred people with neurological conditions and family members to a range of questions examining the impact of their condition on employment, financial circumstances, emotional wellbeing and access to and satisfaction with services. The survey also examined the impact of cuts in health services and changes to benefits and entitlements over the past three years. The findings indicate an increasingly challenging situation for those living with a neurological condition in Ireland. Almost half reported giving up work as a result of their condition and a significant effect of their condition on their overall cost of living and decline in family income. Significant costs were associated with paying for medication and services such as physiotherapy and neurology and aids and appliances on a private basis. Historic difficulties in accessing neurospecialist services remain with many services being reported as having become more difficult to access over the past three years and an increase since 2011 in those reporting that they cannot access services such as psychology and respite care. There was dissatisfaction among a significant proportion of those surveyed in relation to aspects of service provision such as support in planning for future needs, psychological support around the effects of the condition and understanding of their condition by health professionals.

Changes to benefits and entitlements in recent years are reflected in the findings with over significant numbers being refused a medical card for their condition or having it withdrawn and more than 40% affected by changes to the mobility allowance. The emotional wellbeing of people with neurological conditions in this survey is of concern with many respondents reporting feeling depressed or isolated. Most were worried about future cuts in health services and entitlements. Family carers report a significant impact of isolation and feeling unsupported and unrecognised in their role as a carer.

The survey findings indicate a range of challenges experienced by people with neurological conditions in relation to the impact of the condition on their day to day lives, from employment and finances, to access to services to meet their needs and emotional wellbeing and participation in society. From these survey findings it is clear that successive cuts in services and supports for those with disability and chronic illness have also impacted significantly on those living with neurological conditions. The findings also indicate that among the respondents surveyed, there was little evidence of improved access to services for people with neurological conditions and for many respondents, access was reported as having become more difficult over the past three years.

## Neurological Alliance of Ireland

The Neurological Alliance of Ireland is a national umbrella made up of over thirty not for profit organisations working with people with neurological conditions. It aims to promote the development of services and supports for people with neurological conditions and their families through contributing to the development of policy, advocating for and creating awareness of the needs of this population and building a strong network of responsive organisations.

## Introduction

Neurological Conditions affect the brain and spinal cord and affect over 7000,000 people in Ireland. They include common conditions such as migraine, epilepsy, stroke, acquired brain injury and Alzheimer's disease as well as rare and genetic conditions. Neurological conditions range from sudden onset to those which are more progressive. These conditions can impact on almost every aspect of a person's life through the impact of the physical, intellectual, emotional and behavioural changes that can result. In addition, there can be a significant impact on family members living with a person with a neurological condition.

The table below is taken from the NAI publication "The Future for Neurological Conditions in Ireland: A Challenge for Healthcare; an Opportunity for Change (2010) and indicates the current and future projections of the number of people living with neurological conditions in this country.

	UK Neuro-Numbers Report	2006 CENSUS 4.235 million	CSO Population Projection		
			2011 4.488 m	2016 4.811 m	2021 5.070 m
<b>Persons living with condition</b>	17%	725,987	762,960	824,743	869,143
<b>Help with daily activities</b>	0.6%	25,410	26,928	28,866	30,420
<b>Disabled by condition</b>	2%	84,699	89,760	96,220	101,400
<b>Has condition but able to manage life on daily basis</b>	14.5%	615,879	652,683	699,657	737,323
<b>Number newly diagnosed each year</b>	1%	43,559	44,880	48,110	50,700
<b>People caring for person with condition</b>	1.5%	61,709	66,038	70,790	74,601

There is an overall dearth of research on people with neurological conditions, as a single group, in an Irish context. Research has been carried out with individuals and family members with specific neurological conditions and this research has, to date, provided valuable indications of the types of issues experienced by people with neurological conditions in Ireland as a whole. However, the current survey was aimed at respondents across the range of neurological conditions and the NAI is unique in surveying this population to date.

## 2011 SURVEY: LIVING WITH A NEUROLOGICAL CONDITION IN IRELAND

The NAI carried out the first national survey of people with neurological conditions in 2011. This survey was narrower in scope than the present survey and focused mainly on access to services. Comparisons with the results of the 2011 survey will be made where this is feasible based on the similarity of the questions posed to respondents.

The results of the 2011 survey highlighted significant issues in relation to access to neurological care services in Ireland. Particular challenges were reported in relation to accessing a diagnosis with 38% of respondents waiting longer than six months to be diagnosed with their condition. There were significant issues with access to services such as physiotherapy, specialist nurses, neuropsychology and consultant neurology. In addition, respondents were questioned in relation to the support they receive from a not for profit organisation.

### How the Current Survey was Designed

The wide range of services and supports required by people with neurological conditions reflect the scope and degree of the changes that can affect almost all areas of an individual's life. It is estimated that over forty health professionals can be involved in the care of a person with a neurological condition. The needs of the person also change over time, in response to different life stages, the progression of the condition and changes in life circumstances. This is reflected in the range of areas included in the present survey. The survey was

developed in consultation with a number of NAI member organisations working with people with neurological conditions and their families. Many of the questions were included based on the individual comments of respondents to the 2011 NAI survey which highlighted the impact of living with a neurological condition on a wide range of aspects of daily life.

The current survey aimed to examine a number of aspects of living with a neurological condition, as outlined below:

#### Profiling Changes in Access to Services

The NAI was interested in the opinions of respondents as to how access to services has changed over the past three years. This covers the period of time since the last survey of this type. It also reflects a period of significant constraint in health service spending and effective reductions in staff numbers, particularly in community therapy services, due to the employment ceiling and early retirement options.

The past three years have also seen the introduction of specific initiatives to improve access to neurological services. These include the introduction of additional posts in consultant neurology to address the significant dearth of neurologists in Ireland (Even with these increases, Ireland continues to have the lowest number of consultant neurologists in Europe). The NAI wanted to question respondents in relation to their perception of overall changes or improvements in neurological care in the past three year period.

#### Impact of Specific Cuts and Changes to Benefits and Entitlements

The NAI were interested in examining the impact of a number of specific cutbacks and changes in provision on the neurological population. These include more stringent imposition of criteria on the awarding/renewal of medical cards, changes to mobility allowance and cuts to the respite grant.

#### Profiling the Experiences of People with Neurological Conditions as a Group

The present survey includes a broad range of questions aimed at identifying the impact of neurological conditions on a wide range of areas of an individual's life. These include effects on employment, emotional impact, financial burden, participation in activities and family and relationships.

#### Profiling the Experiences of Family Carers

The survey included a series of questions aimed at examining the impact of caring for a person with a neurological condition on health, emotional wellbeing as well as cost of living and employment of family carers.

## HOW THE SURVEY WAS CONDUCTED

Responses to this survey were collected by an online survey tool, Survey Monkey ([www.surveymonkey.com](http://www.surveymonkey.com)) from January to February 2014. The survey was advertised through email, Twitter and Facebook by NAI and by member organisations. The survey was anonymous and involved self report by people with neurological conditions as well as the option of responding on behalf of the person with a neurological condition by a family member.

