



NEUROLOGICAL ALLIANCE  
of IRELAND

## STRATEGIC PLAN 2017-2019

Working Together for the Best  
Neurological Services and Supports



An Roinn Tithíochta, Pleanála,  
Pobail agus Rialtais Áitiúil  
Department of Housing, Planning,  
Community and Local Government

## Chair's Foreward



The Neurological Alliance of Ireland will mark its 20th anniversary in 2018. Established in 1998 by a small group of not for profit neurological organisations, and a committed neurologist, membership has grown to over thirty national organisations representing people with neurological conditions and their families. NAI has established a niche as the national umbrella organisation dedicated to advocating for the needs of people with neurological conditions through awareness raising, policy development and campaigning. We align within the greater disability movement in Ireland and acknowledge the challenges facing people living with chronic health conditions. We look forward to the timely ratification and subsequent implementation of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) as a significant policy milestone.

Since its establishment, NAI has secured crucial recognition for the needs of people with neurological conditions, in the context of a health system, and indeed a society where they continue to be faced with a lack of understanding and response to those needs. NAI has raised the profile of neurological conditions and gives a voice to the 800,000 people in Ireland living with these conditions.

NAI has played a crucial role in creating the awareness and shifting attitudes among policy makers and other stakeholders that led to the development of key initiatives in neurological care, including the development of a national strategy for neuro-rehabilitation and the establishment of clinical programmes in neurology and rehabilitation medicine.

In the term of our last Strategic Plan (2011-2015) we faced a funding crisis that impacted across our membership when core funding was suddenly withdrawn from twelve neurological organisations under the Scheme to Support National Organisations. The NAI led a campaign which successfully secured the restoration of this funding and created a strong awareness of the role and value of neurological organisations when it came to the new round of funding under SSNO in February 2016. Despite the impact of this funding situation across 2014 & 2015, we managed to keep our strategic plan on track and secured a series of important achievements including the launch of a national campaign for neuro-rehabilitation services, publication of a model of care for neurology services and increasing engagement among policy makers, public representatives and other stakeholders.

We developed this Strategic Plan (2017-19) through consultation with our membership. It is an ambitious programme to guide our work in the areas of advocacy, awareness-raising and capacity and sustainability. We are keenly aware of the challenging environment that continues to face us, and indeed our member organisations because of funding constraints and increasing regulation and reporting requirements. We have a history of “punching above our weight” when it comes to our impact and we aim to continue to deserve this reputation.

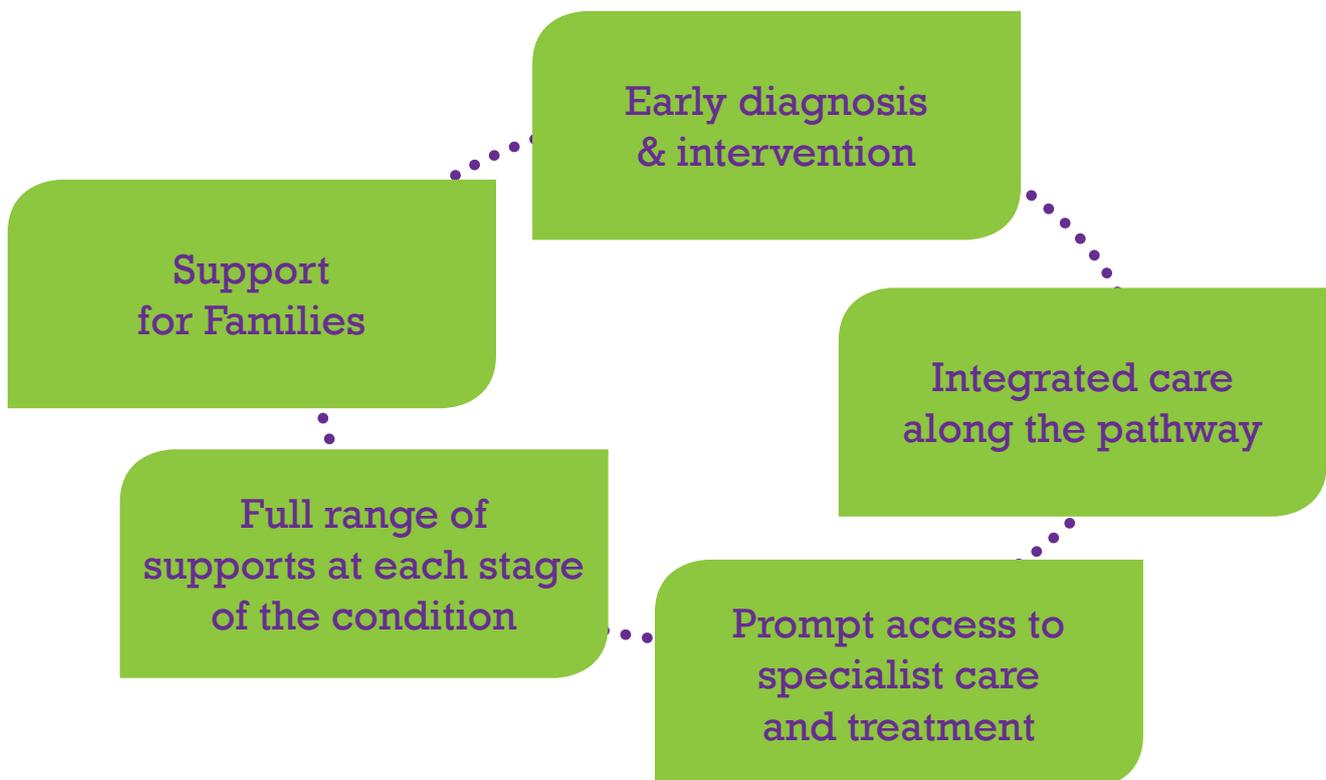
I want to thank everyone involved in the development of this plan and look forward to the continued support of our members and other stakeholders to secure positive change in the lives of Irish people with neurological conditions and their families.

