



The Alzheimer Society of Ireland

STRATEGY 2018- 2020



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SOCIETY *of* IRELAND

WHO CANNOT REMEMBER THOSE
WHOM WE CAN NOT REMEMBER



The Alzheimer Society of Ireland Strategy 2018-2020

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With the growing numbers of people living with dementia (more than 4,000 new cases each year), there has never been a greater need for the organisation to be the national leader in advocating for and providing dementia-specific supports and services in Ireland.

1. Foreword

We are delighted to introduce the new Strategic Plan 2018-2020.

Following an extensive consultation period in summer 2017, we have been able to put together our plan for the coming three years.

We would like to thank everyone for their work on helping to put this strategic document together – persons with dementia, carers, board members, branch members, volunteers and staff from all over the country.

Following the end date of our previous strategy ‘People with Dementia First’, the board of the ASI and the Senior Management Team held workshops to consider a number of issues such as

- Whether we had the right balance between service provision and advocacy?
- Whether we needed to re-balance the emphasis between the different services we provide including, information, advice, home care, day care, respite, social clubs and family carer training?
- What relationship should we seek to have with the HSE and other statutory funders?

We then undertook a major consultation within our organisation which took place right across the country. In total, 10 workshops were attended by more than 200 people, including persons with dementia, carers, branch members, volunteers and staff. All gave their views on our vision, mission, values, strengths, challenges, opportunities, future risks and strategic objectives.

The board held a special meeting to review the outcome of the workshops and a final draft was prepared by the Senior Management Team which has been approved by the board.

We are delighted to present it to you today – it has been a great motivating and unifying experience for everyone involved in the organisation.

The Alzheimer Society of Ireland is the national leader in advocating for, and providing, dementia-specific supports and services. While we have a service or support in almost every country in Ireland the level of services available to people with dementia and their carers remains well below what is required to cater for what is needed.

The recent mapping project, completed by the ASI and the HSE’s National Dementia Office which mapped dementia-specific services nationally showed that we are providing 68% of all dementia-specific services across Ireland.



The support that the ASI gives to people with dementia and their family members and carers is greatly appreciated, but it leaves people too reliant on services that are dependent on volatile charitable donations.

While improved awareness and understanding of dementia is reducing stigma, it remains a problem. We are well aware that people can sometimes still feel afraid or embarrassed about talking to people they know who have dementia and this can lead to a lot of unnecessary loneliness.

While there have been some encouraging research findings, none have yet produced a cure for dementia.

However, some people who have dementia can live reasonably well in their communities – but they have to be supported in order to do this. We want to see a society that is fully inclusive of people with dementia and their families and carers and also a society that ensures the appropriate supports and services are made available.

In order to do this, our strategic priorities over the coming years will be to:

- Advocate for rights and resources for people with dementia and their carers and communities;
- Promote and deliver sustainable dementia supports and services;
- Value and develop volunteering and branches;
- Create a culture throughout the organisation where our values and mission are understood and lived; and
- Strengthen our organisation's capacity to deliver our strategic priorities.

With the growing numbers of people living with dementia (more than 4,000 new cases each year), there has never been a greater need for the organisation to be the national leader in advocating for and providing dementia-specific supports and services in Ireland.

We are looking forward to implementing this plan over the next three years and, thereby making a real difference to the lives of people with dementia and their carers.

I hope you will join us on this journey.