## Report and Discussion of the Findings

A note on interpretation:

The constraints associated with a self report questionnaire, and its impact on any interpretation of the findings of this survey, are acknowledged. The NAI stress that the issues highlighted in this survey, particularly in relation to access to the ease or difficulty of accessing services, represent the self reports of service users. The survey is intended as a reflection of the needs of the sample of respondents based on their own experiences.

The use of an online survey tool has a number of associated challenges and these should be noted in the interpretation of the results. The interaction is not supervised and therefore there is the associated problem of respondents misinterpreting an item, ticking a number of responses for the same item or overlooking an item by mistake.

**NB: Total percentages in each of the tables (for people with neurological condition and family members responding on behalf of a person with a neurological condition) are represented in BOLD type. The first set of results in italics represents the response of the people with neurological conditions who responded to the survey, the second set of results represents the responses of family member on behalf of a family member with a neurological condition.**

(i) Profile of Respondents

In all, there were 601 responses to the survey. Of those who responded 71% (425 people) are living with a neurological condition. The remaining respondents are family members of people living with neurological conditions. Family members were invited to respond on behalf of the person with a neurological condition and they were also asked a number of questions about their own circumstances.

(ii) Profile of Neurological Conditions

Among people with a neurological condition who responded on their own behalf, the most common conditions were epilepsy (21%), multiple sclerosis (27%) and migraine (20%). Among family members responding on behalf of a person with a neurological condition, the most common conditions were epilepsy (25%), multiple sclerosis (18%) and muscular dystrophy (17%).

(iii) Length of time living with their condition

45% of respondents were living with their condition for more than ten years

Three years or less	<b>16%</b> <b>People with Condition 17%</b> <b>Family Member Responding on Behalf of: 13%</b>
3-5 years	<b>16%</b> <i>13%</i> <i>23%</i>
5-10 years	<b>23%</b> <i>23%</i> <i>23%</i>
More than 10 years	<b>45%</b> <i>47%</i> <i>41%</i>

(iv) Receipt of Entitlements

Half of respondents were in receipt of a medical card and 47% were in receipt of a social welfare payment as a result of their condition.

	Yes	No I am not eligible	No I was refused	Applying for at the moment
GP only Card	<b>16%</b> <i>People with Condition 16%</i> <i>Family Member Respondent: 19%</i>	<b>70%</b> 73% 58%	<b>7%</b> 5% 13%	<b>7%</b> 6% 10%
Medical Card	<b>59%</b> 52% 77%	<b>29%</b> 35% 12%	<b>7%</b> 7% 7%	<b>6%</b> 7% 4%
Social welfare payment as a result of your neurological condition, e.g. disability allowance	<b>47%</b> 47% 48%	<b>38%</b> 40% 34%	<b>6%</b> 5% 11%	<b>8%</b> 8% 8%

(v) Employment

Respondents were asked a number of questions in relation to the effects of a neurological condition on the employment and income of the person with a neurological condition. 66% of respondents in total were working before the onset of their condition, 47% reported that they had to give up work while 18% had to reduce hours as a result of their condition. These findings echo the results of recent research on multiple sclerosis which indicates that 50-60% people have had to give up work following diagnosis.

	Yes	No	Does not apply to personal situation
Are you currently working?	<b>28%</b> <i>Person with Condition 35%</i> <i>Family Member Respondent 8%</i>	<b>62%</b> 61% 64%	<b>10%</b> 4% 28%
Were you working before the onset of your neurological condition?	<b>66%</b> 74% 46%	<b>19%</b> 18% 21%	<b>15%</b> 8% 33%
Did you have to give up work as a result of your neurological condition?	<b>47%</b> 50% 39%	<b>37%</b> 42% 24%	<b>16%</b> 8% 37%
If you are still working, have you had to reduce your hours as a result of your condition?	<b>18%</b> 21% 9%	<b>26%</b> 30% 16%	<b>56%</b> 49% 75%
Has your income fallen significantly since the onset of your condition?	<b>56%</b> 61% 42%	<b>24%</b> 27% 16%	<b>20%</b> 12% 42%

*"The current system does not take into account the fluctuating nature of my condition. I am a young woman who wants a successful career in my chose profession. At times, I need the financial support to allow me to manage my condition (relapses) AND to continue in my profession. However, because it is an either/or I am caught in the welfare trap. Either I can continue to only take from the social welfare or the current government changes the system so I can both contribute as well as receive support when I need it.*

(vi) *Help with Activities of Daily Living*

Respondents were questioned about the impact of the neurological condition on a range of activities of daily living at the present time. Those participants in the survey whose needs were described by a family member, required significantly more help with activities of daily living with over half requiring a lot of help in planning their day, over 40% requiring a lot of help with self care (washing/dressing) and over 40% requiring significant help with cognitive activities such as remembering to do everyday things and concentrating on a task.

	Lot of help needed	Some help needed	Does not need help	Does not apply to personal situation
Washing	<b>15%</b> <i>People with Condition: 6%</i> <i>Family Member responding on behalf of: 43%</i>	<b>14%</b> 10% 26%	<b>60%</b> 71% 27%	<b>11%</b> 14% 3%
Dressing	<b>16%</b> 6% 43%	<b>13%</b> 9% 26%	<b>60%</b> 71% 28%	<b>11%</b> 14% 3%
Travelling outside the home	<b>29%</b> 17% 65%	<b>27%</b> 29% 23%	<b>35%</b> 44% 11%	<b>9%</b> 11% 2%
Planning their day	<b>16%</b> 3% 53%	<b>24%</b> 22% 29%	<b>51%</b> 63% 14%	<b>10%</b> 13% 4%
Joining in activities in their community	<b>25%</b> 15% 54%	<b>30%</b> 32% 24%	<b>29%</b> 36% 8%	<b>17%</b> 18% 15%
Remembering to do everyday things	<b>16%</b> 7% 44%	<b>33%</b> 33% 30%	<b>40%</b> 48% 17%	<b>12%</b> 13% 9%
Concentrating on a task	<b>19%</b> 10% 45%	<b>33%</b> 34% 29%	<b>37%</b> 45% 16%	<b>11%</b> 12% 9%
Taking care of the house	<b>31%</b> 26% 44%	<b>30%</b> 35% 16%	<b>25%</b> 31% 7%	<b>15%</b> 9% 33%

(vii) *Access to Services over the Past Three Years*

Respondents were presented with a range of services and asked to describe their experience of accessing this service over the past three years by choosing one of a series of options. 47% of total respondents reported that it had become more difficult to get aid, appliance or specialist equipment and personal assistant services over the past three years. 46% reported more difficulty in getting a day service to meet their needs, while 45% found it more difficult to get respite care.



