

Dementia

PAYING DIVIDENDS

A Report on The Atlantic Philanthropies
Investment in Dementia in Ireland

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ACRONYMS

ACP	Advance Care Planning
ASI	The Alzheimer Society of Ireland
BPS	Biopsychosocial
CACE	Centrally acting Angiotensin Converting Enzyme
CARTS	Community Assessment of Risk and Treatment Strategies
CCS	Caregiver Cognitive Screen
CHO	Community Healthcare Organisations
DCU	Dublin City University
DFC	Dementia Friendly Communities
DNNI	Dementia and Neurodegenerative Network Ireland
DoF	Department of Finance
DoH	Department of Health
ED	Emergency Department
GAA	Gaelic Athletic Association
GADAA	Global Alzheimer and Dementia Action Alliance
GBHI	Global Brain Health Initiative
GDS	Geriatric Database System
GP	General Practitioner
HFH	Hospice Friendly Hospitals
HIQA	Health Information and Quality Authority
HRB	Health Research Board
HSE	Health Service Executive
ICGP	Irish College of General Practitioners
IDEAS	Integrated Dementia Care Across Settings
IHF	Irish Hospice Foundation
LMDAD	Let Me Decide Advance Directive
MCI	Mild Cognitive Impairment
MUH	Mercy University Hospital
NCEC	National Clinical Effectiveness Committee
NDIP	National Dementia Implementation Programme
NEIL	Neuro-Enhancement for Independent Lives
NGO	Non-Governmental Organisation
OECD	Organisation for Economic Co-operation and Development
OT	Occupational Therapist
OPRAH	Older People Remaining At Home
PHN	Public Health Nurse
PREPARED	Primary Care Education Pathways and Research for Dementia
QMCI	Quick Mild Cognitive Impairment
SAT	Single Assessment Tool
SATIS	Single Assessment Tool Information System
SCU	Specialist Care Unit
TCD	Trinity College Dublin
WHO	World Health Organisation
WISH	World Innovation Summit for Health
UCC	University College Cork
UK	United Kingdom
UN	United Nations

EXECUTIVE SUMMARY

ORIGINS

This study examines The Atlantic Philanthropies (Atlantic) investment in dementia in Ireland and its impact on the lives of people with dementia and their families. The evaluation is focused mainly on investments made between 2011 and 2015. Atlantic's recent investment in dementia in Ireland has been significant in terms of its ambition, scale and scope. It has helped to transform the care landscape for people with dementia in the country.

Atlantic has directly invested €33 million in dementia in Ireland and leveraged a further €51 million from government and other agencies, resulting in a total spend of €84 million, not including the recent commitments associated with the Global Brain Health Initiative, which is outside the scope of this report. The investment was broad and far reaching, encapsulating support for personalised community-based care, brain health initiatives, advocacy, education and training in dementia, culminating in ongoing support for the formulation and implementation of the National Dementia Strategy in Ireland. Integration and co-operation among grantees has been important in maximising the return on investment and formal and informal collaboration among stakeholders has increased the probability of successful outcomes in the longer term. Investing in the right people at the right time was a key feature of the Atlantic programme and one of the main drivers of its success.

CONTEXT

Atlantic entered the dementia space in Ireland at a time when the country was confronted by the most serious economic crisis it had ever faced. The imminent threat of national economic bankruptcy meant that there was no chance of generating additional resources to fund dementia care without getting some financial support from outside the public budgetary system. At a time when public expenditure was being curtailed and dementia numbers were increasing, Atlantic intervened to provide a stimulus to dementia care in Ireland, not only directly through the money it spent, but through its ability to leverage

additional spending from government and government agencies. Atlantic also played a critical role in supporting and effecting change through funding a wide coalition of stakeholders in dementia to lobby for a new direction in dementia care and in commissioning the Creating Excellence in Dementia Care research review which played a major role in the development of the Irish National Dementia Strategy.

Through its granting system, Atlantic built up a potent coalition of interests in the country that wanted more than the continuation of what had gone before for people with dementia. Many of its grantees sat on the Expert Working Group to the National Dementia Strategy and had a major influence on priority-setting within the new Strategy. Without Atlantic's intervention, both direct and indirect through its grantees, the official approach to dementia might not have changed much in terms of values or orientation. There would have been no increase in service provision or community-based supports for people with dementia. The National Dementia Strategy contains the seeds for the transformation of care for people with dementia. In particular, the 500 intensive community-based care packages for people with dementia promised in the National Dementia Strategy, if delivered appropriately and built upon, can be the catalyst for the eventual recalibration of the social care system towards home-based provision. These packages only came about because of additional financial resources provided by Atlantic.

Atlantic also recognised that for real change to happen, the current policy frame would have to be nudged towards a new paradigm that recognised the narrowness of the prevailing official mind-set towards dementia and the opportunity that existed to develop more appropriate holistic counter-policy frames. The key emphasis was to facilitate a movement away from a biological model of care based on residential care solutions towards a community orientation that focused on brain health, personalised care for people with dementia, psychosocial interventions and appropriate supports for family carers. While that process is far from complete, and the old model has not disappeared, Ireland, guided by an evidence-based approach, is now on a pathway to a person-centred, personhood-oriented, biopsychosocial model of care for people with dementia.

INVESTMENT

The overall investment consisted of 15 projects across five main themes, namely: service transformation; advocacy and awareness; brain health – prevention and diagnosis; education and training; and measurement, research and evaluation. The investment occurred in areas such as diagnosis and changing the progression of the disease, developing dementia friendly communities, advocating for people with dementia with policy makers and government, training and education programmes for healthcare professionals and carers on dementia and individualised care pathways for people with dementia that emphasised autonomy and choice. The projects funded were: Health Service Executive-Genio dementia projects; Centre for Gerontology and Rehabilitation, University College Cork; Neuro-Enhancement for Independent Lives, Trinity College Dublin; Support and Advocacy Service for Older People, Third Age Foundation; Single Assessment Tool, Health Service Executive; Alzheimer Society of Ireland; Elevator programme, Dublin City University; Changing Minds programme, Irish Hospice Foundation; Health Research Board; National Dementia Strategy, Department of Health; Older People Remaining at Home, Age Friendly Ireland; Creating Excellence in Dementia Care, Trinity College Dublin; Living with Dementia, Trinity College Dublin; Dementia Services Information and Development Centre, Trinity College Dublin; and, in the past year, the Global Brain Health Initiative, which is a collaboration between Trinity College Dublin and University of California at San Francisco.

COLLABORATION

Collaboration among grantees is central to Atlantic's investment programme in dementia. The various agreements with grantees required stakeholders to share expertise and experiences to advance best practice. There are numerous examples of where collaboration has worked to enhance the lives of people with dementia and their family carers. Examples of this include the Irish Hospice Foundation (IHF) working closely with The Alzheimer Society of Ireland to develop the Changing Minds project, which

involves end of life care for people with dementia and education programmes on palliative care. The IHF have also worked with clinicians in University College Cork to promote advance care directives suitable for people with dementia. The Health Service Executive teamed up with Genio to develop innovative personalised care programmes for people with dementia living in their own homes.

Age Friendly Ireland collaborated with local dementia friendly partners to establish the Older People Remaining At Home (OPRAH) project designed to keep people out of long-stay care residential settings. Third Age Foundation, the Health Service Executive and Nursing Homes Ireland have collaborated to advance an advocacy programme for older adults, initially in long-stay care settings. Films produced by the Neuro-Enhancement for Independent Lives programme in Trinity College have been used for a variety of educational purposes by a number of dementia organisations, nationally and internationally. The Creating Excellence in Dementia Care Report provided the research framework for the National Dementia Strategy published by the Department of Health. Education and training programmes developed by the Elevator programme in Dublin City University have provided dementia-specific staff training and development to healthcare professionals within the Health Service Executive and private care providers nationally, as well as banking and retail staff.

IMPACT ON PRACTICE

Atlantic's dementia programme is helping to transform care for people with dementia wishing to remain in their own homes. This has been achieved by supporting the provision of community-based, personalised care services and supports that respond directly to individual-care needs as articulated by people with dementia and their family carers. While it is true that not enough people yet get to impact directly on their own care plan in Ireland, for those who have been given that opportunity, through access to Atlantic-funded personalised care programmes,

IMPACT ON POLICY

the results have been very positive. What Atlantic's investment has shown, and what is now increasingly accepted in Ireland, is that the best results occur when people with dementia are at the centre of decision-making with respect to their own care. If personhood is to be respected, then people with dementia must be centre stage from diagnosis to end-of-life. Through their grantees, Atlantic have engineered a more hopeful focus within practice by focusing on the capabilities of people with dementia rather than their deficits.

The establishment of integrated care pathways between community care and acute care admission is also making it more likely that placement decision-making supports home care first before consideration is given to residential care options. Moreover, creating an awareness of dementia within acute care settings and developing protocols for care relationships will lead to shorter stays in hospital and less costly treatment for people with dementia. Key initiatives on advance care directives have also been developed for people with dementia and a number of training programmes for staff have been rolled-out, leading to positive impacts on end-of-life decision-making for people with dementia in all care settings. Advance care directives are becoming more common place, making it more likely that their preferences are known and respected in relation to end-of-life care.

Education and training initiatives for public and private agencies and organisations have increased awareness of dementia, thereby making it easier for people with dementia to remain visible, integrated and respected in their own communities. Education programmes for healthcare professionals ensure that care is more tailored to the needs of the person with dementia and that healthcare providers are aware of the various attributes of person-centred care. Training for public sector workers ensures a broader understanding among non-healthcare professionals dealing with the public, thereby supporting people with dementia to engage in, and connect with, their community while living at home.

The National Dementia Strategy is the main policy document to emerge from the Atlantic investment programme. While a new Strategy was always on the cards, Atlantic's work stiffened the resolve for real change with respect to dementia, as well as providing practical support in the form of new funding to support that change. Without Atlantic funding there would not be intensive home care packages for people with dementia or a commitment to training and education for primary care providers in the dementia care sector. In addition to supporting the National Dementia Strategy, the Single Assessment Tool (SAT) was co-funded under Atlantic's dementia programme. SAT is an assessment tool for the estimation of care needs, including in dementia, and a parallel carer needs assessment is also being developed as part of the programme. The SAT has the potential to shape health and social care provision in accordance to need and bring real change to the quality of life of people with dementia and their family carers in the longer term.

The politicisation of dementia through increased support for advocacy, mainly through the Alzheimer Society of Ireland, has highlighted the needs of people with dementia and their families to politicians, policy makers and the public, thereby helping to shift priorities in the longer term. The public are now more aware of dementia and slowly the stigma attached to the disease is being eroded. For too long the story of dementia has been untold. That is now changing as the direct voice of people with dementia is heard more and more in the public domain through the Dementia Working Group. Atlantic has helped to strengthen that voice through the Alzheimer Society of Ireland and the expectation is that the story of dementia will continue to be told by those who know it best.

A major component of Atlantic's dementia programme has been to incorporate internal and external evaluation into the grant-making process with a view to expanding the evidence base for dementia-specific services and investments. The evaluation element has contributed to the development of evidence-based policy and practice in dementia and to ongoing public sector reform in Ireland. The Atlantic dementia programme has introduced consistency

and coherence to dementia reform by focusing on what works best for people with dementia, when and where, and the subsequent translation and diffusion of the evidence across the sector.

INTERNATIONAL IMPLICATIONS

Atlantic have been at the forefront of encouraging person-centred care for people with dementia in Ireland. The grantees supported by Atlantic have strong and credible records in seeking to enhance personhood and autonomy for people with dementia. Intensive application of a biopsychosocial model for dementia was, therefore, the bedrock of the Atlantic dementia investment programme in Ireland and documenting both practice and impact has created an evidence base for the implementation of personhood models of care which are internationally relevant. Evaluation has always been central to the Atlantic philosophy and the learnings from Ireland will add to the international literature on best practice in dementia care.

The role of Atlantic is an interesting exemplar for other countries considering engaging with philanthropic organisations and for philanthropists considering investment in the ageing sector, or more specifically in dementia care. The investment programme has created a framework for a new approach to dementia care in Ireland, which can be replicated elsewhere. Atlantic has demonstrated that by providing resources to support the right people and by subsequently developing their capacity and leadership qualities, practice and policy can be transformed. Overall, the investment programme enhanced collaboration among grantees and stakeholders which broadened and deepened its impact, as well as leading to a more integrated care sector. The decision by Atlantic to engage directly with government in relation to policy formulation, resource allocation and policy implementation has created a top-down impetus for change in dementia care in Ireland. Meanwhile, Atlantic's support for stakeholders has ensured a vibrant, bottom-up community of interests committed to lasting change in dementia care in the country. The public are also becoming more knowledgeable about

the disease, its implications and the importance of providing appropriate supports and interventions that reflect the humanity of the condition. The consequence is a movement and momentum for change in dementia care that will not be easily stopped, even when Atlantic leave the stage in Ireland.

CONCLUSION

The full dividend from the investment by Atlantic in dementia in Ireland will not be known for some time. Many of the grants are at an early stage and therefore have not yet been subject to internal or external evaluations. Moreover, the recent Global Brain Health Initiative is only beginning and it will take decades before the full implications of that grant bears fruit globally. What we do know from Ireland is that the dementia landscape has changed significantly in less than a decade. Where once there was pessimism, now we can be cautiously optimistic that dementia has gained important traction in government public policy. It is not that dementia care in Ireland is perfect. It remains under-funded and does not yet have the priority status that it deserves, particularly in relation to community-based provision. But, through careful support of grantees, who have risen to the challenge, Atlantic have succeeded in changing the narrative of the disease, not for everyone, but for some, and more will follow. There has been a paradigm shift in policy towards personhood and the social model of care linked to evidence-based research and evaluation. Now that Atlantic are leaving the stage, the next challenge for the grantees is to ensure that the gains made are capitalised upon and leveraged to continue the upward trajectory of care and support for people with dementia in the country.

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1. INTRODUCTION

This report narrates and evaluates the Atlantic Philanthropies, hereafter referred to as Atlantic, dementia programme in the Republic of Ireland by monitoring its overall effectiveness in supporting new and innovative models for the delivery of care for people with dementia. Atlantic commissioned the work from the National University of Ireland Galway. Evidence is presented on the potential impact of the investment on practice and policy in dementia, now and in the future. While Atlantic's investment in ageing in Ireland began in 2004, their investment programme in dementia expanded considerably from 2010 onwards, largely in recognition of increasing trends in incidence and prevalence rates in dementia and the desire to offer support to a neglected and vulnerable segment of Irish society. The investment coincided with increased attention on dementia from major international agencies and from the Irish government.

Over the coming years, as the population in Ireland ages, dementia prevalence and incidence rates are predicted to increase accordingly. In recent years, dementia has gained the attention of international agencies such as the World Health Organisation (WHO), the Organisation for Economic Co-operation and Development (OECD) and the United Nations (UN), all recognising dementia as a major public health issue and calling for a new approach to how we think about the disease (Rubinstein et al., 2015, OECD, 2015, Winblad et al., 2016, Prince and Jackson, 2009, Prince et al., 2011, G8 UK, 2013). Many countries have responded by developing and implementing National Dementia Strategies to address the complex issues around dementia, including more formal recognition of the social dimension of dementia (Department of Health - Ireland, 2014, Engedal, 2010, Department of Health - England, 2009, FOPH and CMPH, 2014, U.S. Department of Health and Human Services, 2015).

A number of studies have estimated escalating economic burden and costs associated with dementia as prevalence rates rise (Rubinstein et al., 2015, Hurd et al., 2015, Prince et al., 2015, Connolly et al., 2014). Families currently bear most of the cost of providing care for people with dementia. Most people with dementia live at home in the community giving rise to much criticism of the current bias in public policy

in many countries towards financing residential care, often at the expense of community-based alternatives (Colombo et al., 2011). Most countries are now looking at ways to expand and improve community-based supports for people with dementia in ways that reflect existing care arrangements and family relationships (Timmons et al., 2016, Connolly and O'Shea, 2015, Gaugler and Wocken, 2014, Clissett et al., 2013, Cowdell, 2010, Murray and Boyd, 2009, Borbasi et al., 2006). There is evidence to suggest that the recalibration of current pathways of care for people with dementia towards home-based provision and support for family carers may help to slow progression of the disease and improve quality of life (Timmons et al., 2015, de Siun et al., 2014, Hunter et al., 2013). Timely diagnosis and on-going personalised supports are now recognised as being of key importance by people with dementia in dealing with the disease. The biopsychosocial model is gaining acceptance as the gold standard in dementia care (Spector and Orrell, 2010).

There is currently an underinvestment in dementia care in Ireland, as in other countries, relative to its economic and social burden. Finding new ways to support people with dementia and their carers has been the mainstay of recent investment in ageing by Atlantic in Ireland through direct grant aid to a variety of stakeholders, including government. The prize is the creation, for the first time in Ireland, of a single focus on dementia through agreed structures, programmes and interventions that will provide a universal recognition of dementia needs, thereby allowing practical supports for people with dementia and their families to be developed and delivered through the resource allocation process.

Atlantic's investment in dementia in Ireland has focused on 15 different projects ranging in magnitude, duration and scope, all of which address key issues associated with dementia, including: public awareness and advocacy; brain health; service transformation; research, measurement and evaluation; and training and education.

A total of €84 million was invested in dementia in Ireland over the time period as a result of Atlantic's programme of investment. The projects that received funding from Atlantic have helped to shape the experience of dementia in Ireland, instigating a move away from conventional care narratives towards a more complex perspective of personhood and citizenship for people with dementia. Each dementia project funded by Atlantic has been designed with scalability and sustainability at its core. The main objective of Atlantic's programme is to inform and effect practice change, influence policy and fundamentally alter how the health and social care system provides dementia care in the longer-term.

This report will provide an evidence-led account of the impact of Atlantic funding on dementia in Ireland, looking at structure, process and outcomes, incorporating the key lessons and learnings from the overall investment. Although many of the projects are at an early stage of their life-cycle and the internal/external evaluation evidence is not yet complete for the majority of the grants, in some projects evaluation has not even started, this report seeks out the social dividend from Atlantic's investment in dementia in Ireland. The report is structured as follows; chapter two presents dementia by numbers, reporting current and predicted incidence and prevalence rates, and associated costs; chapter three frames dementia in the context of the biopsychosocial model of care; chapter four describes international developments in dementia in recent years; chapter five outlines the structure of dementia care in Ireland; chapter six describes the context and rationale for Atlantic's investment and outlines the methodology used to conduct this study; chapter seven describes the various dementia grants in detail; chapter eight examines the coherence and impact of the projects on policy and practice; chapter nine explores Atlantic's legacy on dementia in Ireland; and chapter ten offers a brief conclusion.

Idle

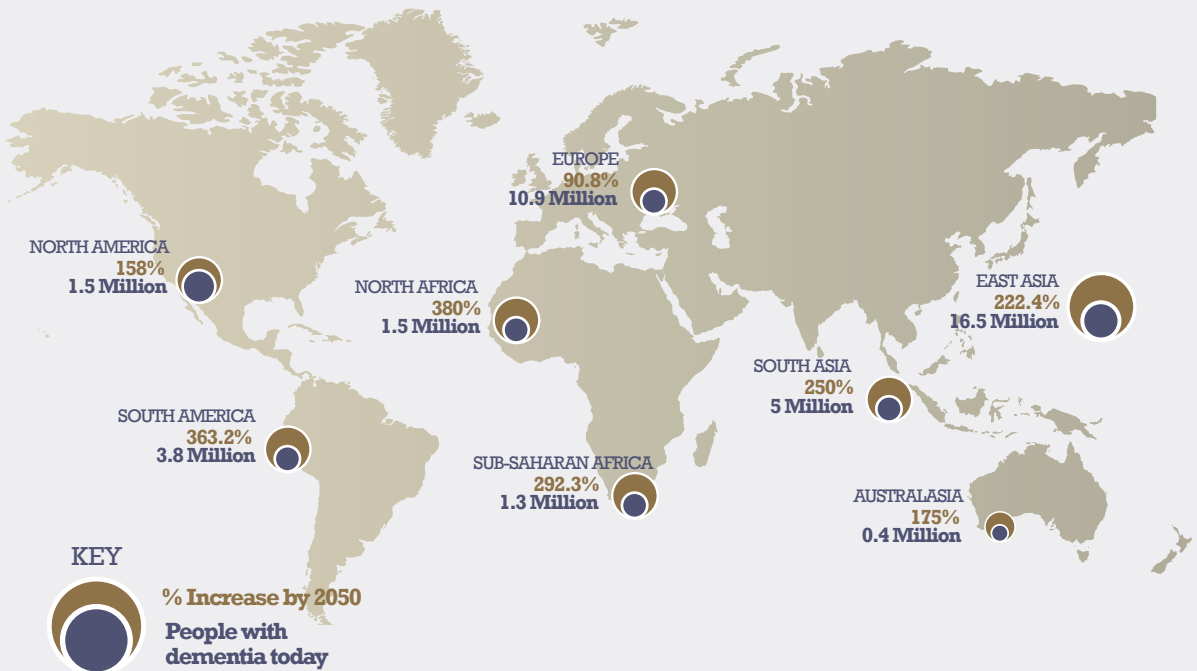
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2. DEMENTIA BY NUMBERS

Dementia is a progressive, chronic disease that mainly affects older people and can impact their cognitive and functional abilities as well as their social skills. It can also affect mood and personality, and management can be difficult for both the person and their families (Prince et al., 2013)¹. Dementia is an umbrella term for the group of symptoms caused by the gradual deterioration of brain cells leading to the progressive decline of functions such as memory, orientation, understanding, judgement, calculation, learning, language and thinking (Luengo-Fernandez et al., 2010). It is a particularly debilitating condition as it affects those capabilities on which everyday life depends. There is no single cause of dementia, with a combination of risk factors, both known and unknown, believed to influence its onset and progression.

Within this risk factor profile, ageing is by far the strongest contributor with the prevalence nearly doubling every five years from the age of 65 years onwards (Lobo et al., 2000). The most common form of dementia is Alzheimer's disease, which accounts for approximately 60 per cent of all cases (Luengo-Fernandez et al., 2010). While early diagnosis can lead to better disease management for patients, there are only symptomatic treatment options. The limited treatments available are often further complicated by care systems that are not well organised, or specific enough, to meet the individual needs of people living with dementia.

Figure 2-1:
The Global Impact of Dementia



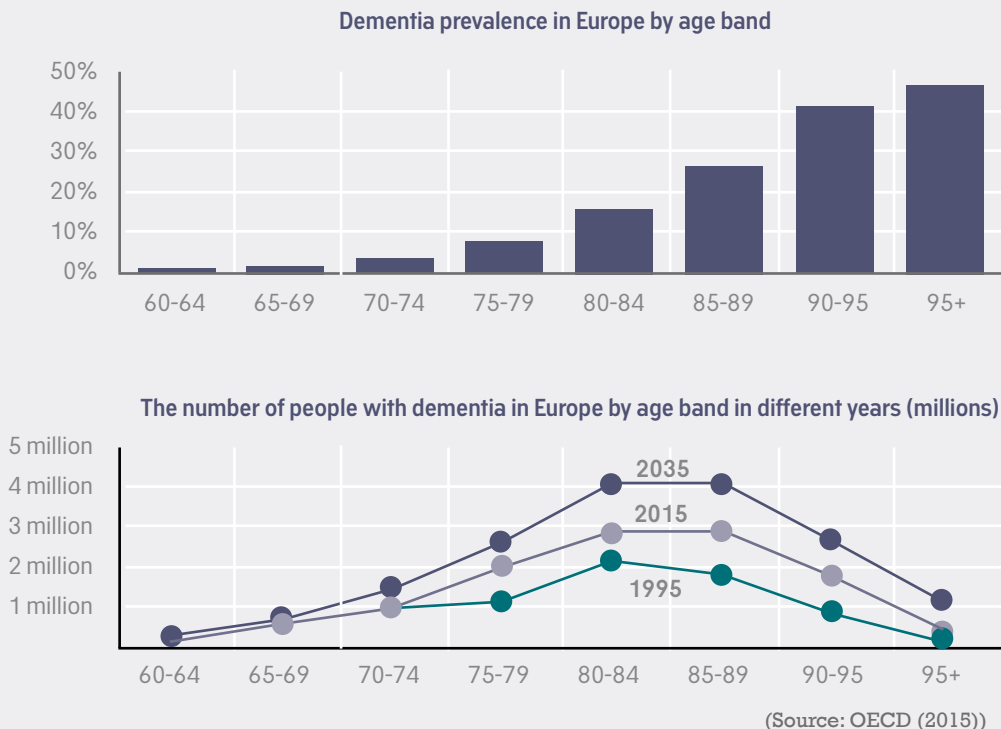
¹ World Alzheimer Report 2013: An analysis of long-term care for dementia

Data source: 'The Global Impact of Dementia 2013-2050', Alzheimer's Disease International (December 2013).