**Chairperson: Shona Logan-King**

## 1. Who we are

The Neurological Alliance of Ireland (NAI) is the national advocacy umbrella organisation for neurological care in Ireland. We are an alliance of over thirty member organisations united in our intention to influence positive change for people living with neurological conditions and their families. Our member organisations are located throughout Ireland. NAI was established in 1998 and since then we have worked consistently to promote the development of services and supports for all those affected by neurological conditions in Ireland.

We understand the lived experience of people with neurological conditions. We know the gaps that exist in services and supports. We seek to bridge these gaps by changing health policy to ensure the full range of appropriate services and supports.



## NAI Member Organisations



### **NAI Vision**

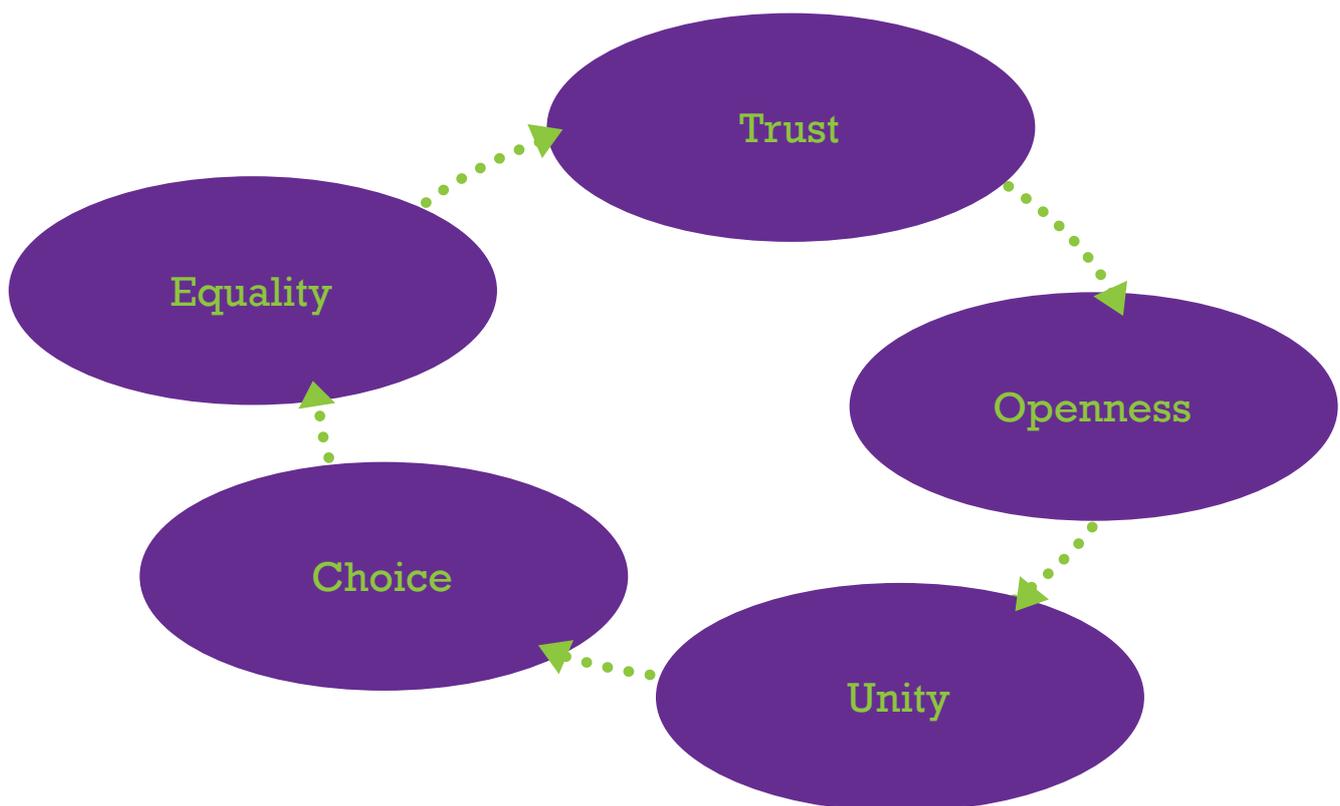
Our vision is an Ireland where people with neurological conditions experience and enjoy full quality of life.