	It has become more difficult to get this service	It has become easier to get this service	It has stayed the same	Have not been able to get this service at all
Consultant Neurologist appointment	<b>28%</b> <i>People with Condition 26%</i> <i>Family Member R 32%</i>	<b>9%</b> 11% 4%	<b>56%</b> 58% 53%	<b>7%</b> 6% 10%
Consultant Neurosurgeon appointment	<b>27%</b> 24% 31%	<b>9%</b> 10% 8%	<b>53%</b> 56% 48%	<b>11%</b> 10% 13%
Specialist Nurse	<b>23%</b> 20% 30%	<b>10%</b> 12% 5%	<b>46%</b> 47% 44%	<b>20%</b> 20% 21%
MRI scan	<b>30%</b> 29% 31%	<b>11%</b> 13% 3%	<b>53%</b> 52% 56%	<b>7%</b> 6% 10%
Physiotherapy	<b>34%</b> 28% 45%	<b>9%</b> 10% 6%	<b>44%</b> 47% 38%	<b>14%</b> 15% 11%
Speech and Language Therapy	<b>42%</b> 28% 52%	<b>11%</b> 18% 6%	<b>34%</b> 38% 32%	<b>13%</b> 18% 10%
Occupational Therapy	<b>37%</b> 33% 42%	<b>8%</b> 8% 8%	<b>40%</b> 43% 37%	<b>15%</b> 17% 14%
Psychologist	<b>36%</b> 29% 47%	<b>9%</b> 10% 7%	<b>31%</b> 38% 22%	<b>24%</b> 23% 25%
Respite Care	<b>45%</b> 34% 54%	<b>7%</b> 9% 6%	<b>24%</b> 30% 19%	<b>25%</b> 28% 22%
Aid, Appliance or Specialist Equipment	<b>47%</b> 45% 49%	<b>7%</b> 6% 7%	<b>34%</b> 33% 35%	<b>13%</b> 6% 9%
Adaptation to my home	<b>42%</b> 37% 51%	<b>5%</b> 6% 4%	<b>28%</b> 30% 24%	<b>25%</b> 27% 20%
Personal Assistant	<b>47%</b> 47% 48%	<b>9%</b> 10% 9%	<b>16%</b> 15% 17%	<b>27%</b> 28% 26%
Day service appropriate to my needs	<b>46%</b> 40% 56%	<b>11%</b> 12% 9%	<b>15%</b> 18% 12%	<b>27%</b> 30% 23%
Social Worker	<b>39%</b> 36% 44%	<b>10%</b> 12% 7%	<b>26%</b> 24% 29%	<b>25%</b> 29% 20%
Support Group	<b>26%</b> 25% 28%	<b>20%</b> 23% 13%	<b>39%</b> 39% 39%	<b>15%</b> 13% 20%

*"Access to physiotherapy is virtually non-existent. In my experience, this is particularly so for people with neurological conditions.*



(viii) *Comparison with 2011 survey results*

Responses to the item "I haven't been able to get this service at all" were compared between the results of the 2011 survey and the present survey in relation to a number of specific services. There was a significant increase in the percentages of respondents reporting they could not get these services.

*Percentage of respondents who reported they could not get this service*

	2011 survey	2014 survey
Consultant Neurologist Appointment	4%	7%
Specialist Nurse	11%	20%
Physiotherapy	9%	14%
Speech & Language Therapy	5%	13%
Occupational Therapy	9%	15%
Psychology	16%	24%
Respite Care	4%	25%
Aid, appliance or specialist equipment	9%	13%
Adaptation to my home	8%	25%

(ix) *(Impact of Cuts in Benefits and Entitlements)*

Respondents were presented with a range of benefits and entitlements and asked about any changes in their entitlement to these services over the past three years. Almost half of respondents, 46% reported a significant effect of increased cost of medications for their condition. 45% reported a significant impact of changes to the mobility allowance and 41% have been significantly affected by cuts to home care packages.

	Big Effect	Some effect	No effect
Reduction in home help hours	<b>31%</b> People with condition: 25% Family Member R: 43%	<b>28%</b> 29% 27%	<b>40%</b> 47% 30%
Cuts to HSE transport services	<b>33%</b> 24% 53%	<b>21%</b> 21% 20%	<b>46%</b> 55% 27%
Cuts to respite services	<b>36%</b> 22% 53%	<b>25%</b> 25% 24%	<b>39%</b> 52% 24%
Cuts to personal assistant services	<b>33%</b> 24% 50%	<b>26%</b> 24% 29%	<b>41%</b> 52% 21%
Having my medical card taken away from me	<b>21%</b> 20% 24%	<b>21%</b> 10% 38%	<b>58%</b> 70% 38%
Being refused a medical card for my condition	<b>38%</b> 36% 44%	<b>12%</b> 11% 13%	<b>50%</b> 53% 44%
Increased cost of medications for my condition	<b>46%</b> 47% 43%	<b>36%</b> 36% 38%	<b>18%</b> 17% 19%
Changes to mobility allowance	<b>45%</b> 37% 66%	<b>23%</b> 24% 23%	<b>31%</b> 39% 11%
Cuts to home care packages	<b>41%</b> 32% 59%	<b>23%</b> 24% 23%	<b>36%</b> 44% 18%

*"My medical card was reviewed. It took four months of lengthy and protracted correspondence to deal with the review. Fortunately, I managed to retain the card, but the process was very involved and difficult."*

*"My medical card will be up for renewal in March and I am concerned that it will not be renewed."*

*"I am on the long term illness scheme however more and more of the drugs i need are being taken off the scheme"*

#### (x) Paying for Services on a Private Basis

Respondents were presented with a range of services and asked questions in relation to paying privately for these services and the impact of this in terms of cost to them. A significant percentage reported paying for these services on a private basis. Over 40% had paid for physiotherapy, equipment, aid or appliance for their condition or consultant neurologist. The most significant expenditure was associated with cost of medications and private health insurance.