The global impact of dementia is shown in Figure 2-1. Worldwide there were an estimated 47 million people living with dementia in 2015 and this number is predicted to increase to 75 million by 2030 and to 132 million by 2050 (Prince et al., 2015)². There are nearly 10 million new cases of dementia each year globally, implying one new case every 3.2 seconds (Prince et al., 2015). In Europe, over the past 20 years, there has been a 50 per cent increase in the number of people with dementia; a similar increase is expected over the next 20 years (OECD, 2015)³. However, the biggest increase in the number of people with dementia in

the future will be in developing countries. Already 58 per cent of people with dementia live in developing countries, a number that is set to rise to 68 per cent by 2050. The fastest growth in the elderly population is taking place in China, India and their south Asian and western Pacific neighbours.

Figure 2-2:
Dementia prevalence rates in Europe



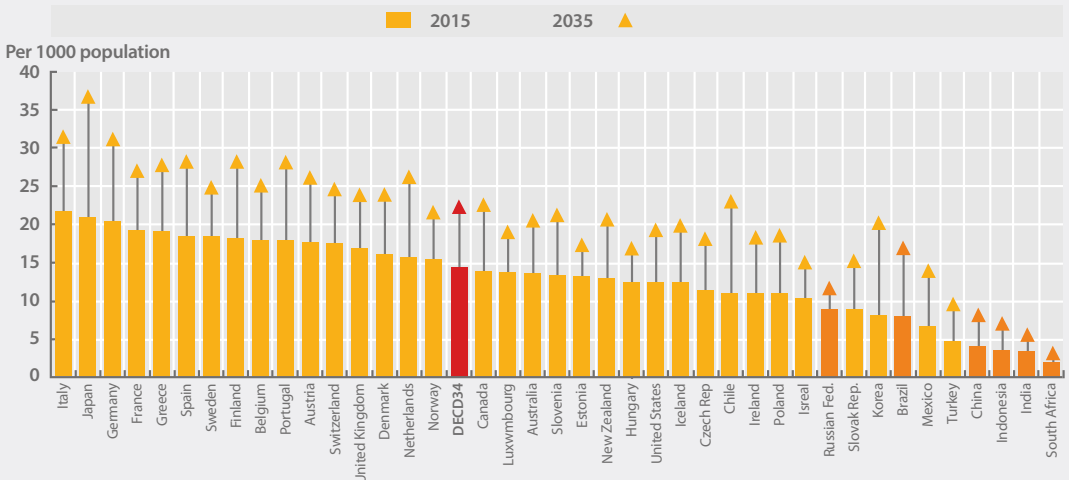
² World Alzheimer Report, 2015: The Global Impact of Dementia, <http://www.worldalzreport2015.org/>

³ OECD, 2014. Addressing Dementia <http://www.oecd.org/health/addressing-dementia-9789264231726-en.htm>

The age distribution of dementia in Europe is shown in Figure 2-2 and is reflective of the almost doubling of prevalence rates for dementia in 5-year intervals above the age of 65 years. The prevalence of any condition is a product of its incidence (the number of new cases in a given time period) and the average duration of the disease episode. Changes in either or both of these indicators could lead to changes in age-specific prevalence. Trends in the two indicators may not move in the same direction; for example, reductions in incidence might be accompanied by gains in duration of survival with dementia, or vice versa, with one effect cancelling out the other in terms of their overall impact on prevalence. There is recent evidence that the risk of dementia in older adults in some countries is declining, particularly in more

economically developed countries, probably due to better primary prevention of cardiovascular risk factors and improved levels of education within the population (Matthews et al., 2013, Manton et al., 2005, Schrijvers et al., 2012). There is also growing recognition of the potential of older adults to strengthen some cognitive abilities, leading to changes in individual behaviours as people age (Blazer et al., 2015). However, rising levels of diabetes and obesity may offset, partly or fully, some of the gains from a more active public health approach to risk reduction and prevention, especially in relation to cardiovascular disease. It is also possible, of course, that rising rates of obesity and diabetes may decrease life expectancy so that people with these conditions may be less likely to live to ages where the risk of dementia increases (Hurd et al., 2015).

Figure 2-3:
Estimated prevalence of dementia per 1,000 population, 2015 and 2035



Source: OECD analysis of data from Prince et al. (2013) and the United Nations

The estimated prevalence of dementia per 1,000 population for a number of different countries is shown in Figure 2-3. The observed differences across countries reflect variation in the age structure of the population. For example, the fact that the prevalence of dementia in Ireland is only half that of Italy is

largely explained by differences in demography, with the population age structure in Italy much older than in Ireland. The incidence of dementia increases significantly at age 75 and over and Italy has proportionately more people in that age category than Ireland.

Table 2-1:

Estimated Number of People with Dementia in Ireland (2011-2046)

Age Group	2011	2016	2021	2026	2031	2036	2041	2046
30-59	2,866	2,935	2,934	2,869	2,854	2,864	2,889	2,991
60-64	1,200	1,301	1,449	1,615	1,738	1,906	2,044	1,896
65-69	2,776	3,287	3,827	4,020	4,485	4,876	5,315	5,645
70-74	4,604	5,532	7,013	7,442	8,367	9,378	10,211	11,188
75-79	7,475	8,213	11,298	12,560	14,055	15,928	17,968	19,692
80-84	10,958	12,265	16,099	17,868	22,348	25,364	29,102	33,196
85+	17,970	21,260	25,595	31,085	40,195	52,512	64,654	77,549
Total	47,849	54,793	68,216	77,460	94,042	112,828	132,182	152,157

Source: Department of Health - Ireland (2014)

While no comprehensive prevalence studies on dementia have been carried out in Ireland, the application of Euro-CoDe age/gender specific dementia prevalence rates to the 2011 Census of Population data suggests that there are currently an estimated 55,000 people with dementia in the country (Department of Health - Ireland, 2014). An estimated 4,236 of these people (approximately 8.5 per cent of all people with dementia) have early onset dementia. Dementia is defined as early onset if it occurs in people younger than 65 years of age. There are also clear East-West regional differences in prevalence rates for dementia in Ireland. While the East of the country has more people with dementia absolutely, the West has a higher proportion of people with dementia in the population. A tentative extrapolation of incidence rates to the elderly population in Ireland suggests that currently approximately 4,000 new cases of dementia arise in the general Irish population every year (Cahill et al., 2012). In common with most other industrialised countries, the majority of people with dementia in Ireland live in the community, recent estimates placing it at 35,000 people. (Pierce et al., 2014). Most of these people do not have a formal diagnosis, many are not aware that they have the disease at all and few are likely to be in contact with the health and social care system.

There are an estimated 50,000 family carers in Ireland looking after someone with at least one of six specified symptoms of dementia (O'Shea, 2003); for

example, an estimated 25,000 carers are estimated to be looking after someone with marked forgetfulness on a regular or occasional basis, while 15,000 people are looking after someone with confusion to the point of interfering with everyday life. Caring for a person with dementia compared with other caring roles, places significant demands and strain on family members (Reed et al., 2014, Morgan, 1997, Lapatin et al., 2012). The evidence on carer burden in Ireland shows that family caregivers of people with dementia are susceptible to significant levels of emotional and psychological strain (O'Shea, 2003, O'Shea, 2007). Studies have shown that caregiver burden is often a contributing factor for admission to long-term care (Luppa et al., 2008, Yaffe et al., 2002). An estimated 20,000 people with dementia live in various communal settings, mainly in public and private long-stay facilities across the country. Official statistics on the number of people with dementia in long-stay care settings suggest less than half that figure, but most commentators accept the higher estimate (Cahill et al., 2012).

The estimated worldwide cost of dementia in 2010 was \$604 billion, equivalent to just over one per cent of global gross domestic product (Wimo and Prince, 2010). Worldwide costs grew to \$818 billion in 2015, an increase of 35 per cent, suggesting that if dementia care was a country, it would be within the top twenty economies of the world (Wimo and Prince, 2010). The worldwide economic cost is divided between informal

care (42%), care provided in long-term residential care settings (42%) and dementia-related direct health care (16%). While families are the bedrock of the care support system for people with dementia, they often face significant financial burdens associated with the opportunity cost of providing care and support for the person with dementia. Direct health and social care costs play a relatively minor role in the overall cost of care. If a person with dementia requires care, it is largely provided by families or within residential care settings.

The overall cost of dementia care in Europe is estimated to be €160 billion (Wimo et al., 2011). In the UK, it was estimated that the health and social care costs for dementia in 2008 (£23 billion) almost matched the combined costs of cancer (£12bn), heart disease (£8bn) and stroke (£5bn) (Prince et al., 2015). The economic impact of dementia, including unpaid care by families, is estimated to be between \$159 billion and \$215 billion per year in the United States (Hurd et al., 2013). Costs are expected to exceed \$1 trillion annually in the USA by 2050 (Rubinstein et al., 2015). Average total costs per incident of dementia in the last 5 years of life (\$287,038) in the USA is significantly greater than that for people who die of heart disease (\$175,136) or cancer (\$173,383), driven mainly by out-of-pocket spending and informal care costs (Kelley et al., 2015).

The cost of dementia in Ireland has been estimated at just over €1.69 billion per annum, 48 per cent of which is attributable to informal care provided by family and friends to those living with dementia in the community (Connolly et al., 2014). A further 43 per cent is accounted for by residential long-stay care, while formal health and social care services only contribute 9 per cent to the total costs of dementia. While spending on formal services is comparatively low, there is growing recognition of the impact of dementia on the acute care sector (Cowdell, 2010, Nolan, 2006). People with a diagnosis of dementia tend to have a significantly longer length of stay in hospital than those without dementia, a finding that holds across a number of co-morbidities. Applying European prevalence data for dementia to patients in the acute care sector in Ireland, suggest the

estimated cost of extended length of stay associated with dementia is almost €200 million per annum (Connolly and O'Shea, 2015). The overall average cost per person with dementia in Ireland is estimated at €40,500, which is consistent with per capita estimates from other countries.

The increase in the number of people with dementia in the world, along with the associated cost of care, suggest policy-makers need to pay more attention to the disease and its implications for public funding and investment in the coming decades. It is no surprise that the WHO has recently declared dementia to be a 'public health priority' which should be on the political agenda of all countries. Even though new evidence suggests that future trends in prevalence and incidence are likely to be modulated to some extent by reductions in risk factors for the disease, linked to positive changes in education, health behaviours, lifestyle and health profiles cross the life-cycle, the numbers of people with dementia will continue to increase, especially in Ireland, where population ageing is at a very early stage.

Capabilities

3. FRAMING DEMENTIA

Before considering the impact of Atlantic's investment in Ireland, some discussion of the philosophical underpinnings, or the framing, of dementia in this country is necessary. Normally, in free societies, we assume that individuals are independent in terms of decision-making and behaviour in their everyday life. The assumption is that both economic and social progress is improved by allowing self-interested, free individuals to choose reasonably the best means to serve their usually given ends. The system works best when no obstacles are placed in the way of individual decision-making. It is only in exceptional circumstances that deviations from individual independence are acceptable. For example, parents and guardians make decisions on behalf of children; health professionals sometimes make decisions on behalf of people suffering from mental illness; carers sometimes make decisions on behalf of elderly kin suffering from severe levels of cognitive impairment.

In each of these examples, the decision-maker is assumed to either know more, or be more rational, than the person for and about whom decisions are being made. By and large, the examples given above are not contested, although concern is sometimes expressed about the potential for self-interested behaviour by the third party decision-makers, in the sense that decision-making may sometimes serve the interests of providers more than the recipients of care. Generally, however, for categories of people deemed irrational, emotionally immature or with failing mental powers, the correctness of referral procedures are not contested. The consequent violation of the personal autonomy principle, so highly prized by everyone, is accepted as inevitable.

The situation of people with dementia is complicated by two factors. First, the loss of cognitive abilities may be a long-term process. People with mild to moderate dementia will usually be able to make decisions for themselves, under normal circumstances. In such cases, it is inappropriate to deny people independence as long as they are in a position to exercise it. Timely diagnosis is, therefore, important since it can allow people with dementia an opportunity to express preferences about future care arrangements and to make other important decisions before their condition

deteriorates.

As the disease progresses, the ability of the person with dementia to reason, and to act in a truly autonomous way, may become compromised. At this stage, under a rationality model of independence, the ability of the person with dementia to play a major role in the decision-making process about his or her own care is undermined. However, this does not mean that other forms of communication cannot be developed and nurtured to replace and/or complement oral communication. In particular, failing mental power does not diminish the capacity of individuals to communicate at the level of emotions and feelings, and through the various senses (Goldsmith and Baxter, 1996). Communication is possible, although it is often a difficult and complex process. It takes time and patience, requiring an understanding and personal knowledge of people with dementia, which, unfortunately, is too often absent. The guiding philosophy must continue to be respect for the autonomy of the person with dementia, linked to a broad interpretation of communication, and a commitment to the primacy of the person with dementia in the decision-making process.

The second complication concerns the role of family carers in the care process. In the majority of cases, family carers are so directly involved in the care process that it is difficult to disentangle their needs from the needs of the person under their care. This must be done, however, because carer and care recipient needs are different and must be treated as so. It is not good enough to equate carer needs with care recipient needs on the basis that what is good for carers must be automatically good for people with dementia. In the desire to acknowledge and advance the role of family carers as partners in care, we should not forget that the person with dementia is also a partner in care, with separate needs and preferences.

The emphasis on individualism and the sanctity of personal autonomy and sovereignty is not to argue that society, and the networks within which individuals are embedded, has no influence on the way we treat people with dementia. Each of us lives our life within a social matrix or network comprising human interaction, language, custom, tradition and

narrative (McIntyre, 1984). As a result of the fusion of these social forces, all individuals are constrained, to some extent at least, in how they act. The making of individual decisions is affected by the various networks to which we all belong.

Our sense of community and solidarity with others is a very important influence on the way we think about people with dementia and the respect we pay to the meaning and purpose of their lives. If people with dementia are not part of our ordinary networks, then we can never be affected by them, or understand their need for autonomy, respect and dignity. We allow ourselves to treat them differently because we do not know anything about the lives they lead. The absence of people with dementia and their carers from everyday life is a denial of rights and citizenship, but it also crucially affects the way we think about our social responsibilities towards them. The solution is to transform dementia from solely a personal experience, to one where society has a role to play in recognising the individual's right to choose their own destiny, which can be achieved by gaining a better understanding of the disease.

One of the difficulties in this area is how little power, or control, people with dementia and their carers have in their dealings with health care professionals. Generally, both parties have to accept what is on offer from the health authorities, whether or not they consider the service offered to be appropriate to their particular needs. Historically, the biomedical model has tended to dominate in dementia care which has led to the dominance of clinicians in decision-making and priority-setting. Consequently, services are not always provided in the form, or to the degree, required by clients, nor are services always delivered at the right time by the right person. People with dementia are encouraged to live in their own homes and families are expected to care for and keep their dependent kin at home, but neither are given the practical support and resources necessary to achieve such independence. It is, of course, very difficult to dismantle the old style, clinician-dominated, paternalistic system associated with health and social care provision and there remains a strong element of provider knows best with respect to social care provision.

The biomedical model of dementia has dominated our thinking on dementia up to recently, focusing on neuropathological explanations for the development and progress of the disease. This assumes a simple causal relationship between neuropathology and dementia (Bond, 1992). Biological factors associated with dementia include: age; genetic factors; physical health conditions; and sensory deficits (Spector and Orrell, 2010). While the biomedical model has played a key role in developing insights into the causes of dementia, to date no cure has been found. However, an understanding of dementia rooted in the biomedical model can help ensure that individuals receive a timely diagnosis, are able to access appropriate support and interventions such as memory clinics and have access to the most appropriate drug treatments. Pharmacological interventions can also help to alleviate behavioural, cognitive and functional symptoms in dementia.

Given that the biomedical model of dementia continues to dominate our understanding of dementia, it is unsurprising that the majority of cost-effectiveness analyses in dementia have focused on pharmacological interventions. The evaluation literature has concentrated on the potential of drug treatments to slow the progression of the disease which has the potential to alleviate carer burden, reduce the rate of hospitalisation and delay long-term admission into institutional care (Knapp et al., 2013). However, the effectiveness of these drugs vary and while they can mask the symptoms of disease, they do not treat the underlying disease, nor can they significantly delay its progression.

Although the biomedical model of dementia has much to offer regarding our understanding and treatment of dementia, it is not broad enough to address all the factors which may impact on an individual's health. The construction of dementia in terms of biological variables alone ignores the social, economic and psychological elements of the illness, resulting in the behaviour of people with dementia being understood without the proper frame of reference (Bender and Cheston, 1997). The biomedical approach to health, as argued by Vogt et al. (2014), is overly scientific and does not see the patient as an active partner in the treatment process.

While the biomedical model has historically dominated policy and practice in dementia, an emerging philosophy internationally has been personhood within dementia. Personhood was first defined by Kitwood (1997) “*as a standing or a status that is bestowed on one human being, by another in the context of relationship and social being*”. In a very general sense, personhood can be understood as the attributes possessed by human beings that make them a person. Brooker (2007) has suggested the acronym VIPS to translate the broader meaning of personhood to an application of person-centred care: people with dementia and their carers must be Valued; they must be treated as Individuals; the Perspective of the person with dementia must inform our understanding; and the person’s Social environment must be attended to because of the fundamental importance of relationships in sustaining personhood. Personhood places less emphasis on the medical management of patients. Instead, it promotes the humanity, rights, connectivities and perspectives of the individual with dementia. The principle of personhood is increasingly acknowledged as important for resource allocation decision-making internationally and in Ireland (OECD, 2015, Department of Health - Ireland, 2014, HIQA, 2015).

Citizenship is also important for people with dementia. It can be defined as ‘a process of proactive engagement’ in society in which ‘differentials of power’ are recognised and addressed through equal status within the Constitution and before the law (Beckett, 2005: p.405). Marshall’s definition of citizenship introduced a rights dimension for the first time consisting of three elements: civil; political; and social (Marshall, 1950). Citizenship incorporates rights and responsibilities, both of which are often denied to people with dementia, such as treating others with respect (Kelly and Innes, 2013). Bartlett and O’Connor (2007) argue that citizenship has a political dimension which is absent from personhood, thereby making it a more effective frame for achieving real change in regard to enhancing the rights of people with dementia. Only full citizenship can guarantee the potential of equal participation for people with dementia and their inclusion in all dimensions of society.

The Irish National Dementia Strategy makes a strong opening statement on the importance of personhood and citizenship for people with dementia in Ireland. The Strategy is geared to progressing the dual and overarching principles of personhood and citizenship by ‘*enabling people with dementia to maintain their identity, resilience and dignity and by recognising that they remain valued, independent citizens who, along with their carers, have the right to be fully included as active citizens in society*’ (Department of Health - Ireland, 2014). In emphasising personhood and citizenship, the National Dementia Strategy has begun the process of moving away from the biomedical model of dementia that has dominated the conversation on dementia in Ireland for decades. Unfortunately, it will take some time before we have fully operational person-centred models of care for people with dementia that reflect the ideals of personhood and citizenship. The biomedical model will continue to be dominant in Ireland for some time yet, in practice, if not in theory.

What is emerging, however, is an increasing realisation that reframing dementia in more social terms has the potential to improve the lives of people with dementia similar to what the social model of disability has achieved for disabled people. The social model of care recognises dementia as a disability as much as a medical condition, for which there is no cure. It acknowledges that the symptoms and behaviours of people with dementia are not the result of the disease process alone, but are impacted by both social and environmental context, as well as the person’s own perceptions and reactions (Kasl-Godley and Gatz, 2000). For example, Sixsmith et al. (1993) suggests that inappropriate care or living environment may contribute to the overall deterioration of the person with dementia, while a more appropriate environment may enable a person with dementia ‘*to realise their potential within the limitations of the changes in the functioning of their brain*’. The inclusion of social elements in dementia care refocuses the nature of caregiving from a medical perspective of the disease and symptom control, to a psychosocial focus on the person, their needs and abilities and the meaning of their behaviour.

In recent years, there has been a push to incorporate psychosocial interventions in dementia care, which have the ability to improve the quality of life for the person with dementia and their caregiver (Johnston and Narayanasamy, 2016). Psychosocial interventions include support groups, physical exercise programmes, reminiscence therapy, cognitive stimulation, crafts, art and befriending. Psychosocial interventions target particular factors and emphasize different goals, for example, reminiscence therapy addresses the person's subjective experience of dementia. Such interventions have the potential to help people with dementia build coping strategies, develop resilience, reduce distress, provide interpersonal connections and optimise remaining abilities, as well as helping to understand the impact dementia has on the self and behaviour (Kasl-Godley and Gatz, 2000). For all of their potential, however, it is important to note that non-pharmacological interventions are generally seen as complementary to medication, rather than as alternatives (Olazarán et al., 2010).

In order to maintain the personhood of the individual with dementia, a model of dementia care which encompasses both the biological factors of dementia and the psychosocial factors is needed. Kitwood (1990) introduced new thinking on dementia focused on the process of the disease, rather than the state of the disease. He suggests the adoption of a larger framework of dementia, which abandon simplistic notions of disease entities and linear causation and embraces the significance of social psychology alongside the neuropathology of dementia. The biopsychosocial approach to care incorporates all of the interacting factors contributing to both the illness and the person: biological, including genetic factors and body system functioning; psychological, for example, mood, personality, behaviour; and social, that is, cultural, familial and socio-economic. The emphasis is on care and individual treatment, as opposed to disease specific treatment and curative medicine (Russell, 2009). Adopting a biopsychosocial approach to dementia allows for movement beyond just the biological determinants of dementia, creating a wider framework for potential interventions (Spector et al., 2016).

The biopsychosocial model of dementia care has significant implications for the clinical domain of dementia care. From a clinical perspective, a biopsychosocial approach is fundamental to the practice of integrative medicine and whole-person care. This understanding of dementia is necessary as a clinical guide as it encapsulates the complexity of the factors which determine the presentation of illness, its progression and the appropriate interventions. A recent study (Spector et al., 2016) focused on the feasibility and impact of training staff from a variety of settings on the biopsychosocial model of dementia. The results from their pilot study found that the biopsychosocial training significantly increased the ability of staff to understand, formulate, and develop different types of interventions for people with dementia. This suggests that the biopsychosocial model of dementia may contribute to an improvement in staff's ability to incorporate information from biological, psychological, and social domains in the development of treatment plans, potentially leading to improvements in dementia care in the future.

The optimal therapeutic model is one that recognises the primacy of caregiving in the treatment of dementia and focuses on delaying symptoms and deterioration while enhancing coping and resilience. A biopsychosocial model of dementia can help maintain the personhood of the individual by targeting and enhancing their strengths and capabilities and by meeting their individual needs as people rather than patients.

Bio
psycho
social

4. INTERNATIONAL DEVELOPMENTS IN DEMENTIA

Traditionally, dementia has not been separated from generic ageing within government strategies, budget allocations and policies. People with dementia have simply taken their place within the crowded ageing sector, without much thought given to the specificity of the disease or its consequences. Diagnosis has typically not been prioritised, given the absence of interventions to alter the prognosis of the disease. Community-based care for people with dementia, when available, has been minimal and provided as part of normal care for dependent older people. The burden of care has been left to family caregivers who are expected to provide the vast bulk of care in the community. As a result, people with dementia, are largely invisible, the majority of them outside the official formal system of care. In such an environment, it is not surprising that fear and stigma dominates in relation to dementia, contributing to delays in seeking diagnosis and care, social isolation and a general reluctance to openly acknowledge the social exclusion associated with the disease.