Pat McLoughlin
CEO



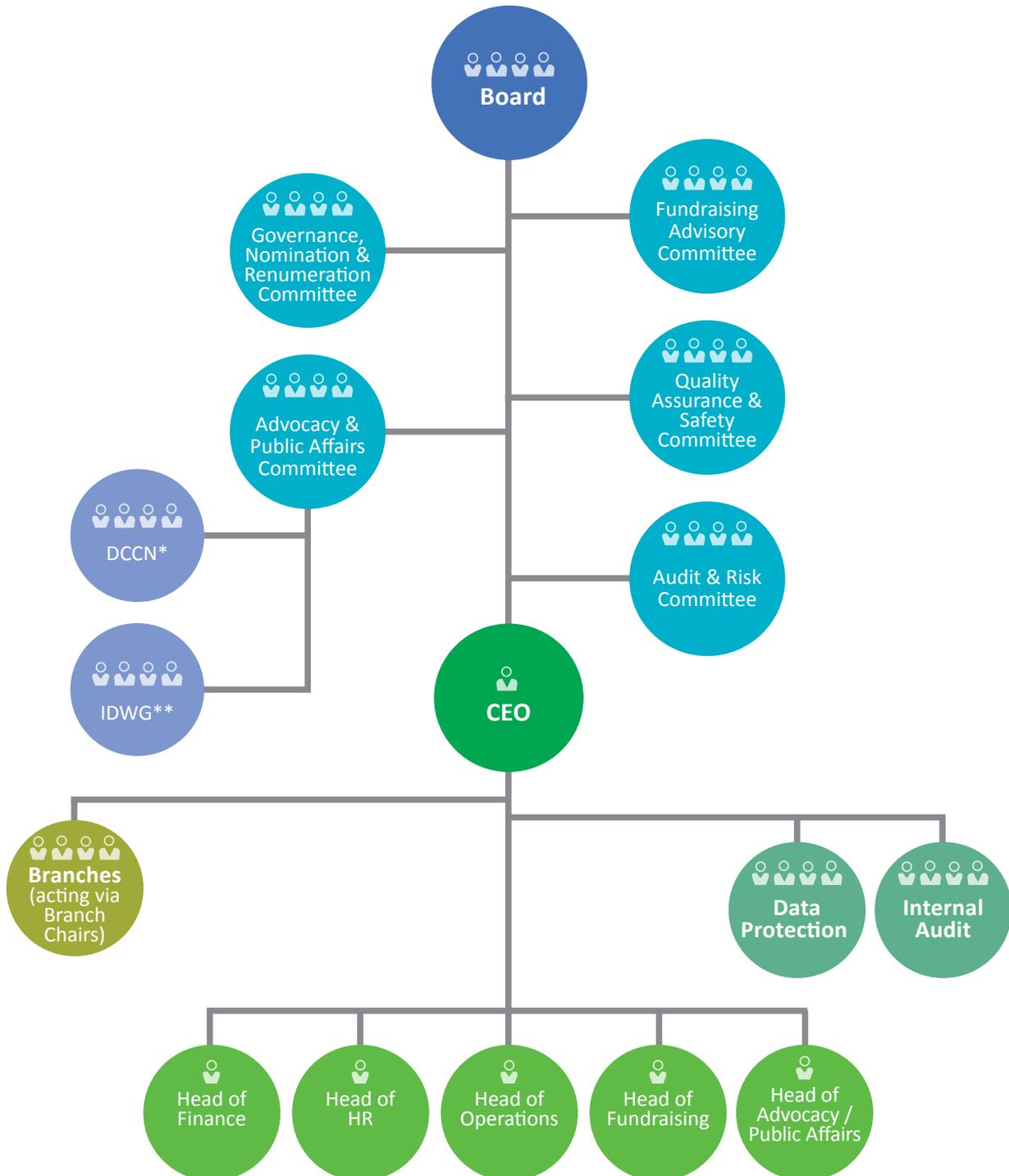
John Clifford
Chairperson



The Alzheimer Society of Ireland 35th Anniversary National Conference

Royal Marine Hotel, Dun Laoghaire
November 20 2017

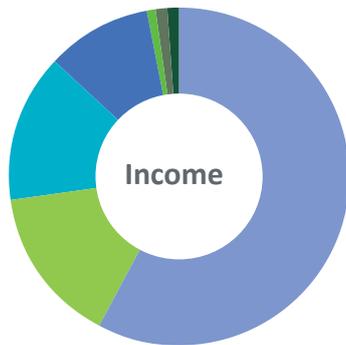
2. Organisational Structure



DCCN* Dementia Carers Campaign Network
 IDWG** Irish Dementia Working Group

3. The ASI in Numbers 2017

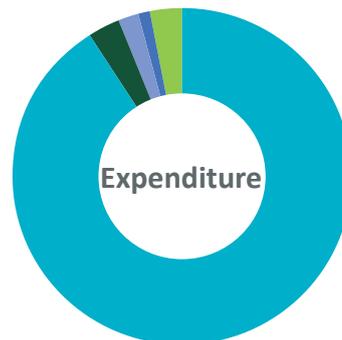
Where our monies come from



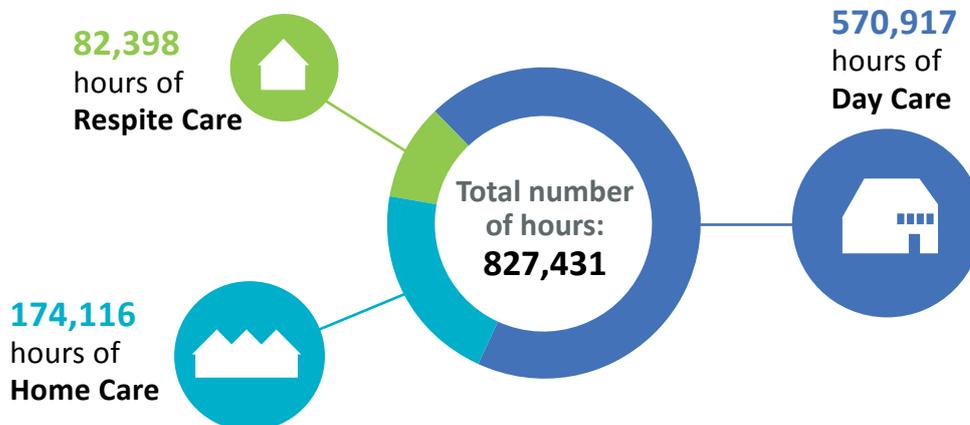
HSE Grants	58%
Fundraising / Donations / Legacies	15%
DSP CE Scheme Income	14%
Client Contributions	10%
Other Grants	1%
Atlantic Philanthropies	1%
Other Income	1%

How we spend it

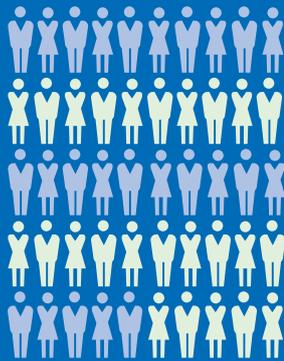
Care Services	91%
Fundraising	3%
Advocacy / Communications	2%
Research / Policy	1%
Governance	3%



Service hours delivered



Alzheimer National Helpline



5,294 people contacted the Helpline in 2017



6% increase
People contacting the Helpline in 2016–17



17% increase
People contacting about their own or their loved one's cognitive health.