	Yes at large expense	Yes at some expense	No it was provided free of charge	Need it but cannot afford it
Speech and Language Therapy	<b>14%</b> <i>People with Condition 6%</i> <i>Family Member R: 19%</i>	<b>10%</b> 16% 6%	<b>62%</b> 59% 63%	<b>14%</b> 19% 12%
Occupational Therapy	<b>10%</b> 7% 13%	<b>9%</b> 12% 5%	<b>62%</b> 58% 67%	<b>19 %</b> 23% 15%
Psychology	<b>19%</b> 21% 16%	<b>13%</b> 17% 5%	<b>42%</b> 33% 57%	<b>26%</b> 28% 23%
Physiotherapy	<b>26%</b> 28% 23%	<b>14%</b> 16% 8%	<b>45%</b> 39% 60%	<b>15%</b> 17% 10%
Neurologist	<b>30%</b> 33% 22%	<b>11%</b> 12% 8%	<b>53%</b> 49% 63%	<b>6%</b> 5% 7%
Equipment, Aid or Appliance for my condition	<b>26%</b> 25% 27%	<b>20%</b> 24% 15%	<b>45%</b> 41% 53%	<b>8%</b> 10% 15%
Paid carer	<b>22%</b> 16% 30%	<b>9%</b> 10% 8%	<b>36%</b> 40% 30%	<b>33%</b> 34% 33%
Medication for my condition	<b>29%</b> 31% 23%	<b>37%</b> 37% 37%	<b>31%</b> 29% 38%	<b>3%</b> 3% 1%
Private Health Insurance, e.g. VHI, Aviva, Laya etc	<b>63%</b> 64% 61%	<b>16%</b> 15% 18%	<b>2%</b> 1% 3%	<b>19%</b> 19% 18%

*"I would like to avail of private health insurance but cannot afford it at present."*

*"health cover becoming so expensive might have to consider dropping it despite the consequences"*

(xi) Receiving Services from a Not for Profit Organisation

35% of respondents reported receiving services from a not for profit organisation. Of these 84% viewed this support as important with the percentage higher for family members (92%).

	Total Respondents	Person with Condition	Family Member
Yes	35%	34%	38%
No	51%	52%	49%
I have in the past but not at the moment	14%	15%	13%
I have never had any support or services from a not for profit org	0%	0%	0%

(xii) Importance of Services from a Not for Profit Organisation

	Total Respondents	Person with Condition	Family Member
Very important to me	48%	68%	76%
Somewhat important to me	36%	20%	16%
Not sure	12%	10%	2%
Not very important to me	1%	1%	0%
Not at all important to me	1%	2%	5%
This question does not apply to my situation	2%	0%	0%

*"It's invaluable to have someone or an organisation you can ring about getting the best advice on your condition"*

*"Just to know someone cares"*

*"I would be lost without my respite angel. I can talk to her and she cares for my son like he is her own. This is invaluable to the whole family."*

(xiii) Satisfaction with aspects of service provision

	Very Satisfied	Satisfied	Not Sure	Dissatisfied	Very Dissatisfied
Info available about condition	<b>28%</b> <i>People with Condition: 34%</i> <i>Family member responding on behalf of 11%</i>	<b>23%</b> 20% 31%	<b>21%</b> 19% 27%	<b>16%</b> 16% 17%	<b>12%</b> 11% 14%
Support in linking to services	<b>17%</b> 21% 4%	<b>25%</b> 25% 24%	<b>25%</b> 24% 31%	<b>17%</b> 15% 24%	<b>16%</b> 15% 17%
Support in planning for future needs	<b>9%</b> 11% 1%	<b>21%</b> 22% 18%	<b>30%</b> 30% 30%	<b>21%</b> 19% 28%	<b>19%</b> 18% 23%
Getting referred to services	<b>15%</b> 19% 3%	<b>24%</b> 25% 20%	<b>26%</b> 25% 30%	<b>20%</b> 18% 29%	<b>14%</b> 13% 18%
Being involved in decisions about care	<b>21%</b> 28% 2%	<b>23%</b> 22% 26%	<b>34%</b> 32% 38%	<b>11%</b> 8% 20%	<b>11%</b> 10% 14%
Support in managing effects of condition	<b>18%</b> 23% 1%	<b>25%</b> 26% 1%	<b>25%</b> 23% 30%	<b>20%</b> 16% 33%	<b>13%</b> 12% 15%
Psychological support around condition	<b>11%</b> 14% 2%	<b>21%</b> 22% 15%	<b>32%</b> 31% 35%	<b>22%</b> 17% 35%	<b>15%</b> 16% 13%
Understanding of condition by health pros	<b>20%</b> 24% 6%	<b>25%</b> 26% 23%	<b>19%</b> 17% 29%	<b>19%</b> 18% 26%	<b>16%</b> 16% 16%
Practical support to live independently	<b>15%</b> 20% 0%	<b>23%</b> 24% 19%	<b>31%</b> 31% 28%	<b>16%</b> 11% 31%	<b>16%</b> 14% 22%

Over one third of respondents were dissatisfied with aspects of service provision to meet their needs, including:

Support in Planning for Future Needs: 40%

Psychological Support around the effects of the condition: 37%

Understanding of their condition by health professionals: 35%

Getting referred to services: 34%

Levels of reported dissatisfaction were higher for family members responding on behalf of a person with a neurological condition.

(xiv) *Feelings/Reactions Associated with having a neurological condition*

Note that in this section a category was included to reflect lack of insight into effects of the condition, as perceived by family members. In some neurological conditions, particularly acquired brain injury, the impact of the condition and its implications may not be perceived to the same degree by the person with the condition.

	Never	Occasionally	Frequently	Almost Always	Lacks Insight (family member response only)
Anxious/Worried	People with Neuro Condition: 5% Family Member responding on behalf of 3%	34% 27%	36% 23%	25% 23%	21%
Depressed	17% 11%	44% 28%	26% 23%	13% 20%	18%
Angry	22% 10%	42% 26%	24% 31%	12% 18%	15%
Isolated	18% 13%	37% 30%	24% 17%	21% 22%	17%

(Note that because of the addition of an item in the family member respondent version of the survey, comparable totals are not available for this question)

61% of respondents with a neurological condition reported experiencing anxiety frequently or almost always, 39% depression and 36% feeling angry. 45% reported feeling isolated. The responses by family members responding on behalf of the person with the condition and people with the condition themselves were not significantly different in this survey, although up to a fifth of family members did respond that the person lacked insight.

*"Not what is wrong but the way I am treated. Nobody asks a person in a wheelchair to prove they are disabled but I carry 2 cards to prove it."*

*"The fact that my condition is not well understood by many in medical profession and generally, makes it harder for me to cope with it."*

*"Because I'm not working anymore I'm finding I feel very isolated from people"*

*"I am too ashamed to tell most of my friends or excolleagues or family about my condition"*

(xv) Impact on Quality of Life, Participation and Other Areas

	Big Impact	Some Impact	No impact	Don't Know (Lacks insight FM only)	Does not apply to personal situation
Cost of Living	<b>46%</b> <i>People with Condition 46%</i> <i>Family Member R 45%</i>	<b>33%</b> 35% 24%	<b>14%</b> 14% 12%	<b>4%</b> 3% 7%	<b>4%</b> 2% 13%
Family and Relationships	<b>42%</b> 40% 50%	<b>40%</b> 43% 28%	<b>13%</b> 14% 9%	<b>4%</b> 2% 10%	<b>1%</b> 1% 4%
Overall quality of life	<b>58%</b> 54% 69%	<b>35%</b> 39% 23%	<b>6%</b> 7% 2%	<b>2%</b> 0% 6%	<b>0%</b> 0% 1%
Participating social activities	<b>57%</b> 52% 70%	<b>31%</b> 36% 18%	<b>8%</b> 10% 3%	<b>2%</b> 2% 5%	<b>1%</b> 1% 4%
Participating in hobbies	<b>55%</b> 50% 68%	<b>31%</b> 35% 17%	<b>11%</b> 13% 5%	<b>2%</b> 1% 6%	<b>2%</b> 1% 5%
Participating training or volunteering	<b>47%</b> 44% 55%	<b>30%</b> 36% 13%	<b>12%</b> 14% 5%	<b>3%</b> 2% 5%	<b>9%</b> 4% 22%
Participating in work	<b>55%</b> 54% 55%	<b>23%</b> 28% 8%	<b>7%</b> 9% 3%	<b>2%</b> 1% 6%	<b>13%</b> 8% 28%

Respondents were asked to rate the impact of their condition on a range of areas of their lives. More than half of respondents reported a significant impact on overall quality of life, participating in social activities and participating in work, hobbies, training or volunteering. These responses tended to be slightly higher where a family member responded on behalf of the person with a neurological condition. Overall, the results indicate the extent to which living with a neurological condition impacts significantly on the individual in their daily life.

