

Neurological Alliance of Ireland Pre Budget Submission 2015

Summary of Recommendations

Health

1. It is vital that urgent steps are taken in the upcoming budget to address the issue of discretionary medical cards. This is a huge issue of concern, not only for those who have had their card withdrawn (and restored on a temporary basis) but for those newly diagnosed who are applying and anxious about their future care.
2. There should be no further increases in prescription charges in the coming budget.
3. The budget needs to contain a specific focus on community based healthcare, addressing the critical situation in relation to therapy services and prioritising the delivery of supports in the community which reduce the impact on acute hospitals.
4. The upcoming budget needs to ring-fence funding for the reconfiguration of community based therapy services in order to develop community based neurorehabilitation teams on a nationwide basis.
5. As part of the implementation of the National Dementia Strategy, the Government must commit to adequately resourcing community based care for people with dementia and their carers.

6. The proposed joint review of funding of health and disability organisations by the Department of the Environment and Department of Health, following the decision to extend funding under the SSNO scheme to July 2015, must ensure that vital services provided by neurological charities are sustained and placed on a secure footing in terms of future funding.
7. The NAI is calling on the Government to address the issues in relation to Mobility Allowance and the Motorised Transport Grant which were closed to new applicants in 2013.

Social Protection

1. The doubling of the waiting period for illness benefit disproportionately affects those with chronic conditions and should be reversed.
2. Steps should be taken in the upcoming budget to reverse the cuts to the respite care grant as identified by groups representing carers and caring organisations.
3. The NAI supports the Disability Federation of Ireland pre budget submission to the Department of Social Protection (June 2014) which calls for protection of income supports and supplementary benefits.

Environment

1. The changes to the housing adaptation grant should be reversed in the upcoming budget.

This is a vital support to enable people to remain in their own homes and reducing people's ability to avail of this support is a counterproductive measure.

Details of NAI Submission

The Impact of Austerity

The cumulative effect of recent budgets on the 700,000 Irish people with neurological conditions have been examined by the Neurological Alliance of Ireland in a nationwide survey earlier this year.

People with neurological conditions were already struggling with the long standing underdevelopment neurological care services in Ireland resulting in long waiting lists for diagnosis and treatment and lack of access to the kind of follow up care that would be taken for granted in other developed countries.

The last three years of austerity budgets have critically impacted the range of health and social protection supports they rely on, resulting in a double blow to people and their families living with neurological conditions.

Over the last three years they have experienced:

1. Cuts to health services, particularly vital community healthcare services and home care supports
2. Increased cost of healthcare due to increased cost of medication and withdrawal of discretionary medical cards
3. Cost of living increases
4. Reduction in income if they are dependent on social protection because of cuts in supplementary benefits, including rent allowance
5. This year, the threatened withdrawal of €620,000 in funding from vital services provided by neurological charities

Survey Findings

The Neurological Alliance of Ireland carried out a nationwide survey of over 600 Irish people living with neurological conditions and their families earlier this year. The survey examined access to a range of health services, benefits and entitlements and questioned respondents about changes they

had experienced over the past three years. The results of this survey “Living with a Neurological Condition in Ireland”, published in March this year, indicate a devastating impact of three years of austerity on people living with neurological conditions.

The findings of this survey will be highlighted throughout this submission. The full report can be downloaded at http://www.nai.ie/go/resources/nai_documents/report-on-nai-national-survey-living-with-a-neurological-condition-in-ireland.

The 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.

HEALTH

The focus of the NAI pre budget submission in relation to healthcare is on:

- (a) The need to address the cost of healthcare for people with neurological conditions
- (b) The need to address the deficit in community based healthcare for people with neurological conditions
- (c) The need to protect vital services provided by neurological charities which were threatened with withdrawal in 2014 and face similar uncertainty in 2015.
- (d) The need to put in place supports to people affected by the abolition of the mobility allowance and motorised transport grant schemes.

Cost of Healthcare

1. Discretionary Medical Cards

The NAI nationwide survey “Living with a Neurological Condition in Ireland” highlighted the impact of the medical card review which saw 15, 300 discretionary medical cards withdrawn between July 2011 and May 2014.