Mobile Information Bus Service

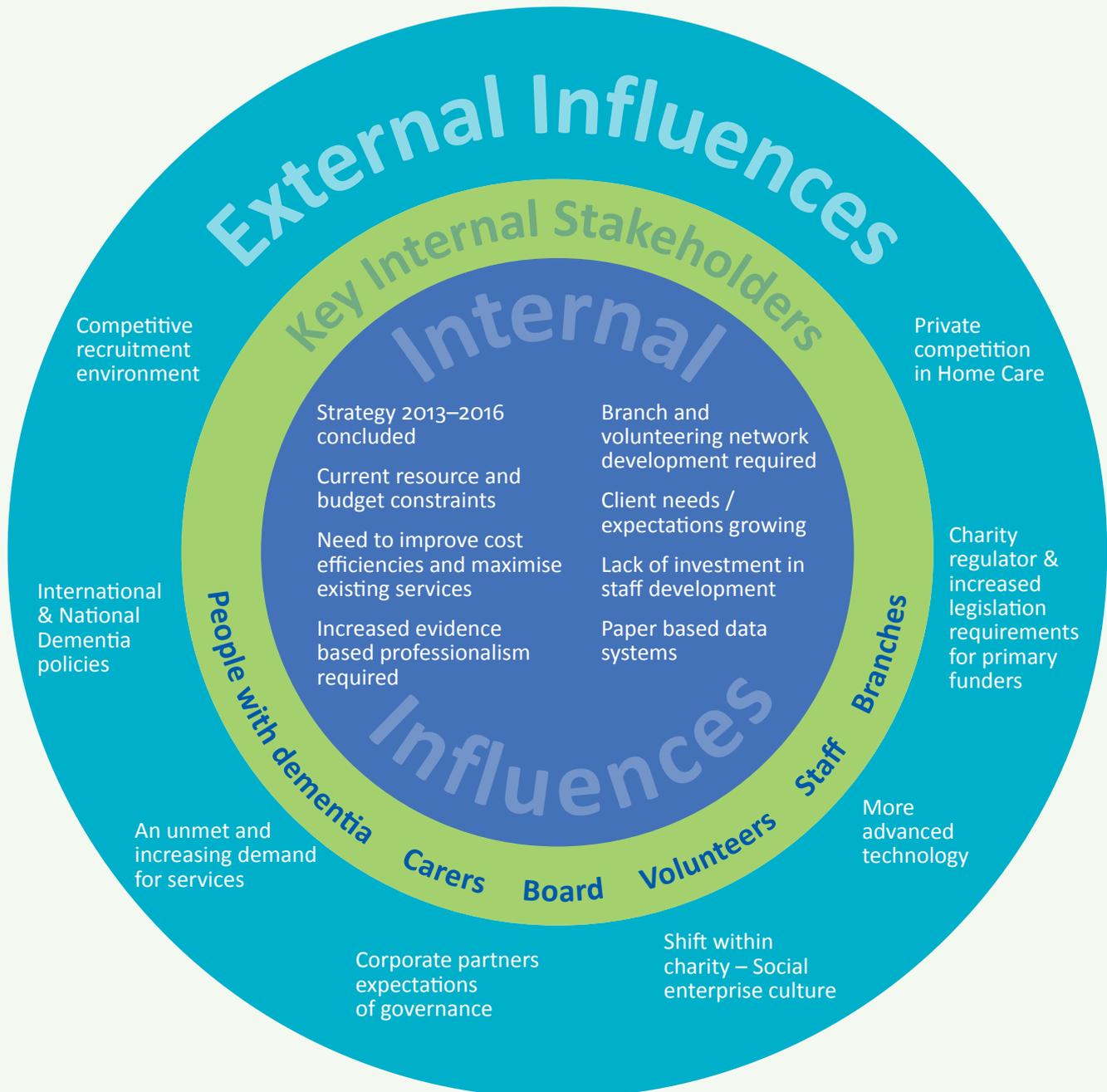


Human Resources

ASI staff received dementia training – Dementia Awareness 1 day course **334** valid certs (**106** trained); Responsive Behaviours 1 day course **286** valid certs (**100** trained).



4. Influences



(a) External Influences

International and National Dementia Policies

- **Dementia in a Global Context**

Dementia is an important cause of mortality and morbidity globally. In 2015, around 47 million people worldwide had dementia, a figure that is predicted to increase to 75 million by 2030 and to 132 million by 2050. There are nearly 10 million new cases every year or one every three seconds. Nearly 60% of people with dementia live in low and middle income countries and most new cases are expected to occur in those countries. Deaths due to dementia more than doubled between 2000 and 2015 making it the seventh leading cause of global deaths in 2015. The economic costs of caring for people with dementia are US\$818 billion worldwide and this is expected to rise to US\$2 trillion by 2030. A Global Action Plan on the Public Health Response to Dementia was adopted at the 70th World Health Assembly in May 2017.

- **Dementia in Europe**

In 2017, Alzheimer Europe published a report *European Dementia Monitor 2017*. This report provides a benchmark of national dementia policies in order to compare and rate the responses of European countries to the dementia challenge. The aim of the European Dementia Monitor is to assess which countries provide the most dementia friendly policies and guarantee the best support and treatment of people with dementia and their carers. On the basis of the findings in the 10 identified categories, Alzheimer Europe established a ranking of countries with Finland first with an overall score of 75.2% and Ireland, with a score of 61.1%, in ninth position.

- **European Alzheimer's Alliance (EAA)**

The EAA is a group of MEPs who have taken a special interest in Alzheimer's. The group now comprises 128 MEPs from 28 countries and it remains one of the Parliament's biggest interest groups. The ASI actively assists Alzheimer Europe in supporting the deliberations of this group.

- **Ireland's National Dementia Strategy**

In December 2014, the Department of Health published Ireland's first National Dementia Strategy. The Strategy set out the Government's plan to meet the needs of people with dementia and their families and carers. The strategy identified six priority areas and 14 priorities. The priority areas that were outlined had the potential, if implemented, to significantly improve rates of diagnosis and people's journey through the health and social care system. A mid-term review of the implementation of the strategy has been published.