*"I feel isolated, and nobody understands what happened to myself. To all and sundry I look okay - so in their eyes I am okay."*

*"Reduced hours in work, No social life as I am too tired and in order to maintain work and a safe standard at work I need to rest when at home"*

*"I cannot participate in all of the above and have lost many friends since becoming ill - as have no energy to socialise - it's a very isolating illness"*

*"I am a 35 year old mother of 3 living in a 70 year olds body"*

(xvi) Financial and Other Concerns

	Big Impact	Some impact	Not affecting	Don't Know (Lacks insight FM only)	Does not apply to personal situation
Worry about financial situation	<b>44%</b> <i>People with Condition: 48%</i> <i>Family Member R 34%</i>	<b>30%</b> 36% 13%	<b>11%</b> 11% 9%	<b>8%</b> 2% 25%	<b>6%</b> 2% 18%
Worry about cuts in health services	<b>46%</b> 52% 29%	<b>27%</b> 31% 14%	<b>11%</b> 11% 11%	<b>10%</b> 4% 28%	<b>6%</b> 2% 18%
Worry about cuts in benefits and entitlements	<b>46%</b> 52% 28%	<b>24%</b> 26% 19%	<b>11%</b> 12% 7%	<b>9%</b> 3% 27%	<b>10%</b> 7% 18%
Seeing less of family members/ friends	<b>36%</b> 38% 31%	<b>29%</b> 32% 19%	<b>22%</b> 24% 17%	<b>4%</b> 2% 12%	<b>8%</b> 4% 21%
People in general not understanding my condition	<b>47%</b> 52% 33%	<b>36%</b> 35% 39%	<b>9%</b> 10% 5%	<b>5%</b> 2% 15%	<b>3%</b> 1% 9%

Almost half of respondents reported that worries and concerns about finances and cutbacks were having a significant impact on them. 47% reported a significant impact of people in general not understanding their condition and 65% are impacted by seeing less of family members and friends as a result of their neurological condition.

*"We the invisible disabled, say no more"*

*"My primary concern is losing access to my treatment which is very expensive. It cannot be paid for privately. The treatment is keeping my condition from getting any worse, with some improvements."*

(xvii) Access to Transport

	Large Effect	Some effect	Not affected at all	Does not apply to personal situation
Difficulty accessing public transport	<b>24%</b> <i>People With Condition: 20%</i> <i>Family Member R35%</i>	<b>23%</b> 25% 18%	<b>23%</b> 27% 11%	<b>30%</b> 28% 35%
Difficulty getting accessible taxis	<b>13%</b> 11% 18%	<b>11%</b> 11% 10%	<b>31%</b> 35% 20%	<b>46%</b> 43% 52%
Cannot afford accessible transport	<b>18%</b> 17% 22%	<b>13%</b> 13% 13%	<b>26%</b> 29% 16%	<b>43%</b> 41% 50%
Have had to turn down a service due to lack of transport	<b>13%</b> 11% 18%	<b>12%</b> 12% 13%	<b>26%</b> 30% 15%	<b>49%</b> 48% 54%

Almost half of respondent reported some difficulty in accessing public transport, 31% cannot afford accessible transport while almost one quarter have had to turn down a service due to lack of transport.

*"I live in the country so public transport is not an option. My driving had been limited but now I have had to stop as I am hemiplegic and it is no longer possible for me to do so...."*



(xviii) *Improvements in Neurological Care Services over the past 3 years*

Respondents were asked to comment on any perceived improvements in the services and supports available to them over the past three years. Overall, there was little improvement and many respondents reported that cutbacks, especially to respite, were making things harder for them.

*Unfortunately not. Waiting lists have increased, funding has decreased. Medication costs have seriously increased. Physiotherapy is not available. Aids and appliances are very limited.*

*None at all. Fear of losing my job due to illness and not been able to work when ill.*

## FAMILY CARERS

(i) *Hours Spent Caring*

Hours Spent Caring	Reponses
Less than 3 hours	14%
3-5 hours	24%
5-10 hours	25%
More than 10 hours a day	37%

37% of respondents reported caring for more than ten hours a day while 82% reported that their health had suffered as a result of caring.

(ii) *Extent to which health has suffered as a result of caring*

Extent to which health has suffered	Responses
Yes to a big extent	23%
Yes to some extent	59%
No	18%

(iii) *Feelings About Caring*

	Very Often	Sometimes	Never	Don't Know
Feeling isolated	43%	43%	9%	3%
Feeling unsupported	33%	38%	28%	1%
Feeling frustrated and/or down	53%	43%	2%	2%
Worry about who will care for the person in the future	61%	33%	5%	2%
Worry about our financial situation as a family	65%	26%	7%	2%
Worry about future cuts in health services and benefits	73%	25%	0%	2%
Feeling unsupported in own right as a carer	60%	28%	5%	7%
Health pros not recognising them as part of care team	28%	42%	24%	6%

73% of carers reported worrying very often about future cuts in health services and benefits, 65% about their financial situation and 61% about who would care for the person in the future. 53% reported feeling frustrated and/or down and unsupported in their own right as a carer. 70% reported that they sometimes or very often felt that health professionals do not recognise them as part of the care team.

(iv) Most Difficult Aspects of Caring

Family carers were asked to describe the most difficult aspect of caring. Some of the responses are outlined below:

*"Watching them in pain."*

*"Excluded from outside world, no one understands your situation, tied to the person you love and care for, guilty for being so able bodied, for having the choice to walk if I couldn't take any more, responsible for the persons well being, hygiene, comfort etc"*

*"Not being able to get any respite, even when I need to go to Hospital"*

*"There are a few, one is constantly worried about him out and about on his own. His change in personality. Our relationship is no longer husband and wife but carer and caree"*

*"It's a seven day a week task, even God rested on the seventh day."*

*"Angry outbursts that upset everyone in the house and sticking to a strict routine."*

*"Not having a quality of life for yourself. You live to look after this person that's all. Your needs come last."*

(v) Carer Receiving Benefits/Entitlements

Approximately one quarter were receiving full rate or part rate carer's allowance. 43% were receiving carers respite grant.