The call to change accelerated towards the end of the first decade of the new millennium. Since 2010, a number of international agencies have pushed for dementia to be recognised as a global health priority. In 2011, The UN General Assembly referenced mental and neurological disorders, including Alzheimer's disease, as an important cause of morbidity and disease burden, for which there was a need to provide "equitable access to effective programmes and health care interventions". In 2012, WHO and Alzheimer's Disease International jointly issued a report that argued why dementia must be treated as a global public health priority. The report set out a range of actions needed to improve care and services for people with dementia and their caregivers, and for individual countries to develop and implement dementia plans. In 2013 the United Kingdom (UK) led a Dementia Summit that brought together G8 health and science ministers, researchers, pharmaceutical companies and charities from around the world to address the need for improved care, better treatments and discovery of a cure for Alzheimer's disease and other dementias. The Summit called for a doubling of funding for dementia research and ambitiously targeted a disease modifying therapy or cure for dementia by 2025.

The momentum generated by the G8 Summit has been maintained by many legacy events, the formation of the World Dementia Council and appointment of a World Dementia Envoy. Now WHO and the OECD are devoting more resources to dementia aiming to sustain the original G8 commitments. A group of global NGO's and civil society came together to organise the Global Alzheimer and Dementia Action Alliance (GADAA) in 2014 to promote understanding about the disease and reduce the stigma associated with it. GADAA is seeking to raise awareness of dementia and in doing so, send a strong message to policy makers that dementia is a serious health issue. The Alliance rejects the old degenerative model of dementia and seeks to promote the concept of person-centred care. This message reinforced the valuable work already underway by organizations such as Alzheimer's Disease International, the Alzheimer's Association and the 10/66 Dementia Research Group.

Responding to the need for a shared global commitment to action, the first WHO Ministerial Conference on Global Action Against Dementia organized in 2015 sought to raise awareness and demonstrate a shared commitment among Member States and stakeholders to put in place the necessary policies and resources to improve dementia care and treatment and ensure that action against dementia rose to higher levels on national and global agendas. The "Call for Action" emanating from the Ministerial Conference highlighted a number of key strategic actions including:

- higher level of priority for dementia in national and international policy agendas;
- strengthening of capacity, leadership and governance on dementia;
- greater public understanding of dementia and reduction of stigma and discrimination;
- improved prevention, risk reduction, diagnosis and treatment of dementia;
- technological and social innovation in dementia;
- increased research and collaboration in dementia;
- better coordination and integration of health and social care.

The need for action was reinforced by the World Innovation Summit for Health (WISH), an initiative of the Qatar Foundation, who put the focus firmly on policy innovation as part of a global response to dementia. To address dementia in a comprehensive manner, WISH highlighted three primary themes: prevention and risk reduction; diagnosis and care; and cure. Action was urged in a number of key areas including: public awareness; brain health; integrated dementia care; research and development; and innovative funding models. A key recommendation was for countries to create a national plan to address dementia and/or include dementia as a priority in UN plans for prevention and control of non-communicable diseases across countries. Similarly, in 2015, the OECD argued for dementia to become a national public health and social care priority worldwide, leading to the promotion of a dementia-friendly society globally. For this to happen, there would have to be an improvement in public and professional attitudes to, and understanding of, dementia for it to become a national priority within countries. From this enhanced understanding would flow an increase in investment in health and social systems of care which would lead to improvements in care and services for people with dementia and their family caregivers.

The upsurge of interest in dementia from international agencies has coincided with an increasing emphasis on cognitive health, which is concerned with the maintenance of optimal cognitive function at all stages of life. Cognitive function in later life is influenced by physical and mental health from early in life, so every life stage matters. Although the study of cognitive ageing is in its infancy, particularly when it comes to controlled clinical trials (Ngandu et al., 2015), there is some evidence emerging on the potential of preventive strategies throughout life to enhance brain health and reduce the risk of dementia in later life (Blazer et al., 2015, Barnes and Yaffe, 2011). What is known is that physical health is good for mental health and that a healthy heart is good for a healthy brain. Some of the key modifiable comorbidity risk factors for dementia are already well known and include: vascular disease, hypertension, obesity, diabetes, depression (Wu et al., 2015). Lifestyle factors such as smoking and physical inactivity also matter, as does education

and social class. Public health policies aimed at whole populations, such as prevention and health promotion through lifestyle modifications, which are important for many conditions, may, therefore, also be important for dementia. Indeed, some of the downward trend in dementia incidence in recent years may be linked to better and more aggressive treatment for cardiovascular risk factors (Matthews et al., 2013, Hurd et al., 2015). Although all of the evidence is not yet in, it is becoming increasingly clear that health factors in early life matter for dementia and that primary prevention can have a major influence on the risk and incidence of dementia in later life.

The Alzheimer's movement now believes that there is sufficiently strong evidence, from a population-based perspective, to conclude that regular physical activity and management of cardiovascular risk factors (diabetes, obesity, smoking, and hypertension) reduce the risk of cognitive decline and may reduce the risk of dementia (Baumgart et al., 2015). There is also strong evidence to conclude that a healthy diet and lifelong learning/cognitive training may also reduce the risk of cognitive decline. There is emerging evidence that social relationship factors that feed into a lack of social interaction are associated with incident dementia. Kuiper et al. (2015) argue that the strength of the associations between poor social interaction and incident dementia is comparable with other well-established risk factors for dementia, including low education attainment, physical inactivity, and late-life depression.

While the recent upsurge in international and intergovernmental focus and attention on dementia is welcome, the disease is still not a priority in the vast majority of countries in the world; for example less than 10 per cent of WHO countries have a national plan to address dementia. This is partly due to different levels of economic development across countries; some countries lack the financial resources to prioritise dementia relative to the more fundamental challenges of poverty and inequality. It is also the case that the economic and social burden of the disease is poorly understood, leading to inaction and inertia even when resources are available. In most countries, dementia is behind cancer and heart disease when

it comes to claims on the public purse. Resources are not infinite and the majority of countries have chosen not to prioritise dementia, despite the economic and social consequences of the disease for individuals, families and communities. It is not surprising, therefore, to find that public funding for dementia within and across countries is generally low and that public services are sparse and fragmented, particularly for community-based care. The care of people with dementia is, by and large, still left to families. When the State intervenes it is mainly to fund acute care and residential care, partially or in full.

How have some countries managed to develop plans and strategies for dementia and others have not? In those countries where dementia has moved up the policy agenda, evidence, advocacy and political engagement have been important factors in creating the environment for change. For example, the Dementia UK report (Knapp et al., 2007), which was commissioned by the Alzheimer's Society in the UK, was an important forerunner to the English National Dementia Strategy, particularly through its emphasis on making dementia a national priority. In Australia, the Alzheimer's Association was again the catalyst for an important report on dementia (Access Economics, 2003) which highlighted the need for a national strategy to confront what was described as "the enormity of the dementia epidemic". In France, the former President, Nicolas Sarkozy, was the driving force behind the French Alzheimer plan, making it one of the priorities of his term as President of France (Lustman in: Couteur et al. (2013)). In Norway, the National Centre for Dementia Research had for years been engaged in evidence-based lobbying before the publication of the dementia plan in that country. Evidence, advocacy and political economy clearly matter for dementia.

The various country plans on dementia that are now available are relatively consistent and increasingly convergent with respect to what needs to be done, with a common emphasis on: primary prevention; changing private and public attitudes to the disease; timely diagnosis; improving quality of life and quality of care; training and education for formal and informal carers; enhanced day care and customised

residential care; developing timely and appropriate care pathways; developing partnerships with people with dementia, their families and communities; and research and policy implementation (Cahill et al., 2012). Most countries with dementia strategies have prioritised core areas of awareness, prevention, diagnosis, provision, impact and implementation (Alzheimer's Society UK, 2013). For example, Australia and Canada have incorporated a focus on public health, primary prevention, risk reduction and delaying dementia. The Norwegian plan - Making the Most of the Good Days – is focused on day programmes for people with dementia, adapting nursing homes to suit the needs of people with dementia and on increasing public and professional knowledge about dementia. The French plan targets public awareness of dementia, diagnosis and specialised provision. Scotland emphasises key service delivery systems, including improving services after diagnosis, better information systems and improved care in general hospital settings.

There is also a uniform emphasis on the importance of involving the person with dementia in decision-making and the role that families and communities play in facilitating people with dementia to live well with the disease. Personhood is the dominant philosophy underpinning all of the plans, allied to a strong rights orientation and the primacy of citizenship. There is, for example, an explicit reference to dignity, humanity and respect for people with dementia in the Australian, English and Norwegian plans. In the Netherland's plan there is a strong commitment to working with the person with dementia to achieve optimal levels of care. The best strategies have succeeded in generating additional resources for dementia, most noticeably in France and Norway, where there has been a significant increase in public investment in dementia care. Sometimes this is achieved by linking increased spending on dementia closely to other public health initiatives, for example in England and Canada. All of the successful plans contain detailed implementation strategies and clear lines of accountability. In France, under Sarkozy, that meant reporting directly to the President on progress every six months.

Dementia, however, continues to lag behind other chronic diseases in terms of budget allocation in most countries, and in the share of resources devoted to research on the topic, relative to disease burden. Some of the reasons for this are: ageism, stigma, lack of knowledge and an absence of awareness until recently that dementia is likely to become much more prevalent as a result of population ageing in many countries. Developing a national dementia strategy is, however, an important first step in ensuring that dementia is on the political radar, thereby making it more likely that additional resources will eventually be channelled in that direction. The evolving international consensus on dementia, as evidenced by WHO, G8 and OECD narratives, analyses and recommendations, and the continuing political lobbying by various national and international Alzheimer's Associations has kept the pressure on with respect to the prioritisation of dementia within and across countries. However, without a national plan, and the financial resources to implement that plan, progress is likely to be slow in effecting real change for people with dementia.

In Ireland, the absence of a rights-based framework for resource allocation makes it difficult for dementia to attract the budget necessary to effect real change in the lives of people affected by the disease. There is no right to community-based social care in this country, making it very difficult for people with dementia to remain living at home as their condition deteriorates. Ireland will belatedly ratify the United Nations Convention on the Rights of Persons with Disabilities in the near future, which may lead to greater autonomy for people with dementia in relation to choosing their own pathway to care, provided resources are made available to support their various choices. That is a very big qualification, given the failure of successive governments to provide adequate public resources for community-based care in the past. Moreover, there is evidence from countries that have already ratified the Convention that dementia has been not always been fully incorporated into the disability framework, leading to concerns about the potential for systemic discrimination against people with dementia who continue to be excluded from international agreements, de facto, if not de jure.

Enab
ling

5. DEMENTIA CARE IN IRELAND

Public provision for older people in Ireland dates from the 18th century. Specific provision was not made for older people, but they were given help if they were poor, sick, infirm, mentally unstable, or unable to support themselves. Houses of industry, or workhouses as they were called, catered for the destitute and were authorised by law as far back as 1703 in Dublin. The workhouse was the central feature of Poor Law relief, but these institutions were residual places and public support was discouraged so thoroughly that only those who were genuinely destitute applied for admission. For many poorer, older people, particularly those in rural communities, the workhouse was regarded as a fate worse than death. It was not until the Poor Relief (Ireland) Act in 1847 that care outside the workhouse, known as “out-door relief”, became possible, but again only for an equally small and destitute group of people.

Things changed slightly after the establishment of the state in 1922, as county homes replaced workhouses as the main source of care for older people, although the philosophy of care did not change very much and there was no specific provision for people with dementia. While some additional provision for community-based care was made by the new State, domiciliary care remained under-developed and undocumented. The Care of the Aged Report (Government of Ireland, 1968) marked a small shift away from institutional care (county home) as the default response to addressing people’s care needs to one based more on enabling older people who could do so to live in their own homes through additional support for home helps, boarding out schemes and community-based meals. But the Care of the Age Report had very little to say on dementia, referring generically to psychogeriatric patients and the need to keep “older people with psychiatric disorders” out of mental hospitals through more careful assessment by Geriatric Assessment Units.

Twenty years later, *The Years Ahead: a Policy for the Elderly* (Robins, 1988) reiterated the underlying philosophy of the earlier report, placing an even stronger emphasis on keeping older people “in dignity and independence in their own home”. Dementia was referenced for the first time in an Irish policy

document with recommendations made to support people with dementia through: screening for early signs of dementia; additional dementia-specific carers to support public health nurses and family carers; additional day care and day hospital facilities; high-support hostels for people with severe dementia; and various new specialist providers in the psychiatry of old age. Initially the Years Ahead report was seen as path-breaking in terms of signposting a new model for the care of older people in Ireland, but it never received the funding necessary to develop the community-based services promised in the report. The transfer of significant resources to community care did not happen. When additional resources were channelled to the ageing sector, it was to the residential sector on foot of the Nursing Home Act 1990. The fact that The Years Ahead had no statutory basis and no legal underpinning made it almost impossible to achieve its core objective – to keep people with dementia living well in their own communities. In addition, for all its innovative potential, The Years Ahead did not adopt a person-centred approach, as we understand it today; there was, for example, no reference to tailored, individualised packages of care for people with dementia.

Ten years after the Years Ahead report, the National Council on Ageing and Older People, an advisory body to the Minister for Health, commissioned a policy report specifically on dementia that they hoped would provide a blueprint for government investment in the area. The subsequent report on dementia titled *An Action Plan for Dementia* (O’Shea and O’Reilly, 1999) highlighted the need for a social model on dementia focused primarily on care in the community and on maintaining and developing what Kitwood (1997) called the “personhood” of the person with dementia. The Action Plan emphasised the need for the development of co-ordinated, multi-layered and well-resourced services, that were responsive to the individual needs of people with dementia and those who care for them. The *Action Plan* also described a model of best practice for the provision and planning of dementia care in Ireland that sought to maximise the autonomy and capabilities of people with the disease.

The Action Plan set out fully costed targets for the future care of people with dementia in the country, making 33 recommendations in all. The plan was modest in terms of its demand on the Exchequer, requiring only €60 million over a three year period for its full implementation. The key resource intensive priorities were as follows:

- public awareness programmes on dementia;
- early diagnosis through enhanced training and education for primary-care workers;
- a case management model of integrated care
- dedicated community-based services, for example, nursing, day care, respite care and occupational therapists;
- dedicated psychiatric services;
- new and expanded psychosocial approaches to complement existing medical and neurological models of service delivery in the community and in residential care units;
- small-scale appropriately designed, special residential care units;
- new services for people with early onset dementia and people with Down's Syndrome.

The *Action Plan* recommended that an Implementation Committee would be established which would commit to delivering a new model of care for people with dementia. No such Committee was ever established, but The Government's 2001 Health Strategy: *Quality and Fairness: A Health System For You* did accept the general thrust of the *Action Plan* and committed to its implementation over a seven year period. However, apart from some minor improvements in training and education, extra respite care, additional specialised dementia units and more old age psychiatrists, the Plan was never implemented, primarily due to a failure to commit adequate resources. The care of people with dementia continued to be an addendum to a largely impoverished and generic community care system for older people.

This neglect continued despite the setting up and disbanding of two different National Dementia Working Groups and on-going calls, particularly from the Alzheimer Society of Ireland (ASI), for the Irish

Government to implement the Action Plan or, alternatively to develop a new national dementia strategy. The Alzheimer Society kept the pressure on successive governments to commit additional resources through its Dementia Manifesto and its campaigning for dementia to be made a national health priority (Alzheimer Society of Ireland, 2007). However, dementia remained a hugely neglected, under-funded and under-prioritized health issue in the Irish health and social care system in the ten years between 2000 and 2010.

This neglect had serious implications for the care of people with dementia in Ireland. Despite GPs themselves acknowledging the benefits of diagnosis (Cahill et al., 2008), it was the exception rather than the rule in Ireland, and the vast majority of people with dementia remained outside the official system of care. The benefits of timely diagnosis to the individual include the fact that he/she may still be able to actively participate in short and long-term care planning and engage in decision-making about important issues, including drug treatments, management of legal and financial affairs and service options. In some instances, getting a diagnosis may be psychologically beneficial since the person experiencing the symptoms may still have insight and want to make sense of the disease and their own behaviours. At a societal level, early recognition, timely diagnosis, and appropriate community-based intervention can reduce health care expenditure by delaying nursing home admission (Mittelman et al., 1996, Turner et al., 2004, Leifer, 2003). These potential benefits were denied to people with dementia in Ireland.

Timely diagnosis is only the first step on the pathway to care for people with dementia. Several people with dementia and their families who participated in the National Dementia Summit in Ireland in 2011 (Alzheimer Society of Ireland, 2011) described how even after getting a diagnosis, they were left to their own devices to source and access appropriate services. This is why some people argue against early diagnosis in the absence of any credible response from the social care system. While there is no consensus about what constitutes a good model for early support services for those newly diagnosed with dementia and their carers, information services and counselling and emotional supports are key elements in the early stages (Cahill et al., 2012). All were largely absent from the system of care in Ireland.

Community-based nurses play a key role in helping to educate people about the risk factors for dementia and about lifestyle choices that can be adopted to minimise the risk of developing dementia in later life. They also provide front-line care to people with dementia, both diagnosed and undiagnosed. Unfortunately, there are very few public health nurses in Ireland with a dementia-specific remit and their workload remains extremely diverse, thereby likely 'crowding out' care to people with dementia. The public health nurse in Ireland is a "Jack of all Trades" (Nic Philibin et al., 2010) expected to provide a myriad of different professional services (post-operative care, medication management, dressings changing) from the cradle to the grave. It is likely, therefore, that only a fraction of people with dementia in Ireland are known to public health nurses and that the service as it currently operates is not sufficient to meet the complex, chronic and fluctuating needs of people with moderate to advanced dementia. Nor are public health nurses likely to have received specialized training in dementia assessment or dementia care. The vast majority (83%) of general nurses, for whom dementia comprises a significant part of their workload, lack specialist knowledge and have not received training in dementia care, with no significant difference between nursing managers and nursing staff (Farrell et al., 2007, De Siún and Manning, 2010).

In Ireland, the Home Help service is a very important community-based support system for dependent older people living at home. Home Help services traditionally consisted of domestic assistance, such as help with cleaning, cooking and personal hygiene. However, since 2012, there has been more emphasis on assisting with personal care services (bathing, dressing, etc.). In 2014, the Health Service Executive provided approximately 47,500 older people with home help services and provided just over 10 million home help hours to these people. The average number of home help hours is 5 hours per week (Department of Health, 2015). Allocation of hours is based on need and availability of resources rather than ability to pay. However, one of the resounding weaknesses of home care services in Ireland compared with those developed and delivered in other countries (such as the UK, Norway, Sweden, Denmark, France and

Australia) is that these services are not underpinned by legislation and are not provided on a statutory basis. Therefore, coverage of people with dementia is again likely to be low, with little attention paid to the specificity of the disease.

In addition to home help services, the Health Service Executive arranges the provision of generic home care packages, normally for people with high levels of need, the majority of who are likely to be on the margin of residential care, or have recently been discharged from acute care. A home care package will normally assist with personal care such as bathing and dressing as well as nursing and services such as physiotherapy and occupational therapy. These discretionary packages support older people with medium to high dependency requirement and are aimed at facilitating these people to remain at home for longer than would otherwise be possible. At the close of 2014, 13,057 older people were in receipt of a home care package, but we do not know how many of these were provided to people with dementia (Department of Health, 2015). However, intensive home care packages for people with dementia only came into being in late 2015 following the publication of the National Dementia Strategy.

The discretionary nature of community-based supports means that the services can be reduced or withdrawn depending on the availability of resources. When public resources are strained, it is much easier to reduce services to people with dementia living at home, or not provide services at all, than it is to cut back on hospital-based services that are much more visible and politically sensitive. There are also gross inequities across the country in relation to service delivery with considerable variation in the type and amount of home care services available (PA Consulting Group, 2009). In some areas, people with dementia receive very few in-home formal support services and certain schemes, which have the potential to reduce caregiver burden and prolong home-living such as Home Care Packages, lack the flexibility and specificity to address the fluctuating needs of many people with moderate and severe dementia. It is no surprise, therefore, to find significant growth in private markets for dementia care in recent years. This is a largely

unregulated market which has developed in response to unmet need, but it also carries the risk of replicating the dual nature of provision that has evolved in response to current financing arrangements for acute care services. Those able to pay get access to care by leaving the public system when they can, leaving behind those who lack the voice to make things better from within the public system (Hirschman, 1970). Day care and respite care also remain under-developed in Ireland, their potential unrealised as part of the holistic care of people living at home with dementia. Even where day services exist, they may not always be used by people with dementia. Lack of knowledge about their availability, geographical distance from day care services, and transport problems, including high costs, are all factors contributing to the low levels of utilisation of day care services by people with dementia. There is no doubt that day care, like respite care, is under-provided in Ireland, given the potential benefits associated with its use (Cahill et al., 2012).

The recent period of austerity has not been responsible for the relatively low level of government support for community-based resources for dementia in Ireland. Even during periods when public resources were relatively plentiful, investment in dementia care has been historically weak, particularly in relation to community-based care. Dementia has, for a long time now, been a neglected, under-funded and under-prioritized health issue in the Irish health and social care system, notwithstanding the commitment contained in the National Dementia Strategy to provide 500 additional intensive home care packages for people with dementia. There is still no protected dementia-specific budget available to support the development and delivery of statutory community-based dementia services. Health and social services are financed from the same budget, resulting in dementia spending being squeezed out by medical and hospital services on one side and residential care spending on the other.

In Ireland, few alternatives to the nursing home model of care exist for older people with dementia who are unable to remain in their own homes. In this regard, the Irish case contrasts strongly with that in the US,

UK, Australia, and other European countries where a range of alternate models to nursing home care exist, including (i) housing with care; (ii) sheltered housing; (iii) hostels; and (iv) specialist care units. In Ireland, however, only a very small number of housing with care schemes exist, providing accommodation specifically to address the complex needs of people with dementia and none are protected by legislation. Accordingly, when older people with dementia need to move from their own home into long-term care in Ireland, there are very few alternatives outside of residential care settings available to them. Moreover, the funding system supports the residential care option ahead of all other choices (Cahill et al., 2012).

In Ireland, long-stay residential care comprises a mix of public, voluntary and private providers. For Irish family caregivers, accessing long-term care for a relative with dementia has not been easy. In the absence of community-based social workers, case managers or advocates, many people have no idea who to turn to for advice about finding an appropriate dementia-friendly nursing home; nor are people aware of practical issues such as wait-listing protocols for nursing homes, assessment procedures and the cost of nursing home care. A recent Irish study has highlighted that access to residential care services specifically for people with dementia tends to be resource-led rather than needs-led (Bobersky and Cahill, 2011) and may involve multiple relocations. The depletion of the public residential care stock in the past decade in response to concerns about demands on the exchequer has changed the public private mix in long-stay care in Ireland towards a predominantly private system of care. Investment in new public facilities has all but ground to a halt as successive governments have sought to control public expenditure on long-term care, supporting tax breaks for private nursing homes instead of building new public facilities.

Not surprisingly, there are also more controls now, through the Nursing Homes Support Scheme, also known as the Fair Deal scheme, on who accesses public and private long-stay facilities as budget controls force difficult choices to be made on who gets what, where and when? There is also a widespread

with dementia are 'getting the door closed in their face' when the diagnosis of dementia is brought up in conversation with certain long-term service providers (Alzheimer Society of Ireland, 2011). Good dementia care is costly to provide and the public subvention system available to cover it is not always seen as adequate by nursing home proprietors, especially for more complex needs. Of course, not getting access to a public bed or a publicly subverted private bed would not be too bad if community care services were available to meet expressed demands. But we have already seen that community care is fragmented and patchy at best, or not available at all, at least not in a form that supports high quality, home-based care for people with dementia.

The vast majority of people with dementia in Ireland living in residential care are cared for within generic care facilities for older people, most of which are too big and not purpose-built for dementia. They are not designed to cater for the complex, challenging and unique needs of residents with Alzheimer's disease and related dementias. This makes the task of providing care to these people by professional care staff very difficult. As is the case in many other countries, concern has often been expressed about the quality of care for people with different levels of cognitive impairment living in these generic nursing homes and about the very heavy and stressful workload borne by paid staff employed in these types of facilities (Murphy et al., 2006). Research in several countries, and in all types of nursing homes, confirms that, quality of life for person's with dementia is problematic in many residential care settings (Moise et al., 2004, Hancock et al., 2006).