- **Understand Together**

Dementia Understand Together is a recent and ongoing campaign to increase awareness of dementia. Launched in October 2016, it is a public support, awareness and information campaign aimed at inspiring people from all sections of society to stand together with the 55,000 Irish people living with dementia. The ultimate aim is to create an Ireland that embraces and includes people living with dementia, one which displays solidarity with them and their loved ones. The campaign is led by the National Dementia Office (NDO) of the HSE, working with The Alzheimer Society of Ireland, Genio and a coalition of over 30 partners from business, academic, health and voluntary and community sectors. The ASI is an active participant in this partnership.

- **All-Party Oireachtas Group on Dementia**

In October 2016, a significant political development saw the establishment of the above group. This group is co-convened by Deputy Mary Butler and Senator Colette Kelleher and the secretariat is provided by the ASI. The aim of the group is to build understanding, consensus and cross-party support for long-term planning and increased investment to support people with dementia and their carers. Members meet monthly in Leinster House and host different events, including quarterly dementia awareness sessions for Oireachtas members which are delivered by ASI.

- **Charity regulation and increased compliance requirements from primary funders**

The ASI supports the development of good governance in this sector. The ASI is a charitable company limited by guarantee. The ASI is compliant with the Governance Code for Community, Voluntary and Charitable Organisations in Ireland, the 'Governance Code'. As a result of the enactment of the 2014 Companies Act, the ASI undertook a review of its memo and articles in 2016. Following on from this review and in accordance with best practice, the ASI adopted a new constitution in November 2016.

- **Corporate partners' expectations of governance**

The ASI has developed its corporate partnerships from two in 2014 to 16 in 2017. Charity partners expect our governance arrangements to be of the highest standards. In return, they provide valuable funding, advocacy and support to our campaigns. The ASI's funding from the partnerships has increased from €75,000 in 2014 to €336,000 in 2017. In addition, the ASI has benefited from providing training and awareness raising within the companies as well as getting practical support and transfer of expertise to the ASI.

- **Private competition in Home Care**

New Home Care funding is now given out as Home Care Packages by the HSE to preferred providers that were successful in the generic Home Care tenders. The ASI could not compete in the tendering process as our homecare services are dementia-specific. The ASI normally only receives new packages where the preferred providers are unable to provide a service. As a result of the new tendering arrangements, home care hours provided by ASI have decreased by 25% from 2013 to 2016. The ASI supports the introduction of greater regulation of home care services that is lacking at present. There is a need to introduce systematic, evidenced-based quality assurance systems for person-centred care provided by highly trained and qualified staff.

- **More advanced technology**

Advancements in technology have provided the ASI with greater opportunities to achieve its mission. The ASI actively uses social media to create awareness of dementia and development of an understanding of it and the ability to live well with it. Social media has also been used effectively to campaign for the rights of persons with dementia and their carers to access proper services and supports. The development of a national registry will have major benefits for the planning and evaluation of services and ongoing research. Assistive technology can enable persons with dementia to live more independently. Social media has also been valuable in attracting volunteers and funding for the work of the ASI. The ASI will continue to leverage the benefit of technology in the broadest sense to help persons continue to live well with dementia.

- **Shift within charity – social enterprise culture**

Charities are of necessity part of the commissioning of services by the State and in particular the HSE. This focus on a service level agreement has equally meant that each organisation has to establish if they are receiving sustainable resources to provide services which the state itself should be providing. The ASI is no different in this respect. The ASI leverages the benefit of volunteering by its board members, its branches and volunteers in all capacities together with the use of buildings, fundraising and clients income to continue to maintain services. During the course of 2018–2020, agreement will be required from the HSE on the services and percentage contribution by the State to support our existing high provision of dementia-specific services. The ASI will continue to examine its cost base to get value for money but will only provide existing or new services based on sustainable funding from the State.



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- **Unmet and increasing demand for services**

The ASI provides a very significant range of services and in many services is the sole provider of dementia-specific services. This strategy was developed based on the reality that we recognise that we are still only reaching a fraction of the people who have dementia and who are living in the community. Despite our achievements to date, we have concluded that if we continue to just do what we are doing and the way we do it, we won't achieve what persons with dementia and their carers require. The unmet need and increasing demand for services which has been acknowledged in the National Dementia Strategy will require sustained increases in investment by the State.