	In receipt of	Have not applied for this benefit	Not entitled to this benefit	Applied for this benefit but was turned down
Full rate carers allowance	24%	26%	36%	14%
Part rate carers allowance	26%	30%	37%	7%
Carers respite grant	43%	24%	27%	6%

(vi) Carer Employment Outside the Home

	Yes	No	Does not apply to their situation
Currently working outside the home	36%	60%	5%
Working outside the home before the onset of family members condition	77%	18%	4%
Gave up work as a result of family members condition	42%	52%	6%
Reduced hours of work	22%	35%	44%
Family Income fallen significantly since onset of condition	64%	25%	11%

77% of family carers were working outside the home before the onset of their family member's condition. 42% give up work in order to look after their family member while 64% reported that family income has fallen significantly since the onset of the neurological condition.

*"Reason I am still working is because once we got the support from medical team they advised me to stay in job, extremely difficult always on call fell I am needed at home, only in work mornings, but have all toileting, dressing, meds done before I go."*

*"I don't know if I'm entitled to a payment. I don't call myself a carer. I'm her husband and do what needs to be done."*

## DISCUSSION OF FINDINGS

Some of the respondents in this survey described people with neurological conditions in Ireland as “invisible” and there is certainly a dearth of research documenting the impact of being diagnosed with or developing a neurological condition in Ireland. This survey aimed to examine a range of aspects of living with a neurological condition in this country, from the effects on employment and financial status to emotional wellbeing and participation in everyday life. The survey also examined access to a range of services and supports and how individuals and families have been impacted by changes to these supports in the current economic environment. The views of family carers were also sought, asking them to describe their experiences in caring for a person with a neurological condition and the impact on family life.

The sections below examine the findings in the context of previous research and reports on the experiences of people with neurological conditions and in the context of the changes in Irish society over the past three years which have seen a cumulative set of measures impacting on those living with a chronic illness or disability.

### *Employment and Participation*

A significant proportion of respondents, though working before the onset of their condition, reporting having to give up work and over half report a significant fall in income and a large impact on their cost of living following the onset of their condition. The scope of this survey did not allow us to examine the reasons why the people with neurological conditions in this sample gave up work. However, some individual responses support the recent findings highlighted by the European Multiple Sclerosis Platform<sup>1</sup> that, in many cases, small changes to the workplace would allow people to remain in work, provision of rest breaks, workplaces which are accessible by wheelchair etc. One issue reported by a number of respondents was the change to illness benefit introduced in the 2014 budget where people are not entitled to claim illness benefit for the first six days of their illness, a doubling of the so called “waiting period”. This impacts in particular on those with relapsing remitting conditions and was cited by a number of respondents as yet another factor decreasing their appeal to potential employers.

Many respondents require help with everyday tasks such as self care, travelling outside the home and concentrating or remembering to do everyday things. Over half of those who responded to the survey reported feelings of anxiety, depression and isolation on a regular basis. One of the most striking aspects of the survey is the isolation associated with having a neurological condition. Almost half of respondents are significantly impacted in participating in social activities, work or training. Physical isolation is affected by access to transport with over half reporting difficulty accessing or affording accessible transport and a quarter having to turn down a service because of lack of transport. However, it is clear from individual responses that the isolation experienced by those having a neurological condition also arises from a perception that their condition is not understood by those around them. Almost all respondents were impacted by people in general not understanding their condition. Respondents also reported seeing less of family and friends because of their condition and fatigue and disability making social interaction difficult. The findings of the current survey are interesting to compare with those of The National Physical and Sensory Disability Database 2008 report on Measures of Activity and Participation (MAP): The Experience of People with Neurological Conditions<sup>2</sup>. This report examined the impact of neurological conditions on experiences of restriction in and barriers to participation in society for a group of people with neurological conditions registered on the database. There was a significant perception of restrictions imposed on daily life as a result of having a neurological condition. 67% of those interviewed were “bothered a lot” by the effects of their neurological condition on participation in employment and job seeking, 62% were similarly concerned by restriction in participating in family life. Over half reported a significant restriction on their ability to participate in social activities.

### *Access to Services*

People with neurological conditions require a range of specialist services to meet the particular needs associated with their condition, often requiring these services over a long time and working in co-ordination with each other to deliver an appropriate response. In addition, this group access a wide range of general health and social care services to meet their needs.

The dearth of services for people with neurological conditions in Ireland has been continuously documented by

the NAI. This survey examined the experiences of service users over the past three years in accessing a range of services for their condition. The aim was to compare the findings from previous NAI surveys and explore the impact of stringent health service cuts over this period which have seen a significant overall reduction in the health spend and the numbers of people working at the front line in service delivery.

Over one quarter of respondents reported greater difficulty in getting an appointment with a consultant neurologist over the past three years. Despite recent increases in the number of consultant posts, Ireland continues to have the lowest number of consultant neurologists in Europe. Though there was a commitment by the Department of Health that no one would be waiting more than twelve months for an outpatient appointment by the end of last year, there were still 2,095 people waiting more than 12 months for a neurology outpatient appointment in November 2013<sup>3</sup>.

The percentages reporting that it had become more difficult to access therapy services were even higher, including occupational therapy (37% have found it more difficult to access this service), speech and language therapy (42%), physiotherapy (34%), social work (39%) and psychology (36%). These findings reflect those of the 2013 NAI survey on neurorehabilitation needs which found that 40% of those who needed to could not access psychology or social work services and 25% could not access occupational therapy services. The 2012 report of the National Physical and Sensory Disability Database 2012<sup>4</sup> reveals a significant issue with access to therapy and rehabilitative services for children and adults with physical and sensory disabilities in Ireland. Of 6,897 people registered or reviewed in 2012, a high percentage were in need of therapy services such as physiotherapy, occupational therapy and psychology. Two categories were available to classify need for these services: 1. Unmet need: consists of those who (a) require assessment (b) were assessed and placed on a waiting list and (c) were assessed but unable to avail of the service 2. Enhanced/alternative service consists of those who (a) require assessment for an enhanced service (b) were assessed as requiring an enhanced service and (c) were assessed as requiring an enhanced service but were unable to avail of the service The percentage assessed as having an unmet need for the following services was reported as follows: Physiotherapy: 16% Occupational Therapy: 50% Speech and Language Therapy: 26% Psychology: 25%. When requirements for an enhanced/alternative service are included, the demands for therapeutic services are even higher: Physiotherapy: 20% Occupational Therapy: 63% Speech and Language Therapy: 42%. Earlier this year, figures were released from the HSE indicating over 16,000 people in Ireland had been assessed and were on waiting lists for speech and language therapy and there are numerous anecdotal reports from local areas of therapy posts remaining vacant or those going on leave not being replaced.