People with dementia are particularly sensitive to their psychosocial environment, and good environmental design is now widely regarded as critical to the care of people with dementia. Indeed, some people have argued that design is as vital to resident care as nursing care or the approach to the organisation of care within the facility (Calkins, 1988, Fleming and Purandare, 2010). In recognition of the special needs of people with dementia in residential care settings, the trend in many countries nowadays is towards providing specialist care in creatively designed small-

scale units (Moise et al., 2004, Cahill et al., 2012). Despite the absence of unequivocal evidence pointing to the value of specialist care units (SCUs), the latter are becoming an expanding feature of the residential long-term care landscape internationally. For example, the first French National Plan for Alzheimer's and Related Diseases (2008-2012) provided for both the development of existing SCUs for people with dementia and the creation of 12,000 new SCU places.

While some dedicated dementia-specific beds are available in public long-stay facilities in Ireland, these are still the exception rather than the rule. Very few people with dementia gain access to specialist care units and even when they do, the size of these units do not always conform with best practice models (Cahill et al., 2012). Moreover, there is no standard definition of what constitutes an SCU in Ireland, nor is there an agreed meaning or definition for the term 'dementia specific bed' within a generic facility. Consequently, we do not have good information on where and how people with dementia are being looked after in residential care settings. The availability of reliable and valid data on the location and quality of SCUs is all the more urgent given the significant concerns about the lack of good, quality specific long-term care facilities for people with dementia expressed by participants at the National Dementia Summit 2011 (Alzheimer Society of Ireland, 2011).

The care process within long-stay facilities is also important in allowing residents to live well with dementia. There is no doubt that the medical and functional needs of residents dominate the care landscape within residential care settings (Murphy et al., 2006). While, to some extent, this is understandable, psychosocial approaches are also needed to complement medical and neurological models of service delivery, but they are largely absent in residential care settings in Ireland, with some notable exceptions (O'Shea et al., 2011). In particular, psychosocial interventions can assist in developing meaningful communication with the person with dementia, using all of the senses, through reminiscence, music and various therapeutic and time-intensive activities (O'Shea et al., 2015). Given the importance of connectivity for personhood within

dementia, new ways of reaching into and out of long-stay settings should also be encouraged through various forms of social interventions. Unfortunately, very few facilities have connectivity programmes that link residents within residential care facilities to the communities that surround them, both within and outside the residential care setting.

This was the background to Atlantic's entry into the dementia space in Ireland. Diagnosis was absent, community care services left a lot to be desired, and there was a strong funding bias towards residential care. The rhetoric of person-centred care existed, but the reality was a system highly geared to supply-side control of the care experience, mainly expressed in medical terms. Dementia was recognised as a serious disease, but it was not prioritised in any way by government or society. When opportunities existed to move dementia up the political agenda through the introduction of an Action Plan for Dementia, they were not taken, even though public budgets were less constrained than they were later to become. There were always those looking to change the landscape for dementia in the country, but their voice was not coherent, nor was it ever collaborative enough, and, in any case, with the arrival of economic austerity there was a resignation among stakeholders that things were likely to get worse, not better.

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6. ATLANTIC'S INVESTMENT: CONTEXT AND METHODOLOGY

6.1 INVESTING IN DEMENTIA

From 2004, Atlantic invested in building the ageing field in Ireland, funding a small number of gerontological centres and leaders as a means of building a strong foundation in research and advocacy. These initial investments included a small number of grants in dementia including: building research capacity and developing brain health and neuroscience at Trinity College Dublin (TCD); supporting the ASI to build an effective advocacy platform; and funding research, education and training at St. James's Hospital through the Dementia Services Information and Development Centre (DSIDC).

From 2011, investment in dementia was accelerated, and dementia became a principal area of focus for Atlantic. The five year period since then, up to 2016, is the main focus of this report. We have described in the previous chapter what policy and practice looked like at that time in Ireland, particularly its fragmented and under-developed nature, but equally, the dementia 'research and development field' in Ireland lacked capacity and focus, and the limited programmes available were piecemeal and of variable quality. The discourse on dementia was pessimistic, reflected in models of care and support that focused on late intervention, mainly through institutional care and palliation. There was no coherent or consistent policy from government, despite the articulation of a comprehensive and innovative Action Plan on Dementia based on a person-centred approach geared to meet individual needs, incorporating a bias towards home care solutions and a programme of comprehensive service provision (O'Shea and O'Reilly, 1999).

Atlantic's response was a phased approach towards the ultimate goal of developing innovative, person-centred supports and services and making dementia a national priority. Initially, from 2011 to 2013, a series of discrete investments were targeted to create rapid momentum across a number of fronts. A central plank

of the initial investment was Creating Excellence in Dementia Care – A Research Review for Ireland's National Dementia Strategy (Cahill et al, 2012), which was designed to provide the vision and template for the government's promised National Dementia Strategy. The Programme for Government 2011-2016 had already committed to developing:

'a national Alzheimer's and other dementias strategy to 1) increase awareness, 2) ensure early diagnosis and intervention and 3) develop enhanced community based services' (Iliffe et al., 2011).

The landmark *Creating Excellence* report provided the research baseline for the deliberations of the Advisory Group to the National Dementia Strategy and the subsequent published work. The report set out dementia prevalence rates for Ireland, provided estimates of economic costs, reviewed current levels of provision and reported on best practice in dementia care locally and internationally. Once the government had committed to a National Dementia Strategy, Atlantic wasted no time in supporting its development and later on its implementation.

As part of this support for the Strategy, Atlantic spent €10 million between 2012 and 2015 on individual projects that leveraged an additional €6 million from the Health Service Executive. Co-investments were made with the Health Service Executive and other agencies that led to:

- the creation of locally-based consortia to model and design innovative, person-centred services and supports in both community and hospital settings, established in partnership between the Health Service Executive and Genio. The latter works to bring together government agencies and philanthropy to develop, test and scale cost-effective ways of supporting people who are disadvantaged to live full lives in their own communities in the areas of disability, mental health and dementia;

- a new Health Service Executive-supported national assessment process, or Single Assessment Tool (SAT), for frail older people to establish clear and appropriate care pathways based on need, with special focus on people with dementia;
- the gearing up of Alzheimer Society of Ireland services in political and policy advocacy, the promotion of Dementia Friendly Communities, and the phased deployment of up to 300 local Dementia Champions (Dublin City University (DCU));
- the skilling up the dementia workforce through a development programme for health and social care professionals and other front line workers, including retail staff and others in contact with people with dementia, and the scoping of long term needs in workforce development and services leadership (DCU);
- the amplification of the often muted voices of people with dementia in institutional care, through support for a national programme of independent peer advocacy – support and advocacy for older people in Ireland (SAGE) (Third Age Foundation);
- the development and dissemination of customised models of End of Life Care for people with dementia working with the Irish Hospice Foundation and University College Cork;
- agreement on a comprehensive package of applied research and leadership grants for dementia with the Health Research Board (HRB).

These investments reflected key areas identified as requiring immediate action, negotiated on a case-by-case basis with the Health Service Executive and other partners. They were primarily designed to build momentum towards a strong, government-led National Dementia Strategy impacting on key areas of practice and policy, into which Atlantic would be confident to place significant resources as part of a coherent strategy with robust implementation plans. The National Dementia Strategy Advisory

Group established by the government contained a membership that was strongly reflective of the grantees and partners assembled through Atlantic's investments. The grantees reflected a philosophy of person-centred care, citizenship, social inclusion and capabilities which were the hallmarks of Atlantic's grant-making process. Many of the grantees were long time advocates and agitators for change in the dementia field in Ireland.

The Atlantic Board met with the Irish Government in early 2013 to highlight dementia as a key continuing area of interest for the organisation, thus providing a framework for on-going discussions in relation to the National Dementia Strategy and future co-financing arrangements. Atlantic also discussed with the Panel on Public Services Reform the potential for dementia to be considered as an exemplar for change in how public services should be designed and delivered; the work of Genio and others showing the way through alternative approaches to caring for people with dementia, particularly in relation to social models of care. Atlantic believed that the National Dementia Strategy provided a policy basis for a new and different approach to dementia in Ireland, which, if accompanied by the establishment of a National Dementia Implementation Programme (NDIP), would place dementia firmly on the government's current and future social policy agenda and would, in time, deliver significant service reforms.

The National Dementia Strategy, when it was eventually published, was progressive in highlighting overarching principles of 'personhood and citizenship' and the need for a 'whole community response' to dementia. A key goal was to enable the person with dementia to maintain their identity, resilience and dignity and recognise that they remain valued, independent citizens who, along with their carers, have the right to be fully included as active members in society. The Strategy sought to translate these principles into practice by refocusing current service delivery to address the individual needs of people with dementia and their carers in a way that was responsive and flexible. The National Dementia Strategy's stated aim is systemic change – i.e. changing societal attitudes to dementia and influencing front-line practice across the whole system

of care. Five Priority Areas for Action were identified: better awareness and understanding; timely diagnosis and intervention; integrated services/supports; training/education; and leadership. Atlantic targeted three of these priority areas for additional investment as follows, within an overall National Dementia Implementation Programme (NDIP):

Integrated services, supports and care for people with dementia and their carers: reconfiguration of existing Health Service Executive resources; dedicated dementia home care packages; emphasis on people with dementia living in their own homes.

Timely diagnosis and intervention: Key role for GP's and Primary Care Team's (PCTs); training and material to broaden the GP and PCT's skills base; guidance on national and local pathways to diagnosis; information about health and social supports.

Better awareness and understanding: Public awareness; health promotion measures; better understanding of dementia signs and symptoms; combating stigma; promoting an approach of 'living well' with dementia; promoting healthy lifestyles among the population.

Taken as a whole, while the National Dementia Strategy emerged somewhat diluted from that initially envisaged by its Advisory Group, it does contain many of the priority areas of concern to Atlantic grantees and remains close to the vision articulated in Atlantic's own Programme Strategy. Moreover, it is certainly more ambitious and coherent than would have emerged without Atlantic's input and financial support. Atlantic has contributed €12 million to the overall NDIP funding of €27.5 million to support the implementation and evaluation of the National Dementia Strategy as a whole with most of the money going to ensure the delivery of intensive home care packages for people with dementia.

In addition, one of Atlantic's key grantees in dementia – Genio – has been assigned a key role in supporting the development of an outcomes and indicators framework for the National Dementia Strategy, including supporting dementia consortia in priority areas and acting as gatekeeper for Atlantic's funding

of Intensive Home Care Packages. Genio's key role in the implementation of the National Dementia Strategy, and its continuing dialogue with the Department of Public Expenditure and Reform, will also help ensure that dementia is seen as a 'case study' in effective service reform over the medium term. The inclusion of Genio in programme verification arrangements for the individualised care packages element of the National Dementia Strategy is very much supportive of non-traditional approaches to dementia in Ireland and reflects a desire to copper-fasten a personalised, person-centred approach, delivered through a social model of care.

The creation of a single focus on dementia through agreed structures for the implementation of the National Dementia Strategy will help in securing some recognition of the rights of people with dementia, as well as providing practical supports for them in the community. The establishment of programme structures which includes evaluations will ensure that the commitments contained in the Strategy will endure, including capacity for critical review and up-scaling of delivery as the numbers presenting with dementia increase rapidly over the next 20 years. Atlantic also believe that the rooting of Irish policy within a person-centred, individualised care model, based on an inclusive philosophy where the person with dementia is seen as a full citizen, can also be transformative in an international context, as an exemplar to societies struggling to cope with an escalating dementia challenge using traditional health care approaches alone.

6.2 METHODOLOGY

The current report on Atlantic's investment in dementia in Ireland will achieve a number of important outcomes for a wide variety of stakeholders in the field, principally in Ireland, but also in other European countries and beyond. The expected outcomes from the analysis include:

- an evidence-led account of the impact of Atlantic's funding for dementia in Ireland;

- the identification and sharing of strategies and practices that have the potential to advance policy and move dementia up the political agenda;
- an account of the influence of Atlantic's investment on the roll-out of the National Dementia Strategy;
- more informed dementia sector as a result of sharing programme findings with NGO's, policy makers and politicians;
- improved methods of working and the adoption of Atlantic's objectives by other stakeholders in the age sector.

There are fifteen dementia grants included in this report, most of which are still on-going. Start dates for the grants range from 2007 through to 2016. Although both internal and external evaluations have been built-in to each project at different points of the grant, ranging from baseline, interim and/or final evaluations, only a small number of completed evaluations were available for consideration in this review. It is still early days for most of the projects under review in this report. Projects with external evaluations available at time of publication were: Elevator – interim evaluation; Sage – baseline evaluation; Alzheimer Society of Ireland – baseline evaluation; Genio community programmes – interim and final evaluations available; Irish Hospice Foundation – interim evaluation and OPRAH project – interim evaluation. As many of the projects are in the early stages, the evaluations have tended to focus on process rather than final outcomes for each grant. Therefore, there is an element of conjecture in this review, particularly in projecting what the long-term effects of the overall investment will be and when these impacts are likely to be fully realised.

A number of methods were used to elicit information for this study. The first stage of the research was a desk-based analysis of each grant leading to the development of a coherent narrative for the overall investment. A main database, owned by Atlantic, containing all correspondence and documents relating to each grant was scrutinised in the first instance to gain an in-depth understanding of each project. The rationale underlying the grant application and logic models outlining the short, medium and long-term outcomes of each grant were reviewed. Interim reports

for each project are returned to Atlantic regularly and budgets are updated accordingly, thereby allowing us to examine the trajectory of spending and progress over time.

Interviews with stakeholders are an important source of information on the issues addressed in the study. Information from grantees was elicited using a semi-structured questionnaire (See Appendix 1) which was sent to each of the grant holders prior to subsequent face-to-face interviews. A total of 15 grantee interviews were carried out. Interviews were held mainly over a four month period in Spring/Summer 2015. The interview guide and subsequent conversation covered the following topics:

- the origins and context of the grant application;
- rationale and conceptual underpinnings of the project proposed in the grant application;
- key objectives of the project;
- overall level of budget and changes over time;
- key performance indicators in relation to practice change, service delivery and policy;
- impact of the project on personhood, awareness, attitudes, voice and advocacy;
- obstacles and learnings;
- alignment between the grantees and the National Dementia Strategy;
- integration and collaboration;
- sustainability and legacy.

The questionnaire broadly served to guide the interview discussion with the grant holder which was recorded and later analysed in NVivo to establish key themes and trends in relation to the overall investment. Following on from the interview, each grantee was invited to complete and return the written questionnaire emphasising the issues that they considered important to a full understanding of their project and its potential impact.

As a follow-up to the individual interview and questionnaire process, a round table discussion was held with all of the Grantees in November 2015.

At that meeting, the authors: presented the key issues emerging from international developments in dementia; established the main themes emerging from the qualitative analysis of the grantee interviews; and provided a domestic policy review of Atlantic's investment in Ireland. A representative from each grant delivered a short presentation outlining the core impacts of their grant and progress to date. Following on from the round-table discussion, each grantee was contacted, at two separate time points via email, to contribute quotes, case studies or vignettes to the study illustrating the effect of the grant's activities on the lives of people with dementia, their carers and other key stakeholders. These case vignettes are presented in boxed text throughout the remainder of the report.

Interviews with officials from the Department of Health and Health Service Executive were held to gain insight into Atlantic's impact on priority-setting and resource allocation in dementia care, based on progress and evidence to date. Secondary analysis of existing national datasets and other public information sources were also conducted. This involved careful review of all relevant documentation (evaluation reports, government policy papers, academic literature, etc.) to provide supportive evidence of the contribution made by Atlantic grantees to dementia reform in Ireland. Trends on Facebook and Twitter were followed to determine the impact of the various grants on process and outcomes for people with dementia. Election manifestos were monitored to determine the effects, if any, of the overall investment programme on political progress in dementia.

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7. ATLANTIC DEMENTIA GRANTEEES IN IRELAND

Atlantic has invested significantly in dementia in Ireland in the past five years. Total direct investment amounts to €33 million since 2011, which, in turn, has leveraged an additional €51 million for dementia from a variety of sources, mainly from government through their direct and indirect support for the various activities being funded (Table 7.1). Since the start of this evaluation, Atlantic has also funded a joint initiative between Trinity College Dublin (TCD) and the University of California at San Francisco (UCSF), announced in 2015, to establish the Global Brain Health Initiative (GBHI). The GBHI, which has an overall funding of \$177 million, will train 600 global leaders over 15 years in the US, Ireland and across the world to carry out dementia research, deliver health care and change policies and practices. The emphasis is on the development of human capital and the diffusion of that talent and leadership around the world to address the challenge of dementia in a variety of locations, settings and economic circumstances.

Atlantic has concentrated heavily on policy impact in recent years and a notable example of this has, as outlined in the previous chapter, been their efforts to garner Irish government support for, and commitment to, a National Dementia Strategy. That has now been achieved, thanks to the persistence of Atlantic in supporting the initial concept and putting in place the research and development framework for it to happen. Atlantic played a critical role in creating and maintaining momentum by bringing together a wide coalition of stakeholders and in funding a number of them in a variety of areas. Atlantic have also provided funding for major elements of the National Dementia Strategy, most notably the provision of intensive care packages for people with dementia on the boundary of care between community, acute care and residential care. Atlantic have also put in place funding support to ensure that research and evaluation are part of the implementation plan for the National Dementia Strategy, thereby ensuring that outcomes and impacts are measured.

Atlantic have also been concerned with advocacy for people with dementia, particularly through their support for the Alzheimer Society of Ireland and their various programmes aimed at enhancing knowledge and information about dementia among the general public, with a view to reducing anxiety about the disease and providing an antidote to ageism and stigma. Although resource allocation has been a concern for Atlantic, particularly the balance of care between community and residential care for people with dementia, so too has the model or prism within which progress in dementia is measured and evaluated. Personhood has been at the core of Atlantic's philosophy in respect of dementia care in Ireland. Funding support for training programmes, such as those offered by the Elevator programme, for health professionals working with people with dementia, has reflected a desire to change both attitudes and patterns of care for people with dementia to reflect the biopsychosocial model that is at the core of the personhood ideal. Support for the Living with Dementia (LiD) project at Trinity College Dublin has also promoted personhood and non-pharmacological approaches to care. The Genio Dementia Programme, which is supported by Atlantic, has been the catalyst for a major innovation in community-based care in regard to the delivery of personalised supports for people with dementia living at home in the community. This is care that empowers people with dementia drawing on their capabilities more than their deficiencies. This chapter disaggregates and describes the various investments by Atlantic in dementia by grant holder in Ireland in the past five years starting with the Genio Dementia Programme.

Table 7 1: Total funding sources for dementia investment programme

Project	Atlantic Funding	Matched Funding Source	Total Funding
Genio Community	€2,000,000	Health Service Executive - €2,000,000	€4,000,000
Genio Hospitals	€1,600,000	Health Service Executive - €1,000,000	€2,600,000
Genio Evidence Base	€324,600	-	€324,600
Health Research Board	€2,700,700	DoH/HRB - €1,870,000	€4,570,700
Age Friendly Ireland	€178,426	Local Partners - €259,000 Home Instead - €30,000	€467,426
Department of Health – National Dementia Strategy	€12,000,000	Health Service Executive /DoH - €15,500,000	€27,500,000
University College Cork	€2,330,000	UCC/Health Service Executive - €2,330,000	€4,660,000
Trinity College Dublin – NEIL	€2,454,399	TCD - €425,000 Other - €12,835,000	€15,714,399
Alzheimer Society of Ireland	€1,524,093	ASI - €1,513,000	€3,037,093
Health Service Executive – SAT	€2,000,000	DoH/DoF - €4,280,925 Health Service Executive - €4,404,325	€10,685,250
Irish Hospice Foundation	€1,500,000	Fundraising/IHF reserves - €1,581,432	€3,081,432
Third Age – Sage	€2,000,000	Health Service Executive - €2,000,000 Other sources - €369,250	€4,369,250
Dublin City University – Elevator programme	€935,000	Health Service Executive - €800,000	€1,735,000
Trinity College Dublin – Creating Excellence in Dementia	€388,132	-	€388,132
Trinity College Dublin – Living with Dementia	€1,200,000	-	€1,200,000
Total	€33,135,350	€51,197,932	€84,333,682

7.1 GENIO

Genio holds responsibility for two core programmes of Atlantic funded investment in dementia care and research in Ireland, one located in community care and the other at the interface between acute care and community-based care. Genio is important for Atlantic due to their expertise and prior experience in developing and promoting the social model of care in the disability sector and in the mental health sector. Genio were a good fit for Atlantic in terms of values and philosophy, but also because of their ability to bring stakeholders together in pursuit of a common objective – in this case working closely with the Health Service Executive to support the development of community-based consortia to allow people with

dementia to remain in their own homes. The HSE-Genio Community Dementia project was based in four sites in Ireland and focused on the development of consensus-based, community-oriented, personalised supports for people with dementia and their families/carers. The four sites selected for HSE-Genio investment, funded by Atlantic, were Kinsale, Mayo, South Tipperary and Stillorgan/Blackrock in South Dublin. Each programme offered the same ‘core supports’, namely: personalised home-based care with a view to developing a range of non-institutional respite options for people with dementia; support for primary care providers in the diagnosis of dementia; provision of assistive technology to people with

dementia; carer support interventions delivered at an early stage to inform and prepare for the progression of dementia and the building of skills support structures along the dementia journey. The overarching objective of the community supports model was to provide person-centred care that would facilitate people with dementia to remain at home and to enable those with dementia that were inappropriately placed in institutions, such as nursing homes and hospitals, to move back to their local community through the provision of appropriate supports.

The HSE-Genio Hospital Dementia project is located at the interface between acute hospitals and community supports for people with dementia with a view to facilitating the development of Integrated Care pathways (ICPs), focused again on keeping people at home for as long as possible and practicable. The objective of the grant was to support targeted projects aimed at reducing the numbers of people with dementia in acute hospitals. The development of ICPs and community-based supports provides an opportunity for people with dementia to achieve potentially better outcomes at lower cost in more appropriate community settings. This programme may have the most impact on individuals with advanced dementia by first speeding up discharge from acute hospitals and second preventing their admission in the first place. Overall the HSE-Genio investment is important in creating the evidence-base for community-based care, not just that it is possible and works, but that it also has economic advantages, most notably in keeping people out of long-stay care. This is an important message for a funding system that is inherently biased towards the funding of residential care and a resource allocation framework that has consistently failed to support community-based care. The Genio grant was critical for Atlantic in creating the demonstration projects that would help build the evidence base for a radical shift in resource allocation patterns for dementia in the future in Ireland.

7.2 UNIVERSITY COLLEGE CORK (UCC): CENTRE FOR GERONTOLOGY AND REHABILITATION

Atlantic funding has supported and facilitated a number of different research strands in UCC, initially in education and training in medical gerontology, but later in co-funding specific dementia research projects⁴. An important goal for Atlantic was to improve dementia care in acute hospitals by focusing attention on the issue, funding pilot improvement projects in acute care settings and seeking to influence public policy on the basis of the research. The Irish National Audit of Dementia in Acute Hospitals was jointly funded by Atlantic and the Meath Foundation, the purpose of which was to gain an understanding of dementia care in acute hospitals. It was the first national audit of dementia care in Ireland's acute hospitals and had been identified by the Department of Health as a gap in current knowledge about the sector. There was very little information on what happened to people with dementia on admission to acute care hospitals, particularly in relation to diagnosis, pathways through accident and emergency departments and acute medical units and staff training and education in dementia.

The grant to UCC also facilitated the development of the Cork Dementia Study which examined 600 admissions of older people to six acute care hospitals, 29 per cent of whom had dementia. Of those that were found to have dementia, just over a third had a formal diagnosis and only a fifth were coded as having dementia on discharge (Timmons et al., 2015). This research was very important in terms of the information that emerged on prevalence, associations and dementia case recognition in acute hospitals in Ireland. The Study also allowed for the investigation of delirium, which is a reversible cause of dementia, in acute care settings. The data indicated that 57 per cent of older people with dementia had delirium on admission to hospital. This led to the development of algorithms for delirium being developed at ward levels in the acute hospitals, as well as the development of national delirium education modules delivered through the Royal College of Physicians of Ireland and

⁴ The on-going projects in UCC are described <https://www.ucc.ie/en/cgr/rp/>

the Nursing and Midwifery Board. The Irish Delirium Society was formed in 2013.

The Centre for Gerontology and Rehabilitation at UCC is also engaged in the development and testing of a national computerised dementia assessment and treatment database. This project is addressing assessments of patients presenting to memory clinics in Ireland in collaboration with geriatricians, geriatric psychiatrists and the Health Service Executive. It is a computerised database which keeps a record of all patient information, generating a consultation note which can be emailed to the patient's GP and a printed copy that can be given to the patient. This makes up the components of the patient's 'Healthcare Record' which the patient has ownership over. It also has a section where members of the healthcare team can make notes and communicate with each other. The goal is to provide a rich database of information on assessment in Health Service Executive memory clinics that can subsequently be analysed to extract valuable outcomes in dementia.