A detailed survey was carried out by the NAI in June 2014¹ to examine the views and experiences of people with neurological conditions, family members and health professionals in relation to medical cards. Of the health professionals who responded:

70% had noted an increase in withdrawal of medical cards

90% had noted a significant increase in review of medical cards

90% had noticed a significant increase in unsuccessful application for medical cards among people with neurological conditions.

60% had noticed changes in the awarding of discretionary medical cards to people with neurological conditions over the past two years, finding it more difficult to get a person with a neurological condition awarded a medical card on this basis.

One fifth of health professionals and other service providers estimated that 20-50% of their clients with discretionary medical cards had had them withdrawn over the past two years.

The survey highlighted the importance of the medical card in meeting the healthcare costs associated with having a neurological condition and in accessing services

(i) Importance of the Medical Card in Accessing Services

¹ NAI Submission on Review of Medical Card Eligibility (2014) <http://www.nai.ie/go/news/30-6-2014-nai-submission-on-review-of-medical-card-eligibility>

80% of people with a neurological condition and family members who responded to the survey viewed the medical card as essential in accessing health services for their neurological condition.

82% of health professionals and other service providers viewed the medical card as essential in accessing health services for people with neurological conditions.

45% of people with neurological conditions and family members responded that there are services they cannot access because they do not have a medical card.

64% of health professionals and other service providers responded that there are services their clients with neurological conditions cannot access unless they have a medical card.

(ii) Importance of the Medical Card in Meeting Healthcare Costs

82% of people with neurological conditions and family members surveyed viewed the medical card as essential for them in meeting the costs associated with having a neurological condition.

68% of people with neurological conditions who do not have a medical card struggle to meet the costs associated with having a neurological condition

73% of health professionals and other service providers viewed the medical card as essential in meeting the costs associated with having a neurological condition.

It is vital that urgent steps are taken in the upcoming budget to address the issue of discretionary medical cards. This is a huge issue of concern, not only for those who have had their card withdrawn (and restored on a temporary basis) but for those newly diagnosed who are applying and anxious about their future care.

2. Cost of Medication

Prescription charges for medical card holders were increased in Budget 2014 from €1.50 per item to €2.50 per item, an increase of 70%. Increases have also been made to the drugs payment scheme threshold (€120 in 2011 increased to €132 in 2012 and to €144 in 2013).

The effect of these changes was evident from the NAI survey “Living with a Neurological Condition in Ireland” published in March 2014, almost half of respondents (46%) reported that increased costs of medication for their condition had had a big impact on them.

There should be no further increases in prescription charges in the coming budget.

Addressing the Deficit in Community Based Healthcare for People with Neurological Conditions

1. Underresourcing of home support and therapy services

The NAI survey “Living with a Neurological Condition” showed the impact of cuts in a range of healthcare supports and services over the past three years. 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. The percentage of respondents reporting that they “could not access this service at all” had jumped from 4% to 25% when it came to respite care. Over 40% of respondents reported a significant impact of cuts to home support including home help. There has been no increase in home help hours in 2013/2014 which represents an effective cut in service provision as the service cannot expand to meet increasing demand.

The steady erosion of community based healthcare services over the past number of years is in contradiction of the Government’s own policy to design a healthcare system which keeps people living at home as long as possible and facilitates healthcare close to their communities. The latest

health policy document, 'The Path to Universal Healthcare, White Paper on Universal Insurance'² promotes reform of the health system which will lead to "the delivery of integrated, person centred care provided at the lowest level of complexity that is safe, timely, efficient and as close as home as possible". The 2009 review of home care packages³ recognised that "Ireland's health delivery model needs to shift from a hospital focus to a system that focuses on delivering services closer to the home".

Inadequate resourcing of community based supports such as home help and home care packages places increased pressure on other areas of the health services. The review of home care packages carried out in 2009 recognised the importance of home care packages in facilitating timely discharge and reducing pressure on accident and emergency departments. There is evidence of growing problems in both these areas of the health services this year. The latest HSE performance assurance report (May 2014) notes that "There appears to be an upward trend in the number of delayed discharges from a consistent range of 583 in early 2014 to 671 by May 2014" The report also points a 2% rise in emergency department admissions this year⁴.