Almost half of respondents in this survey reported that access to a range of disability supports had become more difficult over the past three years: aids and appliances and personal assistant services (47%), day services (46%) and respite services (45%). Up to a quarter of respondents in the current survey reported that they could not access respite care (25%) and personal assistant (27%) services. Cuts to these services over the past number of years have been highlighted by disability groups and groups representing carers and older people. A recent report by the Disability Federation of Ireland highlighted the vital importance of PA services<sup>5</sup> to independent living for people with disabilities and the concerns of service users around retaining this crucial support.

A comparison with findings from the 2011 NAI survey found a significant increase in the percentage of those reporting that they could not access respite care and adaptations to their home. The reasons why people could not access these services are not available from the current findings. However, cuts to the respite grant and housing adaptation grant schemes may be responsible for reports of increased difficulty in accessing these supports. The respite care grant was cut by 19% in 2013 and this cut has not been reversed. The housing adaptation grant schemes were cut by 42% between 2010 and 2014, with changes announced in early 2014 to the criteria and percentage of costs which will be covered. Groups representing those with disabilities and the elderly have argued that these changes will mean less people who need to can avail of these supports.

Over 40% of respondents to the current survey reported a significant impact of cuts to home care packages. One third of respondents reported a significant impact of cuts to personal assistant and home help hours and

HSE transport services. The 2012 report of the National Physical and Sensory Disability Database found a 24% level of unmet need for home help services among 6,897 people reviewed or registered on the database. In their 2014 pre budget submission, Age Action report a reduction in home help hours of 16.6% between 2007 and 2013<sup>6</sup>.

Individual respondents highlighted areas of service need which were not examined in the current survey. These were in relation to education and housing. There is a clear need to examine the experiences of people with neurological conditions in these areas, among anecdotal reports from NAI member organisations of significant difficulties in accessing appropriate accommodation due to changes in the rent supplement in recent years. Education is an area where there is significant anecdotal information available about the difficulty in accessing assessment and education support services, particularly among those with mild or moderate acquired brain injury.

### *Satisfaction with Aspects of Service Provision*

Anecdotal reports and comments from people with neurological conditions and their families highlight their frustration in accessing the supports they require and findings services that meet their needs. The findings of the present survey show that a third of respondents reported dissatisfaction with support in linking them to services, planning for future needs, support in managing the effects of the condition and getting referred to services. Family members responding on behalf of the person with a neurological condition were more likely to indicate dissatisfaction with these aspects of service provision. The high proportions of respondents reporting dissatisfaction in these areas is very concerning and there is clearly a need for further research in this area to examine in depth the specific needs of people with neurological conditions in accessing the services they require and their experience in interacting with these services. Of note, the percentage of respondents expressing satisfaction with involvement in decisions about their care was 44%. This figure was significantly lower for family member respondents (28%). This contrasts with percentages of 67% (hospital inpatient), 52% (hospital outpatient) and 72% (GP care) reported by respondents in the Insight 07 Survey commissioned by the HSE on consumer satisfaction with health and social care services in Ireland<sup>7</sup>.

### *Paying for Care on a Private Basis*

The survey examined the issue of cost of private care with anecdotal reports from NAI member organisations that people with neurological conditions are increasingly being forced to access the services they need on a private basis. This was borne out by the findings. Over 40% of respondents reported paying for physiotherapy, neurology and aids and equipment privately. The survey found a significant impact of paying for medications on people with neurological conditions. Individual respondents outlined the cumulative effect of changes in this area in successive budgets. The prescription charge has increased fivefold from 2011, when it was introduced, to 2014. The Drugs Payment Scheme threshold has increased by 44% since 2010 to €44 currently. In addition, charges have been introduced for medical card holders receiving a number of items on prescription. The costs associated with having a neurological condition were frequently highlighted in the comments of respondents. The Disability Federation of Ireland notes that additional costs of disability such as healthcare, assistance, aids and devices have been estimated to be a third of average weekly income for disabled persons<sup>8</sup>. Over 60% of respondents in this survey reported paying for private health insurance and many noted that they viewed this as an essential protection in order to access the services and treatment they need. However, many individual respondents also noted that they would be forced to drop their cover if their premiums increased any further.

### *Changes to Benefits and Entitlements*

The past three years have seen significant cuts in some of the most critical financial supports to people with chronic illness and disability and those who care for them. This survey found that people with neurological conditions have been impacted significantly by these cuts. 42% of people have had their medical card withdrawn over the past three years while 50% reported that they were refused a medical card. Responses also indicated the level of anxiety among people with neurological conditions and their families in relation to their medical card, a number of individuals commented on the worry and burden associated with the review process. In a presentation to the Joint Oireachtas Committee on Health and Children on the 11<sup>th</sup> February 2014, Professor Orla Hardiman, Consultant Neurologist, outlined the importance of medical cards as an “essential



passport” to services and supports for people with neurological conditions such as motor neurone disease and the difficulty of accessing critical services for the management of neurological conditions in the community without a medical card. The current survey findings are particularly worrying in the context of this comment. The cut to the respite grant in 2013 (€1,700 down to 1,375) has had a significant impact on over a third of respondents. Individual respondents noted that they had used this to pay for healthcare costs and equipment as well as respite. Over 40% reported a significant impact of the changes to mobility allowance. In 2013, the mobility allowance was closed to new applicants although those already receiving payments will continue to do so until an alternative was put in place.

Most respondents are worried that successive cuts over the past number of years do not represent the end with concern about further cuts clear from their individual responses. There is a clear climate of uncertainty and the difficulty in planning financially from year to year that is significantly adding to the concerns of those living with a neurological condition and their family members. Worries and concerns over cutbacks were also reported by a majority of family carers. These concerns also came through in individual responses with families feeling they cannot plan for the future as they do not know what their income may be and what supports may be affected.

### *Family Carers*

Most family carers reported that their health had suffered as a result of caring and over half have given up work in order to care for the person with a neurological condition. The responses of family carers in this survey indicate the challenges involved in caring for a person with a neurological condition with almost all respondents reporting feeling isolated, frustrated and/or down sometimes or very often. The individual responses of carers in the survey stress the extent to which carers are impacted by the personality and behavioural changes associated with the condition. These changes increase family carer’s feelings of isolation as they often disrupt family life. It is of significant concern that so many carers report that they are not recognised as part of the care team or supported in their own right as a carer, particularly in light of the first of the goals of the National Carers Strategy (2012)<sup>9</sup> to “recognise the value and contribution of carers and promote their inclusion in decisions in relation to the person they care for”. Worries and concerns about finances and cutbacks were reported by a majority of carers and it is clear that diagnosis/onset of a neurological condition has a significant effect on family finances; 42% of family carers had given up work in order to care for the person and 64% reported that family income had fallen significantly since the onset of the condition.