### **NAI Mission**

Our mission is to work together to ensure the best services and supports for people living with neurological conditions and their families.

### **NAI Values**

We value and rely on trust, openness, unity, choice, equality and the power of many voices to progress our work.



## NAI Guiding Principles

We hold a set of guiding principles to guide all our work in relation to people with neurological conditions and their families. These guiding principles rest on a shared commitment to:

### Person Centred Services

We are committed to the development of an integrated pathway of person centred services for people with neurological conditions.

### Specialist Services

We are committed to the development of specialist services for people with specific neurological conditions.

### Shared Decision Making

We are committed to shared decision making with people with neurological conditions actively involved and consulted.

## 2. What is our purpose?

Neurological conditions are the most significant cause of acquired disability in adults. Despite being termed as “the greatest public health challenge facing public health systems in developed countries worldwide” by the World Health Organisation in 2004, neurological care services in Ireland continue to be completely inadequate and under resourced.

People with neurological conditions want to live within their own communities and realise their full potential. Neglect and under investment in neurological care means that the 800,000 Irish people living with neurological conditions are daily faced with impossible challenges of delays in diagnosis and treatment, lack of integrated care and the absence of specialist services leading to a devastating impact on these individuals and their families. The benefits for the early and appropriate treatment and rehabilitation of neurological conditions continue to be strongly supported by research, not only in terms of the quality of life of these individuals and their families but also to healthcare costs and the economy of the country as a whole.

Our purpose is to raise awareness of the needs of people with neurological conditions and secure real and positive change in how they are supported to live their lives.

There is a pressing need to change policy, both in order to secure investment in specialist services and to improve the response of our health and social care services as a whole to meet the needs of people with neurological conditions and their families.

As an alliance, we are committed to improving the services available to people with neurological conditions and their families in Ireland. We do this in partnership with our members through our advocacy, campaigning, policy development and awareness-raising work.

### **We work together towards:**

- Deepening awareness and understanding of the impact of neurological conditions so that the need for better services and supports is recognised and responded to.
- Drawing on the full range of our members experience, the testimony of people with neurological conditions and medical expertise to further our cause.
- Informing and influencing health policy to bring definite improvements in:
  - a. **Awareness and understanding** of the needs of people with neurological conditions across the health services.
  - b. **Access** to the full range of services across the pathway from diagnosis through treatment of neurological conditions.
  - c. **Integrated neurological care** in line with best international practice, to include community and home care and the full integrated pathway of medical, psychological, physical and social services and supports.
  - d. Development of **specialist supports and services** for people with neurological conditions and their families.
  - e. **Response** of mainstream health and disability services to the needs of people with neurological conditions.

## 3. Who we work with

We work with a range of stakeholders to change health policy and improve services for people with neurological conditions.