The findings of the NAI survey "Living with a Neurological Condition in Ireland" showed the impact on community therapy services of years of effective cutbacks caused by the recruitment ban and the reduction of the workforce (The HSE service plan 2013 aimed to reduce overall staff numbers by 2,400, 2,600 in 2014⁵. Employment within the health services overall has dropped by 11% (12, 505 WTE's since 2007). In the 2014 NAI survey, 37% of respondents reported that it had become difficult to access occupational therapy services over the past three years, speech and language therapy (42%), physiotherapy (34%), social work (39%) and psychology (36%). The 2012 report of the National Physical and Sensory Disability Database⁶ reveals a significant issue with access to therapy and rehabilitative services for children and adults with physical and sensory disabilities in Ireland. Of

² The Path to Universal Healthcare: White Paper on Universal Health Insurance (2014) Department of Health

³ Evaluation of Home Care Packages (2009) Report Commissioned by the Department of Health and Children

⁴ Performance Assurance Report (May 2014) Health Services Executive

⁵ National Service Plans (2013 & 2014) Health Services Executive

⁶ Report of the National Physical and Sensory Disability Database (2012) Health Research Board

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, for example in January this year it was highlighted that there was no speech and language therapist for adults in Waterford city.

The budget needs to contain a specific focus on community based healthcare, addressing the critical situation in relation to therapy services and prioritising the delivery of supports in the community which reduce the impact on acute hospitals.

2. Need to Invest in Community Neurorehabilitation Teams

The National Rehabilitation Medicine Clinical Programme estimates an unmet need of 5,500 people each year requiring community neurorehabilitation which the NAI views to be a significant underestimate.

The impact of the dearth of community based neurorehabilitation services was starkly highlighted in an NAI national survey on neurorehabilitation needs in 2013. 71% of respondents could not access neuropsychology services, 66% rehabilitation assistant, 55% social work services, 50% counselling services, 44% speech and language therapy and 43% occupational therapy services.

The National Strategy and Policy for the Provision of Neurorehabilitation Services⁷ published in December 2011 commits to the establishment of community based neurorehabilitation teams under a three year implementation process. To date, no community neurorehabilitation team has been put in place since the strategy was published.

The upcoming budget needs to ring-fence funding for the reconfiguration of community based therapy services in order to develop community based neurorehabilitation teams on a nationwide basis.

3. Supporting Care in the Community for People with Dementia

In line with its focus on community based healthcare for people with neurological conditions, The NAI supports the call by the Alzheimer Society of Ireland for steps to support people with dementia to remain at home for as long as possible by:

- Ensuring adequate resourcing of dementia specific home care and community based services and supports
- Ensure equal access to community based supports across the country

⁷ National Policy and Strategy for the Provision of Neurorehabilitation Services in Ireland (2011) Department of Health

-Ensure that budgets for people with dementia are transparent, measureable and ring fenced at regional and national level.

In their 2015 pre-budget submission⁸, the Alzheimer society of Ireland point out the potential cost savings of providing properly resourced community based services for people with dementia, including family carers. Carers for people with dementia providing family care in the community saved the Irish Government €807 million in 2010.

As part of the implementation of the National Dementia Strategy, the Government must commit to adequately resourcing community based care for people with dementia and their carers.

4. Securing vital services and supports for people with neurological conditions

All thirteen not for profit neurological organisations which applied for the National Scheme to Support Voluntary Organisations (SSNO) run by the Department of the Environment in 2014 had their applications turned down. This represented a huge blow to the delivery of vital supports and services to people with neurological conditions and their families in Ireland. Successive surveys, reports and policy submissions by the Neurological Alliance of Ireland highlight the severe deficits in every aspect of our neurological care services. The loss of SSNO funding represents a withdrawal of €620,000 from neurological care services supporting early intervention, home support, helplines, day services and counselling.

The Minister for the Environment, Alan Kelly has restored funding under the scheme at 2014 levels. (which represents cumulative cuts of 17% in this funding over the past three years) for 12 months to the organisations affected. This will only guarantee funding of these vital services until July 2015. He has also promised a review of funding to national charities in the health and disability sector in association with the Minister for Primary Care, Mental Health and Disability in the Department of Health. People with neurological conditions who are critically dependent on the services provided by these charities face renewed uncertainty once again in 2015, as they did this year.