- **Competitive recruitment environment**

The ASI had to make major changes in rates of pay in 2010 and could not afford to fund pay increases or increments since then to its staff. Providing dementia-specific care requires the recruitment and training of staff that are qualified and paid a competitive rate for their work. The ASI reduced the pay of any staff who were paid in excess of HSE as per their requirements, however parallel provision was not made since then by the HSE to provide pay to enable a degree of parity for employees who are paid well below HSE rates. This issue requires an immediate solution to enable the ASI to compete for staff in a much more competitive environment.

(b) Internal Influences

- **Branch and volunteering network**

Branches and volunteering have been key to the development of the ASI and its services from its beginning in 1982. There are now 19 branches and in excess of 400 active volunteers in the ASI. The enhanced role that existing and new branches can play in our vision is given a specific strategic objective in this plan and tangible targets will be set for branch and volunteer development in each year's business plan.

- **Current resource and budget constraints**

The ASI is currently in a stable situation in 2018, thanks to the ongoing generous support of the public and corporate donors. The continued contribution by the HSE of 58% is causing significant difficulties in maintaining existing level of services. This inadequate funding by the State has hindered the development and rollout of new and innovative services to meet the needs of persons with dementia and their carers on their journey. This strategy addresses how the State needs to resource a significantly greater proportion of the cost of providing these essential person-focused services.

- **Client needs / expectations growing**

It is estimated that 4,000 persons are diagnosed each year with dementia. It is clear from the mapping of services project by the HSE/ASI that the existing range, location and appropriateness of services is not adequate and that significant investments in post-diagnostic support services and a range of social supports are required to deal with existing need. By 2036, in less than 20 years, the number of people with dementia is expected to more than double from 55,000 today to 113,000, if a cure isn't found. The ASI believes that people affected by dementia are experts by experience and service developments, policies and strategies should be influenced by them. The Board has established an Advocacy Committee, which includes a member of the Irish Dementia Working Group (IDWG) and the Dementia Carers Campaign Network (DCCN). The ASI supports the concept of 'Nothing about us without us'.

- **Need to improve cost efficiencies and maximise existing services:**

The HSE and many voluntary providers have a range of generic services for older people. Persons with dementia should be encouraged to continue to avail of such services until their needs require specific supports. The provision of a Statutory Home Care Scheme, with dementia-specific packages of care, would provide support to carers and allow persons to continue to use existing services in their local community. The better use of generic services, more specific support services at home and in the community would lead to efficient use of resources.

- **Lack of investment in staff development**

While the ASI has begun to increase investment in staff training and development following a difficult financial situation, more resources will be necessary in the future. The ASI will seek from its funders, on whose behalf it provides services, the necessary resources to pay its staff a competitive rate of pay and the resources necessary for training and development, which ultimately is of benefit to persons with dementia and their carers.

- **Increased evidenced-based professionalism**

The ASI has developed a Quality, Safety and Practice Development Team and has carried out an annual engagement survey with its service users over the past three years as part of a continuous quality improvement strategy of the ASI. The ASI has also introduced audits of its day care services. Results from the surveys and audits are then part of a continuing improvement plan to ensure that we are embedding evidence-based care in our services.

- **Paper based data systems**

Our existing data systems require significant manual input. Real-time information on services, their costs and their outcomes is important for the planning and delivery of services. Our data systems need to be developed to reduce the amount of time which staff spend gathering and analysing such data. The ASI will endeavour to provide additional resources in this area. The ASI commissioned a study into the potential to establish a national dementia registry. The further development of the project is now being funded by the HSE following an allocation from Government from the Dormant Accounts Fund. The ability of the ASI to transfer data with ease to a national registry will require investment in our information technology systems.

5. **Our Vision**

An Ireland where people on the journey of dementia are valued and supported.

6. **Our Mission**

To advocate, empower and champion the rights of people living with dementia and their communities to quality support and services.