The Community Assessment of Risk (Tool) and Treatment Strategies (CARTS) Programme has also been developed at UCC. This is a risk intervention strategy, the first of its kind in Ireland, that aims to identify, quantify, stratify and manage risk related to adverse outcomes, frailty and functional decline among community dwelling, older adults, including people with dementia. The programme is designed to support more effective community-based care for older people by developing evidence-based, cost-effective health intervention strategies that focus on the risk factors that may lead to people being admitted to acute care hospitals and/or residential care.

Other important assessment initiatives associated with this grant include the development of the Quick Mild Cognitive Impairment (QMCI) Screen. This is a short (3-4 minute) cognitive instrument to discriminate between normal, mild cognitive impairment (MCI) and dementia. It has been found to be more sensitive at differentiating normal cognition and dementia from MCI than existing cognitive instruments. The Caregiver Cognitive Screen (CCS) is another instrument that has been developed for use by members of the public where they have concerns about an older adult. Work

has also been funded on exploring the relationship between Centrally acting Angiotensin Converting Enzyme (CACE) inhibitors and the rate of decline of people with dementia, including activities of daily living function.

The grant also supports the implementation of a long-term-care pathway for people with dementia by assisting a multidisciplinary research programme aimed at developing a 'best practice' approach to end-of-life in long-term-care. The underlying objective of this project is the implementation of an advance care planning (ACP) programme using the 'Let Me Decide' Advance Directive (LMDAD). This project also includes the delivery of a palliative care educational programme for staff. Standardised educational programmes in ACP and palliative care have been developed and are available online to facilitate the training of new staff. The goal is to establish a network of centres of excellence in long-term care in Ireland in the areas of symptom control, healthcare utilisation and costs, and staff confidence in providing end-of-life care.

7.3 TRINITY COLLEGE DUBLIN: NEURO-ENHANCEMENT FOR INDEPENDENT LIVES (NEIL)

The Neuro-Enhancement for Independent Lives (NEIL) project in Trinity College Dublin (TCD) was one of the earliest dementia grants supported by AP. The grant was in part a response to a nihilistic view of dementia that nothing could be done about the disease. It was in essence Atlantic's support for a countervailing view that science matters and that brain health is the other side of the coin to cognitive decline. The grant was initially established to develop the necessary human capital and infrastructure to facilitate and promote research on various aspects of neuroscience and brain health. There are three main strands to the programme. The first is research in dementia prevention and cognitive enhancement, with a view to impacting on the trajectories of people with dementia, either through delaying onset or delaying disease progression, thereby enabling more independent living. The second strand involves the development and evaluation of interventions to support people with

dementia, for example, training volunteers to engage in social interaction during meal-time as a relationship intervention in people's homes. The third strand is empowerment through educating people about dementia including the risk factors associated with the disease and how best to counteract these risks. All three of the strands are interlinked, in that research informs the interventions which, in turn, inform the educational element of the project.

Over time the NEIL programme has brought together a core group of Irish researchers to focus on the development of a major programme of research for multi-level interventions to delay and/or prevent dementia. The following is a sample of some recent NEIL research studies aimed at enhancing cognitive function, the identification of markers of cognitive decline and health and well-being in family carers.

Automated Cognitive Assessment Delivery (ACAD): this is an automated, repeatable, computerised, cognitive assessment tool, suitable for online delivery on personal computers and mobile devices.

Active Body, Active Brain: this project involved coordinating a course to train 30 staff from the Alzheimer Society of Ireland (ASI) in Cognitive Stimulation Therapy (CST), to facilitate the delivery of CST in the community, and to evaluate the impact of the project.

Caregiver Support Tool: this is a software application, presented on a touchscreen tablet, aimed at providing instrumental and educational support for spousal caregivers of individuals with dementia.

DemPath: this study aims to integrate care for people with dementia across the Dublin South Inner City community and St James's Hospital in a person-centred way.

De-Stress: Health and well-being of spousal dementia caregivers in Ireland.

FreeDem Films: The aim of this project was to develop and evaluate a series of online films that provide practical information, grounded in science, on maintaining cognitive health. The films were

released in February 2014 and attracted considerable publicity. They have been viewed over 100,000 times in more than 140 countries, and are being used globally for awareness and education by Alzheimer's organisations, hospitals and health service providers.

7.4 THIRD AGE FOUNDATION: SUPPORT AND ADVOCACY SERVICE FOR OLDER PEOPLE (SAGE)

The mission of SAGE is to promote and protect the rights, freedoms and dignity of older people by developing support and advocacy services wherever ageing poses a challenge for individuals. The service was originally initiated by the Health Service Executive in response to a television programme in 2005 exposing extremely poor care for older people in the Leas Cross Nursing Home in Dublin. SAGE was subsequently developed under the governance of Third Age Ireland, with funding from the Health Service Executive and Atlantic. It was recommended that the advocacy service be managed by an independent body so as to avoid the potential occurrence of conflicts of interest which may arise if it was internal to the Health Service Executive. The development plan for the service require it to be available to all vulnerable older people, including people with dementia, in all care settings and in the transition between settings. In terms of dementia, the objective of the programme is similar, namely to provide people with the disease access to an independent advocate, especially those people living in long-stay care settings. As well as carrying out individual casework with clients, SAGE is committed to addressing systemic issues in the care of vulnerable older people and to the development of quality standards for support and advocacy for older people through public consultation.

The purpose of Atlantic's grant to SAGE is to further strengthen the voice and social action of older people by supporting the Third Age Foundation to provide an independent National Advocacy Programme aimed at vulnerable older people, especially people with dementia. The grant has facilitated: the development of an operating plan to scale up the advocacy programme to acute hospitals, long-stay care facilities and communities; the implementation

of data collection systems; the development of customised advocacy for people with dementia in all care settings; and the provision of educational and training programmes for volunteers in all care settings. SAGE now employs four development workers who are focused on developing acute care 'pathfinder' models linked to four academic teaching hospitals. Pathfinder areas have been established in Dublin, Cork and Galway and surrounding counties to provide support and advocacy services for older people in acute hospital settings. Initially a pilot programme, this work will eventually inform support services for vulnerable older people in all acute hospitals. SAGE representatives in acute hospital settings deal with advocacy, voice and transitions for people with dementia in this setting. This is an important addition to the resource allocation process in the places where it exists, ensuring that people with dementia do not stay longer than they should in acute care.

Advocacy is a continuum which requires a whole range of skills, including brokerage, mediation and befriending as well as legal, financial and healthcare expertise. Recruitment and training of volunteer advocates is key, therefore, to the success of the programme. Advocates have to know about many different things when it comes to dementia, ranging from the disease itself, care trajectories, personhood, rights, models of care and family dynamics. As well as conducting one-to-one casework, SAGE aims to strengthen the natural support structures of family and community in partnership with relevant professionals and local development organisations. The service is committed to building Circles of Support so that older people can, wherever possible, live and die in the place of their choice and be supported as they experience transitions between home, hospital, nursing home or hospice. The complex job description means that the ability to communicate and engage directly with many different stakeholders is an important part of the skill-set of advocates. This is particularly the case when advocacy intervention may not always be welcome by families, providers, regulators or funders.

7.5 HEALTH SERVICE EXECUTIVE: SINGLE ASSESSMENT TOOL (SAT)

The Single Assessment Tool (SAT) is a comprehensive IT-based health and social care needs assessment tool for frail older persons, including people with dementia, seeking access to the Nursing Home Support Scheme and home support in the form of home care packages or home help. The purpose of APs investment in SAT is "to match better older people living with dementia with the services they need by supporting a phased national rollout of a new assessment framework for all vulnerable older people". Currently, there is too much variety in regard to the assessment process for older people across the 9 Community Health Organisations, 32 Local Health Organisations and 90 primary care networks that make up the ageing sector in Ireland. SAT will provide a more consistent approach to measuring need among older people across the country, replacing the common summary assessment report (CSAR) as the gold standard in measurement. The SAT involves the adaptation of the InterRAI suite of assessment tools and its application in an Irish context. InterRAI needs-based instruments are currently operational in 35 countries. Psychometric properties have, therefore, been well tested and the SAT comes with proven multiple applications for more efficient clinical and economic decision-making. Assessment is linked to case-mix, quality, screening, care planning and policy, including payment mechanisms, while measurement drives the individualised care plan and the budget that supports it.

The tool is structured for multidisciplinary assessment, with 14 related assessment systems in areas such as community, residential, acute and mental health available. The SAT will provide guidance on evidence-based care planning and will facilitate information sharing, thus reducing the potential for duplication of services. The Health Service Executive are also developing an assessment which seeks to measure the healthcare needs of carers, which will ultimately be incorporated into the InterRAI assessment suite worldwide. Included in the work package is the 'SATIS' (SAT Information System) which is a software system to enable the use of the SAT and carers assessment for effective decision-making in relation to service provision, placement and priority-setting; it also

supports users via e-learning and enables shared records. Training will be provided to approximately 2,000 health care staff through a clinical education and development programme, incorporating both measurement supports and learning opportunities.

The SAT will support national policy on enabling older people with dementia to remain at home in independence for as long as possible. The implementation of SAT has the potential to reduce admissions of people with dementia to hospital and postpone their entry into long-term care. International studies suggest a decline in emergency visits to hospital and reduced admissions to long-stay care, while there is also some evidence of a reduction in inappropriate prescribing of anti-psychotics (Canadian Institute for Health Information, 2016). SAT was initially piloted across four acute hospital sites in Ireland in order to explore the suitability of the InterRAI system in an Irish health care context and was found to have a positive impact in identifying previously unrecognised, and therefore unmet, health and social care needs. The pilot data showed that half of all applicants for the Nursing Home Support Scheme and Intensive Home Care Packages were not receiving any home-based supports at the time of assessment, while 30 per cent of people entering long-stay care were deemed to be in the low dependency category. The programme is now ready, in 2016, to be rolled out nationally to all areas in the coming years. It is expected that the SAT will improve older persons' assessments and quality of care in dementia, as well as facilitating the recalibration of care towards community-based provision, based on standardised assessments of need.

7.6 ALZHEIMER SOCIETY OF IRELAND

Atlantic provides funding to the Alzheimer Society of Ireland's initiative Voice and Advocacy in Dementia, which seeks to promote recognition of dementia as a major national challenge by supporting the mobilization of public support for government action and timely engagement in dementia. The Voice and Advocacy in Dementia programme has three main work packages: National Brain Health Programme,

Dementia Friendly Communities (DFC) and Politicising Dementia. The National Brain Health Programme is designed to educate the public about the importance of brain health at all stages of life. DFCs seek to address the exclusion of people with dementia through the reconfiguration of local communities and infrastructure and by mainstreaming dementia into everyday life within the community. The Politicising Dementia work package comprises four main elements: developing tools for advocacy; political advocacy; influencing policy; and research and capacity-building for successful advocacy.

There are a number of outcomes anticipated from these packages including, the publication and implementation of a National Dementia Strategy – already achieved; engagement with people with dementia in the earlier stages of dementia; empowerment of the people with dementia and carers leading them to be change agents and partners in decision making; and progress towards embedding and sustaining advocacy within ASI over the longer term. The ASI facilitated the first Irish Dementia Working Group in 2013. Since then people living with dementia, who form this Working Group, have raised awareness at national and international conferences, spoken powerfully on radio and television and lobbied government and senior government officials on the needs of people living with dementia. A representative from the Irish Working Group is also a member of the EU Working Group of People with Dementia, where people with dementia from all over Europe come together to advise Alzheimer Europe on policy issues. Regional groups of people with dementia are currently being formed to augment the voice of people with dementia throughout the health and social care system in Ireland. As a result, the conceptualisation of personhood in dementia, as reflected in capabilities, connectivities and relationships, is now more widely shared among the general public, media and by health care professionals. The grant was designed to nurture and develop the ASI as a major agent of change in Ireland, with people with dementia and their carers fully integrated into the advocacy function.

7.7 IRISH HOSPICE FOUNDATION

The Irish Hospice foundation received a grant from Atlantic in support of a project to enable older people, including those with dementia, to live and die at home with dignity, by supporting the development and dissemination of best practice models of innovation and care. Palliative care has been a long-standing concern for Atlantic in Ireland, but this project arose out of the need to address the inequity in access to palliative care that people with conditions other than cancer often experience. The adoption of a palliative care approach into the routine care of a person with dementia will potentially help to address deficits in pain and symptom management, while giving voice to people with dementia so that they may express their values and participate more fully in decisions regarding their future care.

The Changing Minds Programme is the corner stone of the Irish Hospice Foundation (IHF) grant in dementia and aims to ensure that people living with dementia have the best end-of-life experience. It is about both principles and practice; promoting quality end-of-life principles and embedding good practices into the care of people living with dementia. The programme aims to positively transform public awareness and professional attitudes. It sets out to promote advance planning and encourage enlightened care systems, including palliative care, that will deliver as much choice, independence and peace of mind as possible for every person living with dementia. Changing Minds seeks to do this, by interweaving progressive practices from many of IHF's existing programmes into dementia care, as well as introducing innovative care models and resources into all care settings and into the skills sets of relevant staff. Key objectives are as follows:

- engage with the leaders of the health service and civic society to generate support for developing excellent end-of-life care for people living with dementia;
- educate and develop the skills of staff caring for people with dementia;
- promote good models of care using an evidence based approach, with supporting guidance and information;

- introduce systems to support the palliative care needs of people with a life limiting disease at home, including those with dementia;
- introduce successful tools and resources used in acute hospitals into other settings where staff and people with dementia will benefit;
- encourage the public to start a national conversation about end of life care and encourage all, including those with dementia, to engage in early advance planning.

One of the main outcomes envisaged by the grant is that palliative care for people with dementia will be prioritised, particularly for people living at home. The stated focus of the programme is to support people with dementia to die well at home and give people the means to think and plan for their end-of-life. The Think Ahead initiative arose from a Forum on End of Life, a gathering of stakeholders in the field, with a view to supporting people to have more autonomy at end of life, even, as Judge Catherine McGuinness put it at the time, "if they have lost the ability to express it". The Assisted Decision Making Capacity Act 2015 formally recognises, for the first time in Ireland, Advanced Health Care Directives where people state that they do not want certain medical interventions and helps people to make autonomous decisions, which should be of assistance to people that have had a diagnosis of dementia who are at the beginning of that journey. There are various statutory instruments required to enact the Bill into law and the IHF, and various other pressure groups, are actively urging relevant members of government to complete the necessary statutory instruments required to bring this act fully into being.

7.8 HEALTH RESEARCH BOARD (HRB)

The purpose of this grant is to improve the care and wellbeing of people with dementia by supporting a programme to develop independent, peer reviewed, applied research and capacity-building, linked to the rollout of the National Dementia Strategy. The HRB granting process is designed to enhance scholarship, leadership and capacity development within the

dementia research field. The partnership between Atlantic and the HRB signifies a commitment to a new investment programme in applied dementia research that focuses on prevention, intervention and care. The programme comprises of 3 interlocking activities: the National Dementia Strategy competitive fund; Leadership and Capacity Development; and Research and Practice Knowledge. The funding was awarded through generic HRB schemes which were already in place, i.e. Structured Population and Health-services Research Education (SPHeRE), Interdisciplinary Capacity Enhancement (ICE) and the Leadership Award programmes, each of which are targeted at researchers with different levels of experience. The SPHeRE programme supports doctoral level research aimed at making Ph.D. students highly trained technical researchers who can also inform policy and implementation initiatives, thereby improving population health and health service delivery. The ICE postdoctoral initiative is designed to encourage interdisciplinary partnership and collaboration among population health researchers, health services researchers and clinical researchers. The Leadership Award is for established researchers with extensive research and supervision experience, with a view to developing scale and capacity in a particular field, in this case dementia.

To be eligible for funding from the HRB, grant proposals have to address a dementia question of strategic importance and justify why the research needed to be conducted now and in Ireland. Proposals have to involve collaborations among multidisciplinary stakeholders, have the potential for the transferability of research findings into policy or practice and include a knowledge exchange and dissemination plan. The Atlantic grant to the HRB is aligned with the National Dementia Strategy, which specifically mentions the need for a priority research agenda to support the expansion of services and supports in this area. Dementia research in Ireland is still developing, with relatively few leaders having emerged, particularly in the social sphere. The HRB grant, therefore, seeks to transform the current dementia research landscape through an infusion of thought and practice leadership within the sector. This will serve to magnify the impact of Atlantic's overall investment under the National Dementia Strategy framework through the creation

of an independent capacity for commentary and evaluation, particularly in relation to social models of provision.

7.9 DEPARTMENT OF HEALTH: NATIONAL DEMENTIA STRATEGY

Atlantic grant support for the National Dementia Strategy covers five main work packages as follows, some of which are tied to other grantees and grants described in this chapter:

Better Awareness and Understanding. Under the National Dementia Implementation Programme (NDIP), the Health Service Executive Health and Wellbeing Division in conjunction with National Communications in the Health Service Executive, will develop and implement a nationwide support campaign for people with dementia and their family carers⁵. The campaign will seek to maximise impact and co-branding of a range of resources already on stream from stakeholders including DFCs, individual websites and helplines, Dementia Champions, Dementia Awareness Training, and both written and video materials. These will be supplemented and cemented through additional actions including information and promotional materials, local implementation packages, and use of media and advertising. The campaign will draw on the learning of these local programmes, and also that put forward recently in the UK's dementia National Dementia Strategy and in other international settings.

Timely diagnosis and intervention. Under the NDIP structures will be put in place to develop training, education and care pathways so as to optimize the patient's journey through the system from initial presentation with worrying symptoms, through to diagnosis, including supporting different interventions appropriate to need at any given time. The aim is that people receive a timely diagnosis of dementia and dementia sub-type. The School of General Practice at UCC, in collaboration with the Irish College of General Practitioners (ICGP) and Dublin City University (DCU), will provide a programme of education and training for general practitioners and primary care staff.

⁵The Understanding Together Campaign, www.understandtogether.ie

Dementia-specific reference material will be developed to broaden the skills base. Guidance on national and local pathways to investigation and diagnosis will be provided. So too will information about health and social supports available in the local community.

Integrated Services and Supports. An integrated partnership approach will be taken to the planning, development, delivery, evaluation and monitoring of services for people with dementia, with the inclusion of all stakeholders from the public (i.e. local authorities and other state agencies, health and social services), private and voluntary sectors. Under the NDIP, 500 intensive home care packages will be provided for people with dementia, initially focused on people on the boundary of care between hospital care (8 hospitals have been selected) and community-based care. This will be implemented through a joint initiative between the Health Service Executive and Genio. Atlantic/Health Service Executive Joint funding of €22 million will support this work package.

Training and Education. Caring for someone with dementia is challenging, both physically and emotionally. Staff in all care settings need the appropriate skills and competencies to care effectively for people with dementia of all ages. However, available studies suggest that many staff employed to provide care to people with dementia often have little formal dementia-specific training and education. The Health Service Executive will engage with relevant professional and academic organisations to encourage and facilitate the provision of dementia-specific training, including continuous professional development, to relevant occupational and professional groups, including peer-led support and education for GPs, and to staff of nursing homes. The Health Service Executive will develop appropriate training courses for family and other informal carers in keeping with the priorities highlighted in the National Educational Needs Analysis completed by the Health Service Executive in 2009 and Dementia Skills Elevator 2014.

Research and Information Systems. Information on dementia is not currently being recorded on some national databases. This has implications for the

provision of evidence-based services and supports and, for ensuring that resources for people with dementia are targeted effectively. Currently, there is no epidemiological study in Ireland which can be relied upon for providing accurate numbers on the prevalence of dementia in the Irish population. The characteristics and needs of those with dementia or their carers, and the full range of services and treatments that people with dementia are receiving are also unrecorded. The Health Service Executive will ensure that data from the SAT is factored into research to inform dementia care in Ireland, as well as encouraging the recording and coding of dementia in primary care and the development of practice-based dementia registers. The recording and coding of a primary or secondary diagnosis of dementia in hospital records and charts will also be improved to ensure that admissions, re-admissions, lengths of stay and discharge for people with dementia are captured on HIPE (Hospital In-Patient Enquiry).

7.10 DUBLIN CITY UNIVERSITY: DEMENTIA SKILLS ELEVATOR PROGRAMME

The programme aims to build a more educated workforce, incorporating dementia leaders and dementia champions, spread across a wide range of health, social care and community settings, with primary care seen as a priority. The programme is expected to result in an enhanced capacity to plan, implement and evaluate best practice dementia services within the health and social care system. This will lead to improvements in the lives of people with dementia and their carers through enabling people with dementia to age in their own place and time.

The Dementia Skills Elevator is a collaborative effort to complete a thorough dementia education needs assessment and to test and demonstrate specific selected programmes in priority areas. The Elevator is a flexible system of up-skilling, whereby people can step on and off a dementia skills ladder. Elevator focuses on ability (rather than disability) and takes a person-centred approach to dementia care. The main aims of the programme are to improve quality of life

for people with dementia, by utilizing the appropriate skills within local communities to deliver person-centred care that respects the personhood of people with dementia.

Elevator provides dementia awareness training on three levels: I) general dementia awareness training; II) essential skills training for key public-facing workers; and III) dementia awareness training for healthcare workers (including both the public and private sectors). This dementia awareness training will, over time, equip recipients with essential skills to engage and communicate appropriately with people with dementia.

The programme also delivers psychosocial skills training for family carers and health and social care professionals, including validation and related skills, cognitive remediation and multisensory stimulation therapy. Training on ethical care decision-making is a key part of the programme. So too is the establishment of a service leaders and managers awareness programme to enhance knowledge and understanding of dementia among management in the healthcare profession. Elevator is also engaged in collaboration with the ICGP to design and deliver dedicated dementia training for I) GPs; II) practice nurses; III) community pharmacists; and IV) health & social care professionals.

7.11 AGE FRIENDLY IRELAND: OLDER PEOPLE REMAINING AT HOME (OPRAH)

The primary objective of this grant is to support older people with all forms of frailty and disease to remain at home, while increasing their quality of life. The project offers supports to older individuals with low or medium levels of dependency who wish to remain at home in their local communities, with a strong focus on early prevention and intervention. A secondary objective of the project is to reduce multiple hospitalisations and premature entry into long-term care. OPRAH aims to test the feasibility of creating a needs-based and person-centred home-care support system within the Irish social care system. The programme includes all older people wishing to

remain in their own communities and is not exclusive to people with dementia.

The OPRAH project seeks to develop a new approach to providing services to older individuals that involves individualised care plans and specialist co-ordinated services, thus moving towards a needs-based, person-centred, home-care support system. The OPRAH project is consistent with the dementia initiatives managed by Genio; however, OPRAH has a broader scope, offering supports to older individuals with all forms of frailty, not just dementia. The impact of the project will be measured by the extent to which: frail older people are supported to remain in their homes for longer; the number of hospital and nursing home admissions reduced; the extent to which the quality of life of participants is maintained and improved and the needs of the carers are met; and the cost savings that can be realised through this approach.

7.12 TRINITY COLLEGE DUBLIN: CREATING EXCELLENCE IN DEMENTIA CARE

The Creating Excellence in Dementia Care report was commissioned by Atlantic to build a research evidence base in dementia services in Ireland to pave the way for an integrative and relevant National Dementia Strategy. The objective of the grant was to accelerate the development of a National Dementia Strategy by supporting collaborative evidence-gathering research. A major objective of the grant was to review current and future demographic trends in Ireland of those aged over 65 and estimate the prevalence of dementia in the Republic of Ireland. The report also calculated the main economic costs of dementia care, reviewed current service provision and forecasted future demand for services based on estimated prevalence rates. It also conducted a review of best practice in dementia care nationally and internationally. Led by Professor Suzanne Cahill, Creating Excellence in Dementia Care was very important in the development of the National Dementia Strategy and much of the material in the Strategy is reflective of the analysis contained in the report.