### *Role of not for Profit Organisations*

The findings of the current survey support those of the NAI 2011 survey in highlighting the importance of not for profit organisations in supporting people with neurological conditions and their families. Individual responses noted the role of the not for profit organisation in providing vital supports such as specialist equipment, physiotherapy services and respite. In the context of successive cuts to the funding of not for profit disability organisations over recent years, it is notable that 22% had experienced a reduction in services because of cuts in funding to the organisation.

## SUMMARY AND RECOMMENDATIONS

The overall picture from this survey is that living with a neurological condition in Ireland is becoming more, not less, challenging. This population has historically been impacted by the dearth of neurospecialist services and the challenges associated with meeting their complex and changing needs over time. What we are also seeing in these findings is the impact of cutbacks in general health and disability services and changes in benefits and entitlements which are having a significant effect on people with neurological conditions and their families. The Disability Federation of Ireland pre budget submission 2014 outlines the cumulative measures in successive budgets as “chipping away at both disability specific and mainstream supports which represents a complete lack of understanding of the challenges faced by people with disabilities trying to live an ordinary life with health and wellbeing”. They are also contributing to a sense of worry and anxiety about the future that pervades the individual comments throughout the survey. People with neurological conditions and their

families are struggling to cope with the effects of their condition in the context of an ongoing lack of resourcing and development of neurological care services and now, in addition, a steady erosion of critical services and supports for people with chronic illness and disability in Ireland.

The survey findings point to the urgent need to develop neurology and neurorehabilitation services in response to the historic underdevelopment of these areas in Ireland. The focus to date in terms of neurology services has been on putting in place the much needed increase in consultant staffing with Ireland continuing to have the lowest number of neurologists in Europe. There is in addition a critical need to focus on the provision of multidisciplinary teams within neurology services and the development of clinical pathways to encourage effective management of neurological conditions across the health system. Progress in the development of neurospecialist services in Ireland has been slow but with clear improvement in areas such as acute stroke care and the management of epilepsy which demonstrate the potential for effective change. The 2011 National Strategy and Policy for the Provision of Neurorehabilitation Services<sup>10</sup> outlines the need for the development of neurorehabilitation services both through inpatient facilities and through community based geographical teams which would work closely with primary care. There has been some progress to date in addressing consultant staffing in this area but both the results of the NAI 2013 survey on neurorehabilitation and the findings of the present survey highlight the need to address critical issues in relation to access to therapy services such as psychology, speech and language therapy, OT and physiotherapy for people with neurological conditions, particularly in the community. At present there is only one community based neurorehabilitation team based in the Mid West despite the recommendation of the National Neurorehabilitation Strategy that these be established nationwide.

What we have seen in the past three years is an attempt to bring together the efforts of all providers, statutory and non statutory to address the needs of people with neurological conditions across the health services through the work of the clinical programmes. What is needed is to ensure that this effort is matched by resources to support the ongoing work of the programmes and a commitment to the development of an effective community based infrastructure for the long term management of neurological conditions which recognises the range of health and social supports required.

A number of aspects of service provision were examined in the current survey and the findings indicate relatively poor levels of satisfaction overall in areas such as support in planning for future needs, linking to services, managing the effects of their condition and involvement in decisions about their own care. It is also of concern that over a third of respondents were dissatisfied in terms of the understanding of their condition by health professionals. There is a need for more research in this area which involves service users in identifying the aspects of service provision that matter to them and how their interaction with services could be improved.

The survey findings point to the importance of mobilising an effective intersectoral response to the needs of people with neurological conditions given the needs highlighted in relation to employment support, transport etc. This requirement is recognised within the National Neurorehabilitation Strategy "Given the many interrelated factors impacting on quality of life of people needing neuro-rehabilitation, only some of which fall within the responsibility of the health sector, it is imperative that there is a 'whole system' approach in which each unit of authority commits to having clear policies and service protocols in place and that, where possible, there are joined-up and collaborative strategies and synergies in place that ensure that the experience of people being served is positive and beneficial". There is an obvious linkage to be made with the systems already in place around the development of sectoral plans for the National Disability Strategy by a range of Government departments.

The findings of this survey demonstrate the vulnerability of people with neurological conditions to the series of successive cutbacks in health and disability supports over the past three years. As well as leading to increasing hardship for people with neurological conditions and their families, they will inevitably result in poorer outcomes and increased dependence on already overstretched hospital based neurology services, the link between lack of community based services and delayed discharges in neurology services is well recognised. The steady erosion of community based health and disability services makes no sense in the context of the



Government's own policy objective to ensure that "more care is delivered in the community"<sup>11</sup>. Steps taken in the 2014 health spend to increase funding to home care and community based services will not resolve the depletion of these supports over the past three years and further ongoing investment in this area is urgently needed.

The cuts in benefits and entitlements including the cut to the respite grant, medical card provision, sick leave payments and home adaptation grants represent unfair and short sighted policy decisions. The improving fiscal situation should be used to immediately redress the effect of these measures over recent budgets.

We are still, as a country, failing to provide for the needs of over 700,000 Irish people living with neurological conditions and in recent years they have been impacted upon further by the reduction and withdrawal of vital services and supports. The Neurological Alliance of Ireland will continue to raise the issues highlighted in this report and campaign to promote the development of services for all those affected by neurological conditions. The NAI would like to thank all those who shared their experiences with us and contributed to the important insights into the experiences of Irish people with neurological conditions outlined in this document.

## References

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- 4 Annual report of the National Physical and Sensory Disability Database (2012) Health Research Board
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- 7 Insight 07: A National Survey of Consumer Satisfaction with Health and Social Care Services in Ireland (2007) HSE
- 8 Disability Federation of Ireland Pre Budget Submission 2014
- 9 National Carers Strategy (2012) Department of Health
- 10 National Policy and Strategy for the Provision of Neurorehabilitation Services in Ireland (2011) Department of Health and Children
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## MEMBERS OF THE NEUROLOGICAL ALLIANCE OF IRELAND

Acquired Brain Injury Ireland  
Alzheimer Society of Ireland  
Aware  
Cheshire Ireland  
Chronic Pain Ireland  
Dystonia Ireland  
Enable Ireland  
Epilepsy Ireland  
Headway  
Huntington's Disease Association of Ireland  
Irish Heart Foundation  
Irish Motor Neurone Disease Association  
Meningitis Research Foundation  
Migraine Association of Ireland  
Move 4 Parkinsons  
Multiple Sclerosis Society of Ireland  
Muscular Dystrophy Ireland  
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North West MS therapy centre  
Parkinson's Association of Ireland  
Post Polio Support Group  
Syringomyelia Support Group of Ireland  
Spinal Injuries Ireland  
Spina Bifida Hydrocephalus Ireland  
The Irish Hospice Foundation  
The Rehab Group  
Volunteer Stroke Scheme

## ASSOCIATE MEMBERS

Brain Tumour Ireland  
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Irish Association of Speech and Language Therapists  
Irish Institute of Clinical Neurosciences