### People with neurological conditions and their families

- We consult with people with neurological conditions and their families and we understand their needs.
- We represent people with neurological conditions and their families.
- We advocate for best practice services and supports.

### NAI Members

- We listen to and receive the views of our members.
- We support our members through networking, communication and social media.
- We draw on the support of our members to advance our advocacy and campaign work.

### Policy Makers & Influencers

- We work with policy makers and clinical leaders, within the health services, to influence positive change.
- We prepare position papers, policy statements and submissions to inform and shape policy.
- We participate in relevant policy structures and working groups.
- We work with all elected representatives to gain their support for policy change.

### Partner Organisations

- We collaborate with partner organisations on campaigns to communicate our shared messages.
- We support relevant partner organisations and share resources and expertise to progress our work.
- We collaborate with others on projects of shared relevance so as to maximise our impact.

## 4. Our way of working

We are a company limited by guarantee registered as fully compliant with the voluntary code of practice for Community, Voluntary and Charitable organisations. We are governed by a Board of Directors [[http://www.nai.ie/go/about\\_us/board](http://www.nai.ie/go/about_us/board)]. Nominations to the Board are invited each year in advance of our AGM. We are committed to monitoring, tracking and evaluating our work. We develop an annual operational plan which we review on a twice yearly basis and we produce an annual report.

As an alliance we work in partnership with our member organisations. We maximise their contribution through the diligence and dedication of our core team.

### Core Components of our Work as an Alliance

#### Membership

We hold a united voice and take action on issues relating to neurological conditions and care through our dedicated members.

#### Support

We support our member organisations and draw on their input to strengthen and communicate the work of our alliance.

#### Relationships

Our good working relationships with policy makers, HSE, clinical programmes, politicians, media, individual clinicians and voluntary organisations help to progress our work.

#### Policy Information

We influence policy through our policy statements, targeted submissions, campaigns and communication.

#### Advocacy

We advocate for policy change to ensure the full range of supports and services for people with neurological conditions and their families.

## NAI Achievements

1998

NAI established by a group of neurological organisations and health professionals

2000 - 2002

NAI publishes **“Standards of Care”** for the management of neurological conditions in Ireland

2003

NAI is incorporated as CLG

2005

Launch of NAI website nai.ie

2006

First **National Brain Awareness Week** coordinated by the NAI and aimed at raising awareness of the impact of living with a neurological condition

2007

NAI secures agreement with the Department of Health to develop a national neuro-rehabilitation strategy

2008

Joint conference on neuro-rehabilitation organised by NAI and the Department of Health - ‘The Rehabilitation and Long Term Management of Neurological Conditions in Ireland’

2010

Launch of **“The Future For Neurological Conditions in Ireland: a challenge for healthcare, an opportunity for change”**

2011

**Publication of the National Neuro-rehabilitation Strategy.** NAI is invited to join the programme teams for the newly established national clinical programmes in neurology and rehabilitation medicine. The clinical programmes acknowledge the work of the NAI in ensuring strong representation from the not for profit sector to inform the development of the models of care.

2013

**NAI launches Neuro-rehabilitation Manifesto**  
NAI organises a series of neurological wellness days and a national campaign to coincide with European Month of the Brain

2014

NAI leads a successful national campaign for the restoration of critical core funding to twelve neurological organisations providing vital supports to people with neurological conditions

2015

NAI conducts the first National Audit of Neurology Services in Ireland in collaboration with the National Clinical Programme for Neurology

2016

Launch of the NAI campaign **“We Need Our Heads Examined”** calling for action on neuro-rehabilitation.

## 5. Plan for our work during 2017-19

This strategic plan has been informed and guided by a review of our work and consultations with our members. We note the progress made under our previous plans and intend to build incrementally and steadily on this foundation over the next three years.

We acknowledge the context for our work and the challenges and opportunities that we will encounter.

We will persist in advocating for investment in the provision of a full and integrated pathway of services and supports to meet the needs of people with neurological conditions and their families. Over the next strategic phase we will continue to prioritise and focus specifically on health policy.

**Our strategic priorities for 2017-19 centre on three themes:**



## Strategic Priority One - Advocacy

**Advocate for better services and supports for people living with neurological conditions so they may experience and enjoy life.**

Our **advocacy work** will continue to centre on the following actions:

### Action One

**Drawing** attention to the needs of specific groups of people with neurological conditions.

### Action Two

**Informing** wider health and disability policy to develop and improve services and supports so as to better meet the needs of people with neurological conditions and their families.