7.13 TRINITY COLLEGE DUBLIN: LIVING WITH DEMENTIA (LID)

Living with Dementia was a research programme which ran from 2007-2013. The main objective of the grant was to cultivate a programme of psychosocial research that would contribute to the development of timely, responsive and accessible interventions to support the individual diagnosed with dementia and their family caregiver. Programme goals included: the recruitment and supervision of young academics to develop research competencies in the area of psychosocial interventions in dementia care; improved collaboration between practice centres, such as, day-care centres, nursing homes and hospitals and academic research and training centres; and an increase in Ph.D. students in the field of dementia and social care with the ultimate goal of improving practice outcomes, including the dignity and independence of those affected by dementia.

The LiD project was designed to tackle the negative connotations associated with dementia which lead to the marginalisation and discrimination of some people with dementia. Prior to AP's investment in this area, dementia in Ireland tended to be seen as a cognitive brain disorder and viewed through a bio-medical lens, there was a distinct absence of research focus on critical topics such as the subjective experience of dementia, personhood, selfhood, citizenship, rights, autonomy, stigma, person-centered care and quality of life. The approach taken was to increase knowledge in the area by training early career researchers in psychosocial methodologies and impacts, thereby fostering innovation and best practice in relation to personhood objectives. The focus was on capacity building and knowledge enhancement in the dementia care sector, particularly in relation to psychosocial interventions. One of the longer term goals was to make person-centred dementia services part of normal practice where people with dementia are regarded as full citizens and are not the subject of negative attitudes.

7.14 TRINITY COLLEGE DUBLIN: DEMENTIA SERVICES INFORMATION AND DEVELOPMENT CENTRE (DSISC)

The DSISC was established in 1998 as a National Centre for Excellence in Dementia before the entry of Atlantic into the Irish dementia field and is committed to best practice in all aspects of dementia care. The Centre was initially funded by the Department of Health and subsequently received funding from Atlantic through a grant from its Northern Ireland office – hence it is outside the financial scope of this review. The Centre engages in three core activities. The first is the provision of educational courses and training days to staff providing services to people with dementia in a range of care settings. Over the years, through its workshops, extra-mural classes and seminar series the DSISC has trained thousands of health service professionals and has had a major influence on practice in dementia. The Centre has produced training videos and a multitude of other relevant training materials and information packs on dementia. The second is an information and consultancy services which provides a range of information on dementia and dementia related issues, including design for dementia in all types of care settings. The final core activity undertaken at the Centre is research which contributes to the development of timely, responsive and accessible interventions and best practice models for people with dementia. The Centre has been an enduring and important agent for change within the Irish dementia field and a trailblazer for the development of the social model of dementia in Ireland.

7.15 TRINITY COLLEGE DUBLIN AND UNIVERSITY OF CALIFORNIA AT SAN FRANCISCO: GLOBAL BRAIN HEALTH INITIATIVE

The Global Brain Health Institute (GBHI), co-led by TCD and the University of California, San Francisco (USFC), is a major international investment by Atlantic in the area of brain health which was announced in 2015, after the fieldwork for this evaluation was completed. Hence, the grant is not part of this review. However, a brief summary is provided here

to show the global ambition of Atlantic in regard to addressing big questions in dementia, including providing the long-term capacity and leadership for sustainable responses to dementia challenge in various geographical regions. The grant aims to tackle the increasing incidence and prevalence rates of dementia worldwide by encouraging and enhancing an academic and practical focus on brain health. The overall objective of the grant is to develop methods and expertise internationally to tackle the growing issue of dementia in the coming decades by developing a cohesive, interdisciplinary, international team of leaders and experts in dementia. The programme is designed to train dementia leaders in medicine, public policy, social science, journalism, law, business and the arts.

The grant will provide training to 600 early-career professionals in dementia over a 15 year period in the US, Ireland and across the world, all of whom will have demonstrated the potential to engage in interdisciplinary enquiry and the ability to adapt to different cultural contexts throughout their careers. The grant supports a 2-year Fellowship programme and a Scholarship programme ranging between 1 month and 12 months.

GBHI's Fellowship Program has been designed to train and support individuals from diverse fields, including, but not limited to, clinicians and scientists (e.g., geriatricians, psychiatrists, nurses, social workers, epidemiologists, health economists, neuroscientists, policy specialists) but also to include lawyers, journalists, artists, and others. Successful applicants will demonstrate excellence in past activities and strong regional support that will allow successful transition back to their home country. The Fellowship Program provides customised training and mentoring over a two-year period. The aim of the programme is for participants to emerge with an independent clinical, policy or research career. Fellows will be diverse in their origins and objectives. Some will conduct dementia research; others will deliver health and social care programme; all will be expected to change policies and practices in dementia. Trainees will be chosen on their potential to become transformative leaders in the dementia field and will possess GBHI's core values of equity,

opportunity, scientific curiosity and respect. The training programme will provide participants with the skills required to become regionally effective in brain health and dementia care and to implement new models of care. The fellowship programme is geared towards an international audience with applicants from the US, Ireland, Cuba, Latin America and the Southern Mediterranean in the initial call. The call will be extended to include applications from Asia, Africa and Australia in the second wave.

GBHI's Scholarship Program is a shorter duration program designed to train people from broad disciplines including health professions and scientists, but also the community (e.g., journalists, artists, writers, policy makers, entrepreneurs, technologists, anthropologists, ethicists, lawyers). All will be passionate advocates for older people, both healthy and impaired. Scholars should demonstrate the drive to learn about ageing and diseases of ageing and lead change throughout their careers.

According to The Atlantic Philanthropies President and CEO Christopher Oechsli (2016) the overall aim of both programmes is to support people with the *"courage, conviction and capacity to produce systemic change that promotes fairness, opportunity, dignity and inclusion, benefiting particularly those who face unfair disadvantages and vulnerabilities."*

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8. COHERENCE AND DIVERSITY

8.1. THE KEY THEMES

The previous chapter has described the various grants in dementia supported by Atlantic. It is clear that the grants cover a wide range of activities across different areas, addressing a multitude of issues relating to dementia, sometimes converging, others times not. The qualitative analysis has succeeded in distilling the various activities supported by the grants into five

major themes within dementia: brain health; advocacy and awareness; education and training; measurement, research and evaluation; and service transformation, as illustrated in Figure 8.1. We interrogate these themes more systematically in this chapter, focusing on impact and outcomes at both individual and societal levels.

Figure 8-1:
Key Themes



8.2 SERVICE TRANSFORMATION

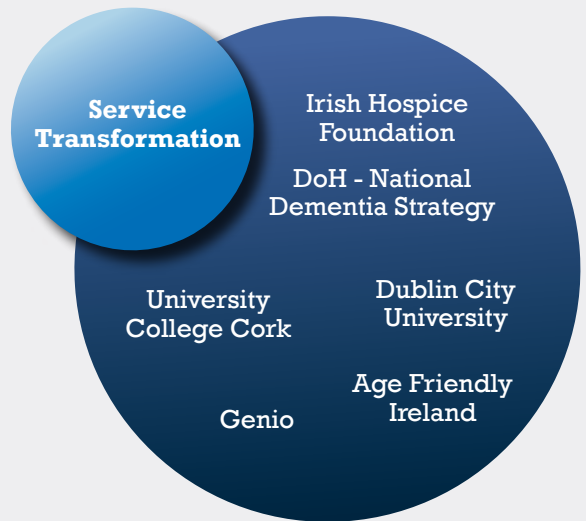
The biggest tranche of Atlantic's investment has been dedicated to transforming services for people with dementia in Ireland (Figure 8.2). Keeping people with dementia living in their own homes has been central to Atlantic's investment strategy for dementia. Innovation in service delivery is also important for Atlantic, particularly support for person-centred care delivered in the home of the person with dementia. A key investment in this space, jointly funded by Atlantic and the Health Service Executive, has been a set of personalised care interventions in four sites, instigated by Genio, an organisation Atlantic helped launch that specialises in human-service innovation. This initiative has involved the reorientation of care and services for people with dementia away from a primarily medical, institutional model toward personalised, community-based services supports for people living at home. A subsequent grant has supported an integrated care pathways project focusing on the transition between community-based care and admission to acute hospital. The HSE-Genio project to develop integrated care pathways in the acute hospital sector for people with dementia is based on the concept of transferrable learning and is designed to improve the overall experience of people with dementia in acute care.

The HSE-Genio dementia programme continues to impress in terms of its ability to deliver individualised, person-centred care to people with dementia (O'Shea and Murphy, 2014⁶; O'Shea and Monaghan, 2015⁷). There has been significant improvement in the integration of the four community-based demonstration projects with existing formal provision within the Health Service Executive. Some projects, for example those in Stillorgan-Blackrock, are better integrated than others; this is mainly due to the community-care origin of that project and its strong relationship to the Health Service Executive from the outset. Similarly, in Kinsale the origin of the project within primary care has made it easier to establish relationships with general practitioners in the area. What is particularly noteworthy is the development of a better understanding amongst existing health

⁶ O'Shea and Murphy (2014) Genio Dementia Programme Evaluation, Year 1 <http://www.genio.ie/system/files/publications/GenioDementiaProg-EvaluationYear1.pdf>

⁷ O'Shea and Monaghan (2015) Genio Dementia Programme Evaluation, Year 2 http://www.genio.ie/system/files/publications/Genio_Supported_Dementia_Projects_-_Report_on_the_Second_Year_by_E_OShea.pdf

Figure 8-2:
Service Transformation



and social care providers in all four sites of the social model of provision underpinning the work of the various projects. This has, in turn, led to a more nuanced appreciation amongst all stakeholders of the importance of individualised supports for people with dementia and their family carers.

The public awareness of dementia has increased significantly over the three years of the project in each of the sites. Some of this awareness has happened organically due to the myriad of social relationships that have been formed as a result of the development of the various Genio consortia. The consortia have facilitated an increase in awareness through their internal and external relationships with mainstream social care provision and through their members' direct engagement in civic, cultural and economic life. Bringing so many different groups together has had a positive effect on the dementia narrative within local communities. That narrative must, however, have a language that is firmly based on personhood and person-centred care. Developing that common language is an on-going challenge that requires patience, conviction and measurement in order to develop a societal understanding of the potential and

capabilities of people with dementia within the social care system and beyond.

Person-centred care is at the heart of the Health Service Executive-Genio project. Individualised supports that reflect the needs and preferences of people with dementia and their families are now evident across all four sites. There has been significant progress in moving the existing care system to a personalised, individualised model that respects and encourages personhood, autonomy, empowerment and social connectivity for people with dementia. People with dementia are being asked what they need, want and value. Dementia is seen as both a medical condition and a social issue. Consequently, holistic models of provision are now much more acceptable and prevalent in the four sites. The Genio approach is also influencing mainstream thinking as the formal system becomes more familiar with the social model of dementia across the four sites, leading to the development of more integrated, embedded and transformative models of care.

The feedback from participants in the HSE-Genio project has been uniformly positive. Attitudes are changing as evident from this comment from a member of the public in Stillorgan-Blackrock:

“They are just like any of us - just because the man has dementia, it doesn't mean that he stops walking, or going to mass or doing any of the things he always liked to do” (Local citizen in Stillorgan-Blackrock)

The following quote from the daughter of a woman with dementia in Mayo illustrates the benefits of an individualised supports service:

“Mum is getting on great, having her hair done at the hairdressers with the help of a support worker. Just very normal living.” (Daughter of Person with dementia)

The Health Service Executive-Genio project has also successfully worked to marry the interests of dementia support workers with that of the people with dementia under their care. For example, in Mayo, a support worker who was raised on a farm was paired with a gentleman with vascular dementia who had farmed all

his life and now missed that life.

Michael's family were about to sell the last of his 3 cattle, but held onto them once they realised that the support worker was taking their dad to see the cattle during her visits and that they were also walking the land and feeding back little jobs that needed doing. They noticed an improvement in their dad because of this naturally paired activity. This is the response of his family carer,
“He knows when to expect her...he has his coat and hat on and his wellies by the door...it's great”

Older People Remaining at Home (OPRAH) is a research programme established to determine the main deficiencies in care and support as experienced by frail older people wishing to remain in their own home into old age. There are approximately 130 participants in total, being served by an OPRAH coordinator in three urban sites and one rural. The role of an OPRAH coordinator is multi-faceted and can be described as advisor, broker, care coordinator and advocate. Some of the main concerns highlighted by people in the community are in relation to social isolation, psychosocial support and the decision criteria for homecare package eligibility. Risk is the biggest concern for family members regarding an older relative remaining at home.

One of the key impacts of OPRAH is highlighting the needs of individuals remaining at home and working with external agencies to provide these services.

For example, Angela and many of her friends live in a suburb of Dublin and were travelling long distances once a week to attend a Warfarin Clinic in the city centre. The OPRAH coordinator identified this as causing undue stress for these individuals and organised a Warfarin Clinic in the local community centre. Angela and her local community can now have their bloods tested locally, eliminating the need to travel long distances.

The OPRAH project put individuals in touch with specialist services as issues arise, such as advocacy or befriending services. OPRAH coordinators also assist people with dementia and their carers' access services and advise them as to their entitlements

Paddy, 78, was spending all day at home alone, in an isolated rural area with the closest neighbour one mile away and the nearest village four miles away. Paddy was assessed by an OPRAH coordinator and identified as being at a high risk of falls, as well as having considerable cognitive issues. He was able to wash and dress himself but needed help with showering and said that he felt very lonely and isolated since having to give up driving for cognitive reasons.

Based on the assessment, an individualised care plan was drawn up. Paddy was referred to occupational therapy and physiotherapy to address his mobility issues and was given a new prosthesis which reduced his number of falls. A home environment safety assessment was also carried out and an increase in home help hours was sanctioned. A Cadex medication reminder watch, pendant alarm and an in-house alarm system to alert his daughter if needed during the night were also supplied. Paddy also now attends a local day-care service two days a week. This has made a very significant difference to his life and, according to his daughter and staff from the unit, *“he has blossomed and is now bringing in quizzes and newspapers for others that attend to do. He also benefits hugely from the twice weekly physiotherapy that he is now receiving.”* Paddy states that he *“looks forward to it (going to the day centre) and loves meeting the other people there.”* The difference it has made to his quality of life *“has been huge.”*

The research programme associated with the OPRAH programme produced an interim report which highlighted separation of care between medical and social as an issue for people with dementia. One participant describes their experience as:

“I think everybody’s in their own little silos and they don’t know if the information is relevant. Nobody is seeking that overall holistic thing. Somebody’s looking at the medical side, somebody else is looking at, you know, the dementia side. (Respondent 13)” Normand and Roe, (2015, p.9).

A major element of the National Dementia Strategy is the roll-out of intensive homecare packages (IHCPs) for people with dementia. This is being delivered through partnership between Genio and the Health Service Executive supported by an investment of €9.3

million from Atlantic. It is expected that as a direct result of this funding up to 500 people with dementia and their families will receive additional resources in eight selected sites around Ireland. While the initial focus will be on facilitating the discharge of people with dementia from acute hospitals as quickly as possible to their own home, there will be an increasing emphasis on keeping people out of acute care in the first instance, through earlier intervention in the community. An independent evaluation of the new home care packages is included as part of the project to establish the effectiveness of the scheme, but it will be some time before that evaluation is complete.

However, there is some early evidence that the IHCPs are making a real difference to people’s lives in the community. Take for example the following case study supplied by the National Dementia Office.

Fred, who is married with two children, was admitted to Hospital in January, 2016, following a fall in which he sustained a fractured left hip which required surgery. He was diagnosed with early onset dementia five years ago. His post-operative recovery and rehabilitation was difficult due to post-operative delirium, Alzheimer’s disease and agitation. Before he was diagnosed, Fred worked as a manager of a processing plant. He was very sociable and was very involved in local GAA*, which was his main hobby.

Fred had previously been assessed and recommended for long term residential care but both Fred & Julia, his wife, had refused this as Julia wanted Fred to remain at home. In his Care Needs Assessment (CSARS) Fred obtained the maximum dependency score and required full nursing care and was considered a high risk of falls and development of pressure sores. Fred could communicate verbally, but could not retain information. Whilst he had considerably reduced mental capacity, he could still articulate his needs and preferences, one of which was to go home. Due to restlessness and safety risks, he required 24 hours 1:1 special care in the hospital. However, his wife who had been his full time carer had her own care needs and could no longer care full-time in the home. Concerns were also raised regarding the effects on the school-going children of him returning to live at home with significant care needs.

A multidisciplinary assessment was carried out in the hospital and a schedule of care was developed for Fred to facilitate discharge, meet his care requirements and also support his wife and family with the caring role. Fred was discharged eight weeks after his admission with an Intensive Homecare Package consisting of: two paid carers providing personal care three times per day, seven days per week; three overnights for paid carers per week; four in-home respite hours per week with a carer who had an interest in the GAA; Nursing/Therapy-PHN/ two visits per week and an OT assessment.

Before Fred was discharged, the social worker had referred the family to their local Alzheimer Society service who provided support and information to the family, in particular age appropriate booklets about Alzheimer's disease for the children. The four in-home respite hours were used watching GAA matches that had been recorded, incorporating discussion of the games. Fred's needs were reviewed monthly by his Primary Care Team and care adjusted as required. Fred has availed of respite in the local Community Nursing Unit and he has had no acute hospital admissions since his discharge. In the absence of an Intensive Home Care Package, it is certain that Fred would now be in long stay residential care and not residing with his family. Fred consistently articulates that he is happy at home and his wife reports vast improvements to family life.

Ensuring that IHCPs get to more people with dementia, at the right time, will ultimately be the real measure of the success of the National Dementia Strategy.

8.3 ADVOCACY AND AWARENESS

Atlantic has funded a number of projects in the area of advocacy and awareness for dementia both among the general public and for people with the neurodegenerative disease (Figure 8.3). Research has shown that accentuating the voice of the person with dementia encourages care providers to tailor support more effectively to the needs and preferences of the individual, thereby promoting person-centred care (Cantley and Steven, 2004b). When that voice is weak or non-existent, advocacy may be necessary to ensure that people with dementia get what they need and deserve.

Cheston (2000: p.475) define an advocate as: *“someone who either speaks on behalf of a user, or facilitates the views of the user themselves and thus acts as an intermediary between the person with dementia and the professionals, seeking to ease the process of communication between them.”*

Providing advocacy to people with dementia recognises they have the same rights as other citizens. In practice, however, it is recognised that providing advocacy to people with dementia can be time-consuming, costly and complex (Cantley and Steven, 2004a).

Figure 8-3:
Advocacy and Awareness



The main grantee in the field of advocacy in Ireland is the Alzheimer Society of Ireland. Advocacy in the ASI is divided into three sections: public awareness; dementia friendly communities; and politicising dementia.

The ASI see its main objective as raising awareness of dementia among the general public as a means to increasing funding for the disease and developing enlightened public policy for people with dementia. Increasingly people with dementia are becoming directly involved with advocacy (Clare, 2003, O'Connor et al., 2007). Following practice internationally, the ASI, in recent years, have formed a group consisting of people with dementia called the “*Dementia Working Group*” and a group for dementia carers called the “*Dementia Carer’s Campaign Network*.” Members of the Dementia Working Group make regular appearances on national TV and radio advocating for people with dementia, creating a better understanding of the disease among the general public and helping to reduce stigma associated with dementia.

“The Irish Dementia Working Group, are known and are being asked more and more to speak at conferences and events and to be involved in research projects. They are embedded in advocacy work

within the ASI but it’s spreading out in terms of other stakeholders as well which is really nice because I see the Irish Dementia Working Group as a resource for anyone working with dementia in the country. It just happens that we are the coordinators and supporters of that group,” Tina Leonard, ASI.

Ronan Smith’s story is a good example of how the Dementia Working Group is helping to transform attitudes to dementia in Ireland. Ronan’s first encounter with Alzheimer’s occurred with his father’s experience of dementia and death from the condition in the 1980s. Thirty years later dementia re-entered his life with a diagnosis of “*probable, early stages of Early-On-Set Alzheimer’s*.” Ronan re-connected with The Alzheimer Society of Ireland, and joined the Irish Dementia Working Group not long after his own diagnosis and is now its Vice-Chair. Ronan was encouraged to become an advocate again and to speak openly about his condition. This work has empowered him and is something he is now very committed to: “*the feeling of wrenching some good from a bad thing is rewarding and the activity and social contact that arises is stimulating and therapeutic*” Ronan Smith, Irish Dementia working Group.

Ronan has appeared on television, on radio and in print, speaking about the condition in order to counter-act the stigma that still attaches itself to the disease, and to spread the message that it is possible to live well with dementia if the proper supports are in place for everyone connected to the disease. Ronan wants to confront and unmask the stigma, the fear that surrounds it and, through his work with The Irish Dementia Working Group, he has been given the platform to do so. Regarding his disease Ronan states “*It’s just another disease, like so many others: it just needs to be seen for what it is, and not feared. So I unhesitatingly and freely ask for compassion and understanding from others whilst demanding my basic human rights to respect and dignity.*”

The visibility of the Dementia Working Group in the national media is having a very real effect on how the general public view dementia and on attitudes within the national media to reporting on dementia and dementia related issues.

“... [Having an established Dementia Working Group] changes how we approach things. You talk about the actions we have done under each category, but I think embedding that gives us a new focus on the abilities and dementia and personhood and all of that, so that is a really big thing.” Tina Leonard, ASI.

The establishment of the Irish Dementia Working Group has had a real impact on the lives of people with dementia and has helped to raise awareness of the stigma attached to the disease. The ASI led a campaign using a range of different communication methods, such as videos, factsheets, brochures and booklets to increase awareness on dementia and reduce the associated stigma. The voice of the person with dementia played a central role in the campaign, both in planning and execution, with major inputs provided by the Dementia Working Group and the Dementia Carer’s Campaign Network for the materials and messages used in the campaign. ASI’s presence in the media has increased hugely as a result of this approach.

Tina Leonard of the ASI explains “The national media coverage, looking at the first six months of 2015, for example, it was up 123 per cent on the same six months last year and last year was up 132 per cent on the previous year ..., you know, and that’s broadcast and print and then if you look at Facebook and Twitter, Facebook over the past two years 63 per cent increase and Twitter has experienced a threefold increase. What you see when you do campaigns is the Facebook going up, the calls to the helpline going up ... there is now a bigger amount of people calling on their own behalf which is interesting and quite new.”

“The stories, the personal stories get the most hits on Facebook.” Tina Leonard, ASI

The type of articles being run in the national print media has also changed to promoting a different and a more positive narrative around dementia than was traditionally the case⁸. Referring to a recent piece in a national newspaper focusing on dementia, Tina explained that there is a new approach by the media:

“They wouldn’t have done the piece without [including people with dementia] and they were assuming that there were people there who would do [it]... It’s just interesting to see because what we, me and my team, really want to do now is move away from a medicalised narrative. We have to work on the sustainability of this and it’s development, because there is so much they could do and there is so many more people we could involve” Tina Leonard, ASI.

Campaigns are now based on people with dementia and are very much about getting the person with dementia out there and making them visible. National media outlets have gone from not wanting somebody with dementia to wanting people with dementia visible and involved in the interview.

Dementia Friendly Communities (DFC) is another initiative run by the ASI across seven sites nationally. Collaboration with other ageing and dementia stakeholder organisations is a major element of this work. The focus is on providing opportunities and activities for people with dementia and support for carers. The success of the programmes are often very much down to the people involved on the ground and collaboration with other projects.

“... We have brought lots of other projects together ... age friendly communities, all the HSE-Genio sites, individual projects like West Cork Arts Centre, the National Concert Hall came to the last one, all people who are engaged in dementia specific projects.” Tina Leonard, ASI.

The ASI give small awards “Azure,” to businesses and organisations that make an effort to make their space more dementia friendly. Links with organisations are also being formed to ensure continuity and sustainability for the DFCs, both as a direct result of Atlantic funding and through other means.

⁸A practical example of the changing narrative around dementia in national media can be found at: <http://www.irishexaminer.com/ireland/i-have-learned-to-live-with-alzheimers-but-it-does-not-define-me-says-fighter-helen-391523.html>

It is hoped the National Dementia Strategy will assist in bringing together all the different DFC initiatives to ensure cohesion, integration and sustainability. Currently the DFC initiative is quite diversified and is not always coherent across the sites. Given the national coverage of the National Dementia Strategy, it has the potential to bring the dementia friendly message together through raising awareness about the importance of engaging with people with dementia within their local communities.

As part of the DFC component of the grant, a number of information sheets have been developed which aim to educate retailers and the general public about dementia friendly language, key messages about dementia, a breakdown of the key elements contained in the National Dementia Strategy⁹ and a guide for retailers and many other service providers on how to support people with dementia¹⁰. The ASI also put together an information sheet describing the early signs and symptoms of dementia and how to go about getting a diagnosis¹¹. The ASI is collaborating with the Elevator programme at DCU towards having a comprehensive set of leaflets and supports available by the end of the project on how to promote the DFC project.