7. Our Values

Respect

Due regard for the feelings, wishes, abilities and rights of others

Empathy

Understanding and sharing the feelings of others

Integrity

Transparent/accountable delivery of all services / strong ethical principles

Inclusiveness

Our community includes all; internal staff, branches, other volunteers and external stakeholders

Striving for excellence

Empowering by continuous learning to ensure best practice and approach

8. The Strategy Development Process



Following the end date of the ASI's previous strategy 'People With Dementia First', The Board of the ASI and the senior management team held workshops to consider:

Whether the ASI had the right balance between service provision and advocacy?

Whether the ASI needed to re-balance its emphasis between the different services it provides including, information, homecare, day care, respite, social clubs and family carer training?

What relationship should the ASI seek to have with the HSE and other statutory funders?

It was decided to carry out a major consultation within the organisation. In total, 10 workshops, attended by 200 people, including persons with dementia, carers, branch members, volunteers and staff gave their views on our vision, mission, values, strengths, challenges, opportunities, future risks and strategic objectives.

The board held a special meeting to review the outcome of the workshops and a final draft was prepared by the Senior Management Team which was approved by the board on the November 6th 2017.

9. Key Messages from Strategy Process 2017



The ASI must work in a determined and unified way to get public and government support to address the needs of persons with dementia and their carers.

The lived experiences of persons with dementia and their carers will be the basis for what ASI campaigns for.

The ASI must develop its existing branch network and expand it and develop volunteering to help it achieve its vision.

The level of HSE funding for current services is unacceptable and continued subsidisation for services from fundraising is not a safe and sustainable basis for future service provision.

All the ASI's services should be of a standard that would represent the appropriate benchmark against which services from all providers can be measured.

The challenges of recruiting, training and adequately paying our staff need to be addressed.

10. Our Strengths



Reputation:

The ASI's positive reputation with people with dementia, their wider community and funders.

Relevance:

The ASI is a nationwide organisation relevant to a growing dementia community.

Our People:

Dedicated staff with expertise in dementia care, branches / volunteers play a key role within the ASI.

Community:

Community based organisation.

Advocacy:

We empower the voice of the person with dementia, carers and their communities.

Services & Supports:

We are dedicated to providing quality dementia specific care nationwide.



11. Current Challenges



The ASI is not adequately resourced and is unable to meet its current and growing demand for services.

The dependence on fundraising and client contribution affects cash flow and long term sustainability for the ASI.

Staff pay and benefits have not kept pace within the sector which has led to a lack of competitiveness.

A lack of investment in IT infrastructure has led to labour intensive data production and the lack of data to facilitate good planning and evaluation of services.

The organisational culture needs to adapt and change to allow for full implementation of the new strategic plan.

Challenges in recruiting, developing volunteers and branch networks.

12. Our Opportunities



To engage and build our grassroots and community approach in relation to advocacy, fundraising and services support the voice of people within the dementia community.

To influence the implementation and continuation of National Dementia Strategy and other policies both nationally and locally using evidence i.e. rights based approach e.g. mapping exercise, dementia register and client tracking system.

To develop quality standards, impact measures and physical environments and training across dementia services.

To facilitate the development of more integrated services within local communities e.g. one stop resource, post diagnosis services and dementia friendly communities.

Change the funding model to enable our mission to be developed and sustained.

To coordinate and influence the focus of new research and to be involved directly in dementia related research nationally and internationally.



13. The Risks and Future Challenges



An internal reputational risk or future reputational risks in the sector.

Limited reserves to withstand a fall off in fundraising or State support.

Loss of competitive ability to recruit or retain staff.

Delays in implementing best governance practice.

The lack of budgets nationally for dementia specific services.

Age profile of volunteers and the difficulty in establishing new branches and new volunteers.





14. Outline of the 5 Strategic Objectives

- 
-  Advocate for rights and resources for people with dementia and their carers and communities
 -  Promote and deliver sustainable dementia supports and services
 -  Value and develop volunteering and branches
 -  Create a culture throughout the organisation where our values and mission are understood and lived
 -  Strengthen our organisation's capacity to deliver our strategic priorities

15. Key Achievements of the 2014-2016 Plan



Despite difficulty in receiving new development funding from the State, significant improvements were made in the provision of services.