### Action Three

**Driving** the implementation of the neuro-rehabilitation strategy and the neurology model of care and the model of care for the rehabilitation medicine programme through carefully prepared submissions, communication and campaigning.

### Action Four

**Campaigning** for investment in neurological care through dedicated funding.

### Action Five

**Partnering** with the DFI and other national organisations and neurological experts on themes of shared importance.

### Indicators of Progress:

**We will monitor the progress of our Advocacy work by tracking the following signs:**

- Expanded openness to improving services and supports with specific policy commitments, dedicated funding, explicitly referenced in the HSE annual service plan and realisation of the commitment in the current Programme for Government 2016.
- Investment in neurological care and dedicated financing by HSE.
- Development of neuro rehabilitation services across the pathway (acute, specialist and community).
- Implementation of the Model of Care for neurology and neuro-rehabilitation services.
- Improved access to neurology services for the diagnosis and treatment of neurological conditions.
- Access to innovative medicine.

## Strategic Priority Two - Awareness

**Expand awareness of the reality of living with neurological conditions.**

Our **awareness expanding work** will centre on:

### Action One

**Promoting** NAI as a trusted alliance of member organisations committed to the development and improvement of services for people with neurological conditions.

### Action Two

**Promoting** NAI as a trusted alliance of member organisations committed to the development and improvement of services for people with neurological conditions.

### Action Three

**Communicating** our messages to decision makers, policy makers, politicians, media and clinicians through our presence, our membership, campaigns, submissions, reports, website and social media platforms.

### Action Four

**Deepening** relationships within our alliance and outward with specific decision makers and influencers in the media, politics, the HSE, medical, social care and research worlds so that our work is championed and disseminated widely.

### Action Five

**Using** evidence informed neurological research to support our advocacy and awareness work.

### Action Six

**Creating** space for people to share their experiences to enhance understanding of neurological conditions.

### Indicators of Progress:

**We will monitor the progress of our awareness raising work by tracking the following signs:**

- Number of media mentions, stories, blogs and articles dedicated to deepening society's understanding of neurological conditions.
- Number of political engagements, parliamentary questions and mentions of neurology related matters in the Houses of the Oireachtas.
- Number of relevant submissions and references to neurological conditions in reports that inform the policy discourse.
- Number and profile of people engaging in our campaigns.
- Feedback (from our members and other stakeholders) recounting positive shifts in attitudes to and understanding of neurological conditions.

## Strategic Priority Three - Capacity & Sustainability

**Strengthen our organisational capacity and sustainability to achieve our purpose as an alliance**

Our organisational **strengthening, capacity building and sustainability work** will centre on:

### Action One

**Attending** to our governance, structures, systems and processes to ensure we operate in accordance with best practice.

### Action Two

**Strengthening** our way of working together, as an alliance, so as to harness the full capacity of member support and clinical expertise to drive the work and achieve the priorities set out in this plan.

### Action Three

**Supporting** the continuous development of the capacity of our members to respond to the needs of people with neurological conditions and their families, particularly within the context of an evolving charity and health landscape.

### Action Four

**Meeting** the financial and monitoring requirements set out in our funding agreement with Pobal under the Scheme to Support National Organisations in the Community and Voluntary Sector (SSNO).

### Action Five

**Sourcing** new and necessary resources to further develop and sustain the work of NAI.

### Indicators of Progress:

**We will monitor our progress of our organisational development work by tracking the following signs:**

- Completion of our annual work programmes in an efficient and effective manner as evidenced through annual reviews of our progress.
- Membership satisfaction and continued commitment and contribution to the shared work of our alliance, e.g. through working groups, joint campaigns, platforms for shared learning.
- Continued compliance with the Governance Code.
- Sustainability of the work of NAI through different funding streams, resources and supports.

## 6. Funders and Supporters

We acknowledge the support of a multi-annual funding programme through the Scheme to Support National Organisations (SSNO), provided by the Department of Housing, Planning Community and Local Government and administered by Pobal.

We value the support from industry sponsors, subscriptions and from our member organisations. This investment enables us to progress our work.

We express appreciation to all NAI members as it is through our shared endeavours that we realise our power as an alliance.

## Neurological Alliance of Ireland

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