A baseline evaluation of the ASI's activities, conducted at the initial stages of the Atlantic investment, recognised a lack of awareness regarding dementia in political circles. As a result, a key priority for the ASI has been to increase knowledge about the relevance and importance of dementia in the political sphere. A number of activities have been undertaken to raise political awareness of dementia. The ASI have succeeded in mobilising support from all elected MEPs for the European Dementia Pledge. The pledge requires three commitments from the signatories: to join the European Alzheimer's Alliance; to ensure dementia is prioritised in the EU's public health and research activities; and to make MEP's available to their national Alzheimer's Society and to people with dementia from their country.

⁹A breakdown of the key elements contained in the National Dementia Strategy can be found here: [http://alzheimer.ie/Alzheimer/media/SiteMedia/UserImages/Orchard/ASI-NDS-4-Page-A4-\(Feb-2015\)-Web_3.pdf](http://alzheimer.ie/Alzheimer/media/SiteMedia/UserImages/Orchard/ASI-NDS-4-Page-A4-(Feb-2015)-Web_3.pdf)

¹⁰The guide for retailers on how to support people with dementia can be found here: <http://www.alzheimer.ie/getattachment/Get-Involved/Dementia-Friendly-Communities/Dementia-Friendly-Communities/8-retailers-2.pdf.aspx>

¹¹A factsheet on early symptoms and diagnosis: understanding dementia can be found here: http://www.alzheimer.ie/Alzheimer/media/SiteMedia/HelpLine%20and%20Information%20Resources/Info%20Pack%20PDFs/A1_Early-symptoms-and-diagnosis.pdf

Some political highlights associated with the ASI's political campaign in 2015 were: a Dáil debate in which 17 TDs participated; an MEP event in Brussels; two presentations to the Oireachtas and one of the biggest political parties in the country committed to include dementia as a major health priority in their election manifesto.

“Then at the start of this year (2015) we decided to have a general forum... because the National Dementia Strategy was now published we had a major information session in the Dail. One of the opposition political parties invited us in and 22 TD's and Senators showed up which was brilliant. A member of the Dementia Working Group spoke and a member of the National Dementia Carer's Network spoke and they were absolutely powerful” Tina Leonard, ASI.

In addition, Atlantic's funding enabled the ASI to hire a policy officer whose job description is to write policy submissions to the government.

“What you need here is a human resource and that's what Atlantic has enabled us to do, hire a policy officer and that is one fulltime person that makes a heck of a lot of difference”. Tina Leonard, ASI

‘Nothing about you, without you’ is the tagline for Third Age Foundation's support and advocacy service for older people – (SAGE). SAGE advocacy services are available to older people in nursing homes, acute hospitals, community settings, hospices and hostels and to those in the process of transition between settings and services. Through SAGE, six areas have been identified as key to developing a more inclusive and supportive environment for older people: respect, social justice, competence and compassion, accessibility, independence and accountability. The SAGE service includes, but is not specific to, people with dementia.

Through SAGE, advocacy is now increasingly recognised as a national issue in Ireland. The Health Service Executive's social care plan outlined the need for a national advocacy programme while HIQA has recommended the establishment of an advocacy service through the hospital system. A report from the Ombudsman also cited the need for an advocacy

service in the acute care system in Ireland. However, this recognition of need has not yet fully borne fruit through changes in the regulatory framework for advocacy. However, the imminent introduction of the Assisted Decision-Making (Capacity) Act 2015 should help alleviate many issues associated with personal representation. Prior to the Act, there was no legislation underpinning advance directives, which gave rise to practical difficulties especially for people wishing to plan for care at the end of life (Irish Hospice Foundation, 2015).

Recruitment is key to effective advocacy for older people. The problem is finding the right kind of advocate who has the time and the skills to address the issues that arise. Mervyn Taylor from SAGE described the ideal advocate as being able to:

“Help people remain at home through widening and deepening their circle of support.”

Initially the advocacy programme was established by the Health Service Executive in response to a crisis within the long-term care sector. While the original advocate volunteers received a lot of theoretical training in human rights, most were not prepared for the realities of providing advocacy, particularly in a nursing home environment. Practical dilemmas experienced by older people are so diverse that often it requires vast life experience on the part of advocates to address them. The demands on the average volunteer also require a set of specialist skills, particularly in respect of mediation and the law. The investment required in recruiting the right people as volunteer advocates and providing training for them is huge. A good advocate is similar to a social worker, but also needs to be very aware of local supply issues and have some legal skills.

A couple of case studies will show the complexity of advocacy support delivered through SAGE and the importance of a diverse range of advocacy skills. The first example is that of Seán, a single older man living alone in the community.

Seán has a challenging relationship with some of his siblings, who believe he has serious cognitive difficulties and, therefore, want to make him a Ward of Court against his wishes. Seán contacted an Advocacy Provider within SAGE, as he required legal support to challenge the Ward of Court procedure. The Advocate took time to develop a relationship with Seán, so that she could fully reflect his wishes and preferences in a mutually agreed advocacy support plan. With her support, Sean was able to create an enduring power of attorney, which would come into effect when he reached the stage that he was unable to make decisions for himself. Seán was more confident in navigating many legal and clinical meetings with the support of the Advocate and thus felt fully empowered in this process.

In order to implement an effective and coherent advocacy service it is important to first have an idea of the issues facing the individuals being advocated for, in order to tailor the skillsets of the advocates. SAGE are of the view that an advocacy service cannot deal with people with dementia in isolation, because if you take away the dementia the person is still old and experiences all the issues associated with it. SAGE advocates are liaising with the Wards of Courts office, but also in issues relating to family dynamics, resources and the law, which are the most common issues that arise in dementia care. Developing the proper skill-sets for advocates in these areas remains an enduring challenge. SAGE has also published quality standards for the services they provide, so that they can be held accountable for these services. These issues are all part of ensuring proper governance for advocacy provision, which is important for the operation of an effective service.

Another example of the impact SAGE has had is the story of Philomena who originally got in contact with her local SAGE Advocate through the Director of Nursing in a long-stay facility where Philomena's husband, Henry, had been admitted in the previous week.

Philomena was very distressed that she could no longer take care of her husband at home. They had been married for 50 years and as she stated *'he had always been there for her'*. They had no children and so had little family support and they *'really lived for each other as a couple'*. As Henry's dementia symptoms escalated, Philomena found it difficult to cope and found it hard to talk about it to anyone, as she felt that she would be *'letting Henry down'*.

She was advised that Henry's needs would be best met in long-term care and a bed came up in a local nursing home very quickly. Philomena had to make a decision over a weekend, which did not allow her to fully process the move to long term care. The 'Fair Deal' process was alien to her and left her uncertain as to what would happen if she postponed making a decision. An Advocate from SAGE met with Philomena and encouraged her to talk about her feelings, which she did for over an hour – bringing about a huge sense of relief as she had never talked about her problem with anyone else before. Once this conversation was over Philomena and the Advocate went to visit Henry and he seemed to be significantly more content than he had been for the first few days after he arrived. The Advocate then helped Philomena complete the 'Fair Deal' form and explained what was involved. Philomena is now speaking to the families of people with dementia herself through a family forum providing support and advice on the transition to long-stay care. She says that she *"is in a much better place now" (emotionally) and Henry is content in his new surroundings"*.

The "Think Ahead" programme, commissioned by the Irish Hospice Foundation, was originally aimed at the general public and encourages people to think about care and supports at the end of life. As part of the Atlantic programme, the Think Ahead project will be adapted for use with vulnerable adults, such as people with dementia, and those who might not have the same level of literacy or need an advocate to engage in advanced planning. The main objectives of the Think Ahead programme are to increase public awareness and interest in end-of-life care and advance planning by providing a service that's there for people when they want to engage with it. This raises the question, when is the right time to have a discussion on end of

life with a person with dementia, which, according to Marie Lynch of the Irish Hospice Foundation is:

"When the person wants to talk about it. That is my personal opinion. And then if I was doing it right and I had the right assessment tools I would be enabling the person to have those conversations when the person wanted ... it is very personal."

A study is currently being undertaken to establish the feasibility of adapting the Think Ahead form to people in nursing homes. Acceptability is quite high among individuals with stable health states residing in nursing homes. There is recognition of the need for advanced care planning, but stronger links with the Health Service Executive are required to achieve further progress. With this in mind, and with respect to developing a strategic approach for the advancement of advance care planning from a legislative perspective, the Irish Hospice Foundation are collaborating with a national planning group within the Health Service Executive. The collaboration will help incorporate Think Ahead into the structures of the Health Service Executive. However, a main concern highlighted by stakeholders in the interim independent evaluation of the Think Ahead programme is the sustainability of the project in its current form:

"Think Ahead needs a champion and resources to engage with people, ... to do nothing would be disastrous," Weafer (2015)

In addition to adapting the Think Ahead form, the Irish Hospice Foundation have in consultation with the ASI developed four information leaflets for people with dementia on end-of-life issues. These leaflets provide guidance for people with dementia on: how to plan for the future; gain an understanding of late-stage dementia; make sense of loss and grief when a family member has dementia; the grieving process following the death of a family member with dementia. The Foundation are using part of their grant to evaluate how this information can be integrated across different care settings.

Family members especially found the leaflets useful in providing *"good information and support for people," "really excellent, and I found the leaflet really helpful,"* Weafer (2015).

Atlantic also supported the development an advance care directive education programme in UCC. The UCC initiative, Let Me Decide Advance Directive (LMDAD), is led by Prof William Molloy and is an advance care planning and palliative care education programme. It is similar to the Think Ahead project as it empowers people to make explicit their healthcare preferences. A two-year feasibility study for the LMDAD was carried out in three nursing homes in Kerry/Cork (Cornally et al, 2015). Focus groups were carried out with staff in the homes to evaluate the systematic implementation of the advance care programme.

“...we are just negligent to look after people without finding out what their wishes are and I think we have no right to look after people without asking them- give them the opportunity,” Cornally et al. (2015)

The documentation process associated with LMDAD is rigorous and involves an education element for people about choice and end-of-life care preferences. It includes a competency assessment to determine who can understand the process and therefore make valid choices. The project captures preferences regarding transfer to acute care and resuscitation while also educating the individuals as to who makes the choice – the individual themselves or healthcare professionals or family members – and when. Engagement with nursing homes and individuals are key elements to the Let Me Decide project.

Those completing LMDAD must first undergo the Mini-Mental State Examination (MMSE) and another screening instrument developed by Prof Molloy to establish capacity. Following on from the success of this study, the programme is currently being rolled out in long-term care facilities in Kerry and Cork with funding obtained from the Health Research Board (HRB). Included in this roll-out is an examination of the quality of care at end-of-life in long-term care facilities. The nursing homes which Let Me Decide has been introduced have seen a significant reduction in hospitalisations, which has had a positive impact on health care and emergency department use. It has also been very well received by residents in the nursing homes. The project also includes a palliative care educational programme for staff. The Let Me Decide project has also reduced the practice of transferring

dying people from residential to acute care settings. It has also helped to alleviate the stress of children and partners making end-of-life care decisions on behalf of a loved one.

“...We have had a reduction in the number of transfers to acute hospital at the end of life, the staff are happier that they are not seeing dying residents transferred out of their home to a busy ED.” Cornally et al. (2015)

“I have had daughters crying at meetings you know. Because they never knew what their parent wanted and they were reluctant to bring it up with them I think”. Cornally et al. (2015)

It also helps prevent differences of opinion when it comes to family members making care decisions and alleviates stress associated with the situation,

“And the family are aware of [the Let Me Decide form]. The uncertainty and how we are going to deal with the family and they are all going in different directions - it is all done, there is no anxiety, there is no arguing between families.” Cornally et al. (2015)

One of the strands built in to the National Dementia Strategy Implementation Programme is a campaign to raise awareness of dementia, and reduce stigma. There are three main objectives to the campaign entitled “Dementia Friendly Ireland,” one, to build a community in Ireland that is better informed, more supportive and responsive to those who have dementia; two, to support care services, health care workers, community groups, retail and service industries, so that people with dementia are accepted and supported, as needed, to enable them to live as included members of our communities; and three, to increase public knowledge on the lifestyle risk factors for dementia and support prevention.

A systematic review of the literature was carried-out to establish how previous international campaigns to reduce stigma were conducted. In addition, qualitative studies have been undertaken to assess public and stakeholder attitudes and current knowledge of

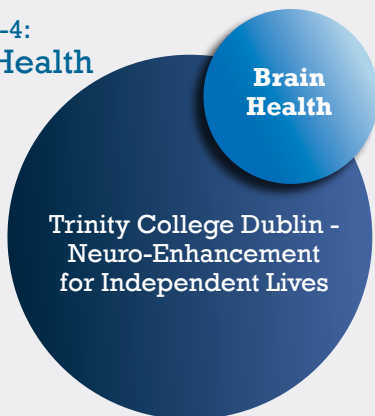
¹²Cornally, Nicola, et al. (2015), 'Evaluating the systematic implementation of the 'Let Me Decide' advance care planning programme in long term care through focus groups: staff perspectives', BMC palliative care, 14, 55-64.
<http://bmcpalliativecare.biomedcentral.com/articles/10.1186/s12904-015-0051-x>

dementia and its risk factors; attitudes towards people with dementia; the impact of a dementia diagnosis on people with dementia and their carers, as well as the impact of a potential diagnosis on the interviewee. The qualitative study included people with dementia, care providers, carers and other dementia experts. The study shows a deficit in knowledge among the general public regarding general understanding of dementia and modifiable risk factors associated with dementia. There is also fear and anxiety associated with a potential dementia diagnosis among the general population. The Health Service Executive will seek to address these issues in their upcoming awareness campaign which will be officially launched at the end of 2016.

8.4 BRAIN HEALTH - PREVENTION AND DIAGNOSIS

A key component of Atlantic’s dementia programme is the importance of brain health in the population (Figure 8.4). Translating that message for the public in a way that influences how people behave in relation to their own health is an important element of dementia policy (Low and Anstey, 2009). Key risks associated with dementia are depression, obesity, diabetes, physical inactivity, cognitive inactivity or low educational attainment, present smoking and hypertension (Middleton and Yaffe, 2009, Prince and Jackson, 2009). Getting people to minimise their exposure to these risks is an important part of any strategy to reduce the incidence and prevalence of dementia.

Figure 8-4:
Brain Health



Brain health, dementia prevention, diagnosis and changing the trajectory of the disease are the main focus of research activities undertaken by the NEIL project. NEIL initially received core funding from Atlantic to establish the programme, with an emphasis on capacity building and developing leadership in the area. To date, the project has exponentially increased the level of funding attracted to the area of brain health both nationally and internationally, with the details illustrated in Table 8.1 below. Success has been achieved at three levels, funding, research and training.

“... Conduct research which is aimed at dementia prevention and cognitive enhancement ... to prevent or delay, we’re interested in changing trajectories ... to enable independent living. The second arm is about the development and evaluation of interventions, ... [for example, the] work that I do with the films ... training up volunteers to go into people’s homes to deliver a meal time relationship-based intervention [this entails social interaction combined with meal times]... And then the third arm is empowerment through education..... But everything feeds into the other. So research informs intervention development, intervention development informs our education. So enhance, enable, education, empower is our tagline,”
Sabina Brennan, TCD.

Table 8-1:
NEIL Programme Outputs

Funding	<ul style="list-style-type: none"> • 22 national and international sponsors
Training	<ul style="list-style-type: none"> • 43 interns and volunteers receiving training in neurological assessment • 14 Masters students • 7 Ph.D.’s completed
Research	<ul style="list-style-type: none"> • 25 research programmes undertaken focusing on delaying dementia, identifying risk and protective factors for dementia and promoting cognitive reserve through development of scalable psychosocial interventions

The core funding from Atlantic provided capacity, leverage and the opportunity to figure out how to make the project grow and be successful. There are major gains from having dedicated staff solely to write research proposals.

“What the Atlantic funding allowed us to do is have a broader, bigger vision, a more coordinated approach but always feeding into goals and that wouldn’t be possible normally because you’re constantly working project to project” Sabina Brennan, TCD.

Having multi-disciplinary research leadership and a coherent and coordinated research effort helps in attracting new funding. The Atlantic grant consolidated neuroscience research as an international brand at TCD and allowed it to grow rapidly in terms of scope and scale. One of the main impacts of the Atlantic investment as identified by the grantee is that:

“There’s so much more could be achieved for a relatively small investment on a small team of people, the right people. It’s many fold the effect that we’ve had.” Sabina Brennan, TCD.

There is a strong participatory element to the brain health programme at NEIL that is viewed as hugely important to the research process. Within the brain health programme, all the results of studies are summarised in a way that is that is accessible to both participants in the research and the general public. NEIL has a number of major successes in relation to participation, prevention and communication. Participation has been enhanced through actively including the general public in research projects, while prevention and communication has been supported through the various peer-reviewed publications and dissemination reports prepared on each of the research initiatives. NEIL prides itself on dissemination of findings and research outcomes through public seminars and social media. Thus far, over 100 public talks have been held on the subjects of awareness, stigma, health literacy, practice advice and ageism. A key belief within NEIL is that for any intervention the core user, in this case the person with dementia, should be involved in the process from the outset up to and including the dissemination process.

The FreeDem Films¹³ are about making sense of dementia and are a good example of what can be done in a creative way to address fears about memory loss and dementia and provide practical advice about brain health. The adoption of the films nationally and internationally is a testament to the success of the programme. Future films are being developed for interactive training to support local organisations and businesses, post offices, banks with a view to educating people in the community about dementia and help reduce the stigma associated with the disease and become more dementia friendly.

“All you need is very simple knowledge to address stigma and to make people not afraid of the customer who comes in and may appear confused, behave out of character or have trouble with everyday tasks or business transactions” Sabina Brennan, TCD.

NEIL has developed a paradigm for dementia prevention and cognitive empowerment for people with dementia which has been highly influential nationally and internationally. Ultimately the project aims to reduce incidence levels of dementia; improve wellbeing, independence and sense of empowerment in older people worldwide; reduce stigma associated with dementia; and change GP practice and brain health behaviours. So far, NEIL has increased and diversified resources for research and capacity building in the area of brain health to ensure long term sustainability; engaged at-risk older people and the general population in educational preventative initiatives; and developed programmes for improving cognitive function and increasing the sense of empowerment among older people. Increased awareness and better understanding of brain health, including awareness of modifiable risk factors for dementia is now a key objective in the Irish National Dementia Strategy. The work of NEIL has had a major influence in helping to prioritise brain health as a key policy objective in Ireland and internationally. That influence will be further enhanced in the coming decades when the GBHI grant reaches fruition.

¹³ The FreeDem Films can be viewed at <http://www.hellobrain.eu/en/>

8.5 EDUCATION AND TRAINING

Education and training for professional healthcare personnel, family carers and the general public is an integral part of Atlantic's investment in dementia (Figure 8.5). An evaluation carried out by researchers in DCU identified eleven key priority areas as needing investment and support through dementia education and training; following consultation with a group of dementia experts, this was subsequently reduced down to seven (Irving et al., 2014). The outcomes of this analysis informed the Elevator training programme at DCU which was grant-aided by Atlantic and developed in conjunction with the Health Service Executive.

Figure 8-5:
Education and Training



The different programmes are developed with different audiences in mind, ranging from health professionals dealing directly with people with dementia to those employed in the retail or banking sector who deal with the general public and only see people with dementia occasionally.

The feedback from the interim, external evaluation of the Elevator project suggests that the programme is reaching a very wide audience (Innes, 2015). Success for this project is achieving a more nuanced understanding of what person-centred care is and

for care providers to translate the dementia care rhetoric into everyday practice, by creating choice and empowerment for people with dementia. The Elevator project works in collaboration with the Alzheimer Society of Ireland and the Health Service Executive, who participate in training and aid the development of online training materials for carers. The value added for the Elevator project is that the training courses gain traction and become embedded in the health and social care system, leading to a general acceptance that these courses are relevant and worthwhile. The strategy is to push people to think about dementia, to be creative in response to the disease and to take into account what their actions mean for the person with dementia, ultimately leading to longer-term behavioural and practice change. The goal of the educational programme is to increase understanding and awareness around person-centred care. According to Dr Kate Irving, Project Director, high level outcomes for the project are:

“A more educated dementia workforce spread across a wide range of health, social care and community settings; more timely and appropriate initial pathway to diagnosis and other supports to enhance primary care services; full capacity to plan, implement and evaluate strength based dementia solutions in a given context, in collaboration with stakeholders.” Kate Irving, DCU.

Elevator also provides a general dementia awareness programme for the public. The aim is to develop familiarity with, and awareness of, dementia, and to tackle stigma in relation to the disease.

One stakeholder who participated in the online training thought it was a “*great concept and thought provoking. I love it - the message is so straight forward. I will show that at the next Alzheimer Café evening.*” Another found it “*short and sweet but very powerful, and effectively expressing a very important message - I love the video.*”

The programme includes a short video presentation, delivered by an individual with early stage dementia. The short 72 second video is freely available on the Elevator website with an associated facilitators' pack to assist with group delivery.¹⁴

¹⁴ <http://dementiaelevator.ie/level-1-general-dementia-awareness/>

Training is provided to service providers in retail, emergency services, transport and financial services.

Tom, a shop assistant found the training videos for the retail training very good, that they really highlighted what to look out for when working in a retail shop, or even when out doing your own shopping and come across someone who may be vulnerable. Evaluating the video Tom said, *“as a shop assistant it was good to watch the video clips on how they dealt with each situation. It opened my eyes to more than just forgetting what they were doing. The shop layout, lighting, floors never occurred to me. It highlights the everyday difficulties that sometimes we are inclined to forget.”*

A training programme for the financial sector has now been developed with buy-in from the Central Bank, the Irish Banking Institute and the Irish Banking Federation and will be delivered as part of staff training for successful engagement with vulnerable people. This training has the potential to be tailored for other organisations and sectors such as the GAA, Bridge societies, the emergency services, transport companies, etc ¹⁵.

The Elevator programme has identified lack of understanding regarding ethical decision making in the health and social care system. Based on this knowledge, an online decision-support platform to offer practical support with everyday ethical care decision making has been developed. The training is provided at two levels: foundation level and a degree level module. The project offers support in *“negotiating difficulties in nutrition, hydration, responsive behaviours, assessment of pain in dementia, continence in dementia, sleep medication, antipsychotic medication, basic communication and carer support,”* (Elevator Programme, 2015).

The foundation level course is tailored for carers in the home and healthcare assistants. It offers guidance on the problems they face and provides support by way of a framework to follow which will help them recognise when an ethical issue arises and how to enlist help. The degree level module provides a framework for ethical decision making in clinical practice with a view to promoting person-centred care, essentially it's about:

“Ethical decision making, about having again this cadre of people who can cascade good nuanced messages of dementia down through the system ... they're all about getting capacity within the system to deliver a more person centred type of care.” Kate Irving, DCU.

Dementia awareness training is also provided for health and social care workers (including both the public and private sectors) through the expansion of the current Health Service Executive's dementia awareness programme. The 3-day (11 modules) educational dementia programme provides participants with the knowledge, skills and attitudes required to deliver high quality, person-centred care to the person with dementia and their carers. This programme equips attendees with essential skills to engage and communicate appropriately with people with dementia. Psychosocial skills training has also been developed with two levels, a basic level for family and carers of people with dementia and the advanced training which is targeted at healthcare professionals. The aim of this training exercise is to increase awareness of dementia, to be able to look past the disease, to take the person and their preferences into account and understand certain behaviours and the potential causes of adverse behaviour. Materials addressing self-stigma for people with dementia and their carers have also been developed, including a video that has been viewed over 4,000 times.

A training programme tailored to GPs was developed and rolled-out in conjunction with the Irish College of General Practitioners (ICGP). Evidence from previous studies suggests a low level of understanding with respect to person-centred care in dementia among GPs in Ireland. GPs tend to emphasise the medical model of care over a more holistic approach, which is now widely recognised as the better suited model of care for persons with dementia (Taft et al., 1997, Kitwood, 1997, Buron, 2008, Gilliard et al., 2005). In breaking down person-centred care, each person is considered to be different and there is no one-size-fits-all model of care.