⁸ Alzheimer Society of Ireland. Pre Budget Submission (2015)

The proposed joint review of funding of health and disability organisations by the Department of the Environment and Department of Health, following the decision to extend funding under the SSNO scheme to July 2015, must ensure that vital services provided by neurological charities are sustained and placed on a secure footing in terms of future funding.

5. Mobility Allowance

Mobility Allowance and Motorised Transport Grant schemes were closed to new applicants in February 2013. It is vital that the forthcoming budget addresses this need through the proposal of appropriate supports to those affected.

The NAI is calling on the Government to address the issues in relation to Mobility Allowance and the Motorised Transport Grant which were closed to new applicants in 2013.

SOCIAL PROTECTION

Changes to Illness Benefit

A change to illness benefit was 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 on people with neurological conditions who may experience periodic worsening of their symptoms.

The doubling of the waiting period for illness benefit disproportionately affects those with chronic conditions and should be reversed.

Respite Grant

The respite care grant was cut by 19% in 2013 and this cut has not been reversed. Responses of those who replied to the NAI survey “Living with a Neurological Condition in Ireland” highlighted the critical importance of this grant with family members using it to cover healthcare costs, to provide a

break so that they themselves could go into hospital or care for other family members, take care of younger children etc.

Steps should be taken in the upcoming budget to reverse the cuts to the respite care grant as identified by groups representing carers and caring organisations⁹.

Protection of Income Supports and Supplementary Benefits

The Disability Federation of Ireland, of which NAI is a member group, are calling for an increase of €20 as an interim measure to introduce an adequate income for people with disabilities that reflects the level of at risk poverty and deprivation they experience and the extra cost of living with a disability. They are also calling for supplementary benefits such as Household Benefits Package, Domiciliary Care Allowance and Free Travel Scheme to be protected.

The NAI survey “Living with a Neurological Condition in Ireland” found that 47% of respondents had to give up work due to their neurological condition and 47% were in receipt of a social welfare payment because of their condition. 56% had experienced a significant fall in their income since the onset of their condition.

Due to the importance of social protection payments to people with neurological conditions and their families, the NAI supports the recommendations of the Disability Federation of Ireland in this area.

The NAI supports the Disability Federation of Ireland pre budget submission to the Department of Social Protection (June 2014) which calls for protection of income supports and supplementary benefits.

DEPARTMENT OF THE ENVIRONMENT

Home Adaptation Grant

⁹ Care Alliance Ireland Pre Budget Submission (2015)

25% of respondents to the NAI survey “Living with a Neurological Condition in Ireland” reported they could not meet their need for adaptations to their home, a significant increase from the 8% who reported this in the NAI 2011 survey. Individual responses point to the impact of the changes introduced in January 2014 which make this entitlement more difficult to access for those who require it.

The changes to the housing adaptation grant introduced in January 2014 should be reversed in the upcoming budget. This is a vital support to enable people to remain in their own homes and reducing people’s ability to avail of this support is a counterproductive measure.

FURTHER INFORMATION

The Neurological Alliance of Ireland would welcome the opportunity to make a presentation on the areas addressed in this submission. For further information contact Magdalen Rogers, NAI Development Manager at naiireland@eircom.net or 01 8724120.

List of NAI member organisations

Acquired Brain injury Ireland

Alzheimer Society of Ireland

Aware

Epilepsy Ireland

Cheshire Ireland

Chronic Pain Ireland

Dystonia Ireland

Enable Ireland

Epilepsy Care Foundation

Friedrich’s Ataxia Association of Ireland

Headway

Huntington's Disease Association of Ireland

Irish Heart Foundation

Irish Hospice Foundation

Irish Motor Neurone Disease Association

Meningitis Research Foundation

Migraine Association of Ireland

Move4Parkinsons

Multiple Sclerosis Society of Ireland

Muscular Dystrophy Ireland

Neurofibromatosis Association of Ireland

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 Rehab Group

Volunteer Stroke Scheme

Associate Members

Brain Tumour Ireland

PSPA Ireland

Irish Association of Speech and Language Therapists

Irish Institute of Clinical Neurosciences

Myaware

Irish Society of Physicians in Geriatric Medicine