The key priorities of the plan were:

- Maintenance and development of dementia-specific services;
- The ASI is recognised as the leading advocacy organisation for people with dementia and their carers;
- Expand and develop family advisory services;
- Volunteering and branch development;
- Corporate excellence in developing organisational structures, Governance, Finance and Fundraising.

While the ASI continued to provide over 68% of all dementia specific services and up to 100% of some services in Ireland, it is disappointing that the State has not developed both the range and extent of services itself or provided voluntary organisations with the necessary capital and revenue to meet existing demands. During 2016, the ASI and the HSE commenced an audit of all dementia specific services to assist in the planning and provision of services and to ensure that new services are based on need. The ASI is working closely with the HSE and other partners in the Understand Together campaign to increase awareness of dementia and attract persons to specific services that will allow them live well with dementia.

The following outlines key milestones achieved during the 2014-2016 Plan:

- 8 new Dementia Advisers were appointed providing initial and ongoing support to persons with dementia and their carers;
- 12 programmes of Cognitive Stimulation Therapy were undertaken;
- Annual surveys of clients' satisfaction with services were conducted;
- Day care audits and health and safety audits were introduced to ensure that quality of service is embedded in our services;
- New organisation structures were introduced to maximise efficiency in our operations;
- The Irish Dementia Working Group (IDWG) was established to ensure that persons with dementia had a voice in all aspects of our work;
- The Dementia Carers Campaign Network (DCCN) was established to ensure that carers had a voice in all aspects of our work;
- Family carer training was provided to more than 1,000 people;
- Our Alzheimer National Helpline, provided through volunteers, continued to respond to 5,000 calls per annum;
- Pilot project establishing a volunteer register, supported by training, mentoring and embedding a culture of volunteering was introduced successfully and is being rolled out within the ASI in 2017/2018;
- Fundraising targets were exceeded, with ASI raising over €3 million per annum through generous contributions of the public and charity partners;
- 16 Corporate Charity Partners supported the funding of ASI by 2016;
- The Human Resources function and a national shared services function was developed to support both national and local managers in their roles;
- Risk management process was embedded in the organisation;
- The ASI became fully compliant with the Governance Code for Voluntary Organisations.

16. Explanation of terms

About dementia:

- There are 55,000 people living with Dementia in Ireland today and that number is expected to double over the next 20 years to 113,000 in 2036.
- Each year over 4,000 people develop dementia. That's at least 11 people every day and anyone can get dementia – even people in their 30s/40s/50s. 1 in 10 people diagnosed with dementia in Ireland are under 65.
- Dementia is progressive. There is currently no cure. Dementia is not simply a health issue but a social issue that requires a community response.
- The majority of people with dementia (63%) live at home in the community. Over 180,000 people in Ireland are currently or have been carers for a family member or partner with dementia with many more providing support and care in other ways.
- Each year over 4,000 people develop dementia. That's at least 11 people every day and anyone can get dementia - even people in their 30s/40s/50s.
- 1 in 10 people diagnosed with dementia in Ireland are under 65.
- The overall cost of dementia care in Ireland is just over €1.69 billion per annum; 48% of this is attributable to family care; 43% is accounted for by residential care; formal health and social care services contribute only 9% to the total cost

Figures referenced to Cahill, S. & Pierce, M. (2013) *The Prevalence of Dementia in Ireland*.

Support services provided by the ASI:

- | | |
|---------------------|------------------------------|
| • National Helpline | • Dementia Adviser Service |
| • Social Clubs | • Mobile Information Service |
| • Support Groups | • Family Carer Training |
| • Day Care Services | • Alzheimer Cafés |
| • Home Care | |

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Twitter: [@alzheimersocirl](https://twitter.com/alzheimersocirl)

The Alzheimer Society of Ireland National Helpline
is open six days a week

Monday to Friday 10am – 5pm and Saturday 10am–4pm

Call 1800 341 341 or email helpline@alzheimer.ie

Patron: Micheal D Higgins, President of Ireland

Directors: John Clifford, *Chairman*. Tom Noonan, Donal Malone, James Nevin, Patricia McParland, Ann Twomey, Ronan Smith, Kieran McGowan, Taragh O'Connor, Noel Heeney, Eugene McCague, Mary Gaughran (to June 2018), David Fitzgerald (to June 2018).

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