¹⁵ <http://www.elevator-pst.com/#>

“If you meet one person with dementia, you have met just one person with dementia,” Kate Irving, DCU.

The Dementia Champions programme builds knowledge, expertise and leadership in dementia care. On a practical level, as part of the dementia champions training, each student is required to set up and implement a change project in their environment. The projects range in setting from community to hospital and the aim is to impact directly on people with dementia. To date the projects have included: setting up memory rehabilitation groups; dog therapy for dementia; improvement of staff awareness of the concept of ‘mental’ bedsores, improving communication between the ASI and Primary Care Teams. Each project directly impacts the lives of between 10 and 15 people with dementia; to date approximately 800 people with dementia have been directly affected by the programme. The aim is to build the momentum and leadership through training by deploying a cadre of Dementia Champions to act as change agents within their settings. Champions work in collaboration with managers/services to develop and enhance structures/processes to support a person-centred culture of care delivery to people with dementia.

All of the courses are delivered by locally trained facilitators, ensuring that geographically each county has access to a programme by identifying appropriate hotspots for delivery. Facilitators are sourced by encouraging the most enthusiastic participants in the basic training course to complete the Dementia Champions training. The ultimate goal is that the basic level of training will be delivered to all health and social care professionals interacting with people with dementia in Ireland. However, one of the real difficulties within the project remains achieving national coverage. To overcome this, the Elevator project is undertaking a national tour whereby a bus providing training will visit different areas around Ireland. The training programme has had real traction within certain communities, but the task now is to reach universal coverage.

An “Elevator Award for Innovation in Dementia” was established as part of the Dementia Elevator project. The aim of the award is to reward an initiative or

project that contributes in a meaningful and significant way to the everyday lives of people living with dementia. The successful applicant receives € 1,000 in prize money to help develop a dementia related project or expand an existing project in a novel way.

The winners of the 2014 Elevator award were “The Kildare Past Times Choir”. The choir was already established, but was in need of a boost to expand its operation. Since winning the Elevator prize, the choir has made a huge difference in many lives of people with dementia and their carers. Speaking about her involvement with the choir, Peggy, who has dementia, told a national newspaper that *“I’m as happy as can be, when I’m in the choir with the girls, and the men are nice too,”* Sunday Independent, 2015.

The Elevator programme has close working links with both the IHF and the ASI. The links help to avoid unnecessary duplication and supports training and educational campaigns that complement and enhance each other. For example, the training in everyday ethical care decision-making offered by the Elevator programme was developed in consultation with the IHF and ASI. The ultimate goal of the Elevator programme is that the different training courses become embedded as part of the standard training for staff across different sectors. As described by Kate Irving, DCU:

“I think if each of the educational options found a life of its own and got momentum, got traction ... you just offer the education and people take it up because now it’s visible and it’s accepted as the norm that we have this education ... that pushes people to think and to be creative and to not just look at this kind of managerialism ... but to get people to think creatively about what person-centred care means for this person.”

The work programme at DCU has had a significant impact on the development of the Primary Care Education, Pathways and Research of Dementia project (PREPARED), which is being led by Dr. Tony Foley at University College Cork, as part of the roll-out of the Irish National Dementia Strategy. The remit of the UCC-led PREPARED programme is to support general practitioners and primary care

team personnel in delivering integrated care in the community at a national level. Educational content is based on a needs-assessment developed from interviews with GPs, public health nurses (PHNs), physiotherapists, occupational therapists (OT), family carers and people with dementia about what they each feel allied healthcare professionals need to know about dementia and its implications. The main activities undertaken by the PREPARED programme are education and the development of integrated care pathways. Workshops on dementia care are being held in general practices nationally, focusing on the key themes that have emerged from the needs assessment. Included in the programme is the means for self-audit for GPs, allowing them to compare their performance against international standards, focused especially on making a dementia diagnosis and subsequent disease management. A website¹⁶ has been developed which provides relevant information to people with dementia, families, carers and healthcare professionals. The website includes a social directory that lists services available around the country, providing information about local services, including day-care and Alzheimer Society links locally. This repository is being developed in collaboration with the Alzheimer Society of Ireland.

The Irish Hospice Foundation provides three levels of training specifically on end-of-life care, including support for people with dementia. The intensity ranges from basic training, entitled 'Building Excellence', to intermediate, 'Growing Excellence', to the most intensive level of training 'Strengthening Excellence.' The first level of basic training provides an end-of-life-care toolkit, membership to an online support network, as well as providing additional resources such as posters, DVDs and bereavement leaflets. The second level of training is more intensive and requires trainees to attend two off-site workshops on end-of-life care. The third strand is a more concentrated support scheme provided to on-site facilitators by four co-ordinators based in Cork, Dublin, Limerick and Sligo to help improve specific aspects of end-of-life care that need to be addressed.

Comments from workshop participants included:
"I learnt a lot about end-of-life care that's important to the individual, family & friends and I feel that our changes though small are massive to the nursing

home. It is already showing our aim for person centred individual care." Healthcare professional

Another nurse participant, *"enjoyed all the discussions around end of life care, but the workshop also created mindfulness of what we can improve on."*

The Irish Hospice Foundation's Changing Minds Programme addresses deficits in knowledge and skills for healthcare professionals regarding communicating with people with dementia about their end-of-life care. The training programme provides guidance for healthcare staff to understand how the individual communicates and educates them with the tools which will enable a person to make decisions regarding their end of life when they are ready. From the outset, the focus of the Changing Minds Programme has been on personhood, citizenship and the social model of care. A number of initiatives with respect to service transformation at end of life, in all care settings, have been established, such as, the Hospice Friendly Hospitals (HFH) programme which has been introduced into long-term residential care as a result of this investment programme. A 12 part toolkit as an aid for care staff to address end-of-life care with their residents, including people with dementia, was developed as part of the programme. The roll-out of the Hospital Friendly Hospital model to residential care is on-going, 51 residential care settings were signed up to the project by end October 2015 with 100 expected by end 2016.

In addition, as a result of observed deficits in skills, a series of guidance documents were developed by the IHF. Issues addressed in the leaflets include pain at end of life, especially with respect to unspecified and un-communicated pain¹⁷; facilitating discussion on future end-of-life care with persons with dementia¹⁸; medication management¹⁹; hydration and nutrition²⁰; ethical issues at end of life²¹; loss and grief²² and advance care planning and advance care

¹⁷<http://hospicefoundation.ie/wp-content/uploads/2016/09/Final-Guidance-Documents-5-Pain.pdf>

¹⁸<http://hospicefoundation.ie/wp-content/uploads/2015/08/IHF-G-Doc-Fac-Dis-Fut-EOLC-PWD.pdf>

¹⁹<http://hospicefoundation.ie/wp-content/uploads/2016/09/Final-Guidance-Documents-7-Medication.pdf>

²⁰<http://hospicefoundation.ie/wp-content/uploads/2016/09/Final-Guidance-Documents-4-Nutrition-and-Hydration.pdf>

²¹<http://hospicefoundation.ie/wp-content/uploads/2016/09/Final-Guidance-Documents-6-Ethics.pdf>

²²<http://hospicefoundation.ie/wp-content/uploads/2016/07/Final-Guidance-Documents-3-Loss-Grief.pdf>

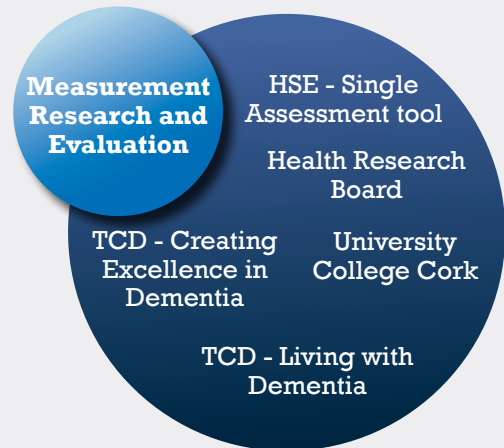
directives²³ (Irish hospice Foundation, 2016). The Foundation followed National Clinical Effectiveness Committee (NCEC) protocol in developing the guidance documents with the goal of developing one standard document for end of life care in residential care settings once complete.

For those wishing to die at home, the Atlantic investment also enabled the Irish Hospice Foundation to focus on providing their night nursing programme to people with dementia. In 2014, 84 people with dementia were supported to die at home, an increase on previous years. From initial observation, it is clear that the majority of people with dementia availing of the IHF's service to die at home are female, have greater access to GP care and family carers provide between 12 and 24 hours care per day. As a result of close collaboration between the IHF and the ASI, the understanding of dementia within the IHF is now much stronger; people are now more comfortable talking about end-of-life issues specific to people with dementia. People with dementia have also been directly involved in different elements of The Changing Minds project and have been included in the development of the different elements of the work-streams.

8.6 MEASUREMENT, RESEARCH AND EVALUATION

Measurement, research and evaluation are critical for the development of an efficient and equitable dementia care system (Figure 8.6). There is a deficit of evidence based research in dementia in Ireland. In recognition of this deficit, Atlantic, the Department of Health and the Health Research Board have come together to offer a number of research awards in dementia linked directly to the delivery of the National Dementia Strategy. The HRB are now funding applied research that aligns with the National Dementia Strategy, including building capacity and developing leadership in the sector through the establishment of a competitive Research Leadership Award in Dementia.

Figure 8-6:
Measurement, Research and Evaluation



Atlantic brought about a change in the research funding landscape by enabling conversations which were not just focused on the research initiative, but actually about changing service delivery and the mind-set of researchers, care providers and funders. Evaluation was embedded within the delivery of care, which is one of the unique elements of the Atlantic model. Grantees were expected to initiate and support evaluations of their project and respond to those evaluations by changing the nature and focus of their work if necessary. As a result of the emphasis on evaluation, outcomes and impact became central to grant writing and funding awards. The person with dementia became centre stage in the decision-making process. The funding calls instigated by Atlantic also resulted in more direct engagement between the Department of Health and the HRB regarding the role of research, data and evidence in policy formulation and policy implementation. Ultimately success for the research project is about making a difference to the lives of people with dementia, their family carers, health professionals and organisations delivering care.

²³<http://hospicefoundation.ie/wp-content/uploads/2016/07/Final-Guidance-Document-2-ACP-AHD.pdf>

“At the end of the day it really is about ... has [the research] actually made a difference on the ground to the organisations who are actually trying to deliver services and make decisions and has the research and the data that’s been generated [aided this]?” Teresa Maguire, HRB.

The importance of encouraging a wider research community to get involved in dementia and broaden the spectrum of researchers beyond the typical players was recognised from the outset by Atlantic. The research community on dementia in Ireland is small, particularly in the social sphere, so broadening the base of potential researchers in dementia was an important element of the research strategy.

The HRB noted:

“The power that Atlantic brought with them in terms attendance at meetings and their ability to promote collaboration among people that don’t normally get together”. Teresa Maguire, HRB.

As a result, the HRB received grant applications from a range of research disciplines, including economics, social policy, psychology, gerontology, engineering, nursing and occupational therapy that they would not have received previously on dementia topics such as:

- raising awareness and reducing stigma;
- connected health to enable more people to stay at home;
- resilience and different approaches with respect to caregivers in particular;
- design and fit-for-purpose healthcare facilities – hospitals, long-term residential care, (although nothing on housing or community);
- better and earlier diagnosis;
- issues around communication;
- cognitive screening;
- pain assessment and management;
- young onset dementia;
- link between stroke, cognitive function and dementia;

- primary prevention;
- biopsychosocial modelling of care.

The HRB want to continue to connect different disciplines together, not just researcher to researcher but also to include, people with dementia, various research users and health and social care producers. This means that grant applicants need to think carefully about methodology and research dissemination, so that all stakeholders are represented in the research process.

“we’d like to see come out of this ... more collaboration, across disciplines, across universities and maybe even internationally from this project. Patient involvement will also be important in future grants.” Teresa Maguire, HRB.

Atlantic have been central in developing and expanding the research base for dementia in Ireland and in providing funding opportunities, through the HRB, for the research community to come together to compete for these funds. One of the most interesting developments has been the support provided by the HRB for Dementia and Neurodegeneration Network Ireland (DNNI). This Network links leading researchers across several disciplines in the areas of dementia and neurodegeneration; it is novel in its multi-disciplinary focus and strategic in its objective to enhance research co-operation and co-ordination in dementia across the island of Ireland. By facilitating collaborative consensus and policy-based projects and supporting knowledge exchange and public patient events, the new Network seeks to develop and improve: an understanding of the causes and mechanisms of dementia and neurodegeneration; the effectiveness of different models of care; and the policy changes required to improve the quality of life for persons with dementia and neurodegenerative conditions. If the Network were to make progress in any, or all, of these areas it will make a significant long-term contribution to basic, clinical and social research in dementia, domestically and internationally.

The inter-disciplinary nature of the Network is innovative and reflects the emerging international evidence of the role of multi-modal influences on

dementia and neurodegeneration. It reflects the members' belief that the integration of knowledge and practice from diverse research traditions has the potential to radically improve our understanding of dementia in relation to prevention, care and quality of life. Dementia and Neurodegeneration Network Ireland also works collaboratively with the Structured Population and Health Services Research Education Network which strives to increase cross-disciplinary interaction and collaboration in the area of population health and health services research. Co-operation between the two networks has the potential to bring together researchers, practitioners and policy-makers in a variety of overlapping domains, thereby further widening and deepening enquiry and scholarship in dementia.

In UCC, Atlantic has really brought a cohesive element to clinical research in gerontology via the formation of a dedicated Centre for Gerontology and Rehabilitation. The grant ensured 50 per cent of the clinician's time was dedicated to research. This has resulted in the Centre now being recognised as a national and international leader in clinical dementia research, including integrating research across different disciplines and faculties. The Centre has had an impact on the Irish National Dementia Strategy. A national audit of dementia care in acute settings was carried out by the Centre (de Siun et al., 2014) and was used to inform the acute care needs of people with dementia in the National Dementia Strategy, including the importance of responding to their particular sensory and psychosocial needs in acute care settings. A key focus of the research in University College Cork is delirium, a condition that people with dementia in acute care are at high risk of developing if the acute care facilities are not tailored to meet their complex needs.

Suzanne Timmons, UCC highlights the dangers associated with an admission to acute care *“an older person doesn't have the same resilience and some of the hospital processes may actually damage them”*.

One of the most important benefits of developing research capacity in dementia at UCC has been the involvement of the Centre for Gerontology and Rehabilitation in the Cork Integrated Dementia Care Across Settings project (IDEAS). The Cork-IDEAS project is about improving care for the person with dementia in the Mercy University Hospital (MUH) and in the community.

The objective is to develop an integrated care pathway for people with dementia (including early onset dementia) so that there will be capacity to accelerate supported discharges from hospital and diversion of patients from presenting to emergency departments through advance planning with community-based health and social care support services. The view on the programme in UCC is that:

“Eventually [we would like to see] that all hospitals have a dementia pathway and care bundle, with delirium being absolutely an intrinsic part, that these are not add-on's, these become mandatory and core.” Suzanne Timmons, UCC.

Researchers in UCC have developed the Geriatric Database System (GDS), which has the potential to shed light on the healthcare resource use of people with dementia and involve the client directly in their own healthcare.

William Molloy, Director of the Centre for Gerontology and Rehabilitation in UCC, explains how the system works in practice, *“you generate a consultation note at the end and you give the consultation note to the patient ... and the patient has a copy and you start to give the patient what they call 'My healthcare record'... Different specialists can see who is treating and ... the patient actually gets educated about their healthcare and gets involved and gets co-opted onto the team so they understand what everybody is doing and what you want them to do”*.

The GDS records the presenting complaint, the history of the presenting complaint and a general medical, drug, social and family history for each client of the memory clinic.

“For example,... I could generate a script and I could generate the request to the PHN, I could copy the PHN on my letter and I could give the patient information about the PHN and the community services available and how to access them.” William Molloy, UCC.

In addition to health service information, the GDS is linked to the drugs formulary making it possible to generate an information leaflet on a new prescription, as explained by William Molloy, UCC:

“I could also give them information on the new drug, what the side-effects are, when they should call the doctor, what to expect and I can give it to them and the consultation note and they walk out of the clinic with all of that information complete.”

Atlantic’s investment programme in dementia has also contributed to the development of a number of screening tools at UCC. The community assessment of risk and treatment strategy The Community Assessment of Risk and Treatment Strategy (CARTS) programme has been developed as a risk intervention strategy that aims to screen, triage, assess and manage risk in relation to three adverse outcomes: institutionalization, hospitalization and death, among community-dwelling older adults. The goal of the CARTS programme is to keep older adults healthy, independent and active in their own homes by developing tailored, cost effective health intervention strategies in an expedient way and to manage the factors that are putting older adults at risk. Two tools have been developed by the CARTS programme: the Risk Instrument for Screening in the Community (RISC) and the Community Assessment of Risk Instrument (CARI). The screening instruments quantify the impact of multiple predictors of adverse outcomes to generate a unique risk score for each of the three outcomes of interest. RISC captures three elements of core concern, mental state, activities of daily living and medical state. It is a quick pre-screen tool that establishes the level of risk of frailty and adverse outcomes. Those that are found to have a high RISC score undergo the second assessment tool, CARI. The latter is a short comprehensive geriatric assessment which further sub-divides the three categories measured in RISC to gain a better understanding of patient risks and needs. Each is graded in severity from mild to severe.

Atlantic have also been at the forefront of supporting a national single assessment tool Single Assessment Tool (SAT) for dependent older people in Ireland, including people with dementia. Their support for the introduction of a nationally standardised comprehensive assessment of care needs for older people in Ireland has now come to fruition. Following a consultation and review process, the InterRAI suite of assessment tools has been chosen as the most suitable instrument for assessment of the care needs of older people in Ireland. As Michael Fitzgerald of the Health Service Executive says:

“There has been a requirement for a long period of time to come forward with such a tool that can be used to bring a consistent approach and sound good practice in the area of assessment of people in relation to their dependencies and to use the tool as a guidance to matching it to resource requirements for such individuals”.

The tool will assesses older people with complex health and social care needs and link functional hierarchy to care received. For the first time, resource allocation can be directly linked to care needs. There are a number of key performance indicators for the SAT, two with a dementia specific focus: increased detection of people with dementia without a formal diagnosis and measurement of carer distress associated with caring for a person with dementia. As the tool will assess the general population for care needs, it is anticipated a better understanding of the actual number of people with dementia in Ireland will result. In addition, due to access to standardised data, assessment will aid care planning and resource allocation, impact positively on quality of care, provide information on case-mix and influence public policy and priority-setting for dementia.

One of the key contributions by Atlantic to research and development in dementia in Ireland was their funding of the “Creating Excellence in Dementia Care”²⁴ report which was designed to increase the evidence base on dementia in Ireland and to inform the National Dementia Strategy. The Creating Excellence report, which was produced in collaboration by TCD and the National University of Ireland Galway, was a landmark document in dementia care in Ireland, as it set the policy and research baseline for the deliberations of the Advisory Group to the National Dementia Strategy, thereby influencing the tone and content of the eventual strategy. It arose from a joint recognition by Atlantic and the Department of Health that the latter needed help and support to write the National Dementia Strategy and that outside expertise, that which was both experienced and credible, was the best way to proceed. Without the Creating Excellence grant, it is unlikely that the National Dementia Strategy would have been delivered on time, i.e. within the lifetime of the incumbent government, and it is

²⁴ http://www.atlanticphilanthropies.org/app/uploads/2015/09/Creating_Excellence_in_Dementia_Care_2012.pdf

doubtful if it would have been written at all, certainly not in the form that eventually emerged.

Another key contribution of Atlantic's investment was the development of a research programme, led by Professor Cahill, that produced 14 higher degree theses, including eight Masters and six Ph.Ds. The Ph.D. research projects focused mainly on three thematic areas (i) long term care, including housing with care and specialist care units, (ii) quality of life and pharmacological interventions and (iii) non-pharmacological interventions including reminiscence. More specifically, research projects undertaken by the Ph.D. students at the LiD included:

- the examination of experiences of residents with dementia and their family caregivers of moving from a traditional long-stay care setting to a specialist dementia care unit;
- reminiscence work in four dementia care settings in Ireland using Interpretative Phenomenological Analysis involving in-depth interviews with people with mild to moderate dementia, facilitators of reminiscence and family carers;
- quality of life and dementia, investigating the expectations and experiences of people with dementia and their family caregivers recently prescribed cholinesterase inhibitors;
- a feasibility study investigating the barriers and enablers to the development of housing with care services in an Irish context. Case studies of sheltered-housing for people with dementia were developed as part of the research;
- exploration of ethical issues in the processes associated with multi-disciplinary team care planning meetings, involving the participation of people with dementia and their family carers and communication strategies to enhance the involvement of people with dementia.

The research work helped inform healthcare professionals, policy makers and planners regarding best practice in relation to the relocation and care of people with dementia in specialist care units. The reminiscence work highlighted the need for education and support for reminiscence facilitators to effectively carry-out their work and to increase the availability of psycho-social interventions, while also emphasising

the overall positive benefits of reminiscence work. The feasibility study of housing with care for people with dementia in Ireland gave a rich insight into the reasons such a scheme has been to date unsuccessful in the Irish context compared to other countries.

One of the Ph.D. students trained by the programme describes her experience, *"Obtaining the Atlantic scholarship in 2009, to undertake my PhD and the LiD training, afforded me the opportunity to gain new insights into quality of life by involving people living with dementia and their care partners in the research process. I am now employed as a Project Officer with Alzheimer Europe and I can definitely say that the research skills and competencies acquired through the Atlantic funded PhD programme have broadened my understanding of dementia and personhood and have provided me with the necessary frameworks to work effectively and to make a significant contribution to the field."* Ana Diaz Ponce, Project Officer, Alzheimer Europe."

The work of LiD researchers also highlighted the need to move away from a solely medical model of care to include psychosocial interventions and for increased awareness around the disease as a means of tackling stigma.

One of the key aspects of the LiD project according to Suzanne Cahill, TCD, was that *"for the first time, dedicated funding was made available to support an agenda which augmented clinical and biomedical research, by engaging directly with people living with dementia, elevating their voice, investigating their lived experiences, examining the meaning they attached to non-pharmacological interventions and exploring the effectiveness of new models of service delivery"*

Over its lifetime, the LiD programme hosted 20 public seminars and four international conferences to bring best international practice and expert experience to the attention of those responsible for the planning, development and delivery of dementia services in Ireland. Outputs also included three flagship research studies and a number of publications in international peer-review journals. In addition, six information kits aimed at informing the general public about dementia

have been published on various topics including²⁵ : Coping with the Early Stages of Dementia: A Guide for people worried about Memory and Cognitive problems or those recently diagnosed with Dementia; Life for Caregivers after Placing a Relative with Dementia in a Nursing Home: A Guide for Family Caregivers and Nursing Home Staff; Finding a Suitable Nursing Home for a Relative with Dementia: A Guide for Family Caregivers to Placing a Relative with Dementia in a Nursing Home; Living in a Nursing Home: Quality of Life: The Priorities of Older People with a Cognitive Impairment; Memory Clinics in Ireland: A Guide for Family Caregivers and Health Service Professionals; and Cognitive Impairment and Dementia: A Practical Guide to Daily Living for Family Caregivers.

A Guide on dementia care in Ireland written for the general public, including those diagnosed with dementia, their family caregivers and those experiencing the symptoms of dementia but who have not yet been formally diagnosed was also developed at LiD. The Guide, the first of its type in Ireland, was developed to disseminate to the public, in an accessible form, the key findings contained in the report entitled *Creating Excellence in Dementia Care: A Research Review to inform Ireland's National Dementia Strategy*. This report was the outcome of a research review commissioned and undertaken to provide the evidence base for Ireland's National Dementia Strategy. The Guide entitled *Future Dementia Care in Ireland: Sharing the Evidence to Mobilise Action*, reflected LiD's mission of making research accessible in a very tangible manner to the general public and promoting the public good. This Guide offers a clear example of the way in which LiD sought to communicate research in a form that was easily accessible to those most affected by Alzheimer's disease and related dementias.

²⁵ All information kits are available to download at <http://dementia.ie/publications/guides-books>

Change

9. ATLANTIC'S LEGACY

Atlantic entered the dementia space in Ireland at a time when the country was confronted by the most serious economic crisis it had ever faced. The imminent threat of national economic bankruptcy meant that there was no chance of generating additional resources to fund dementia care without getting some financial support from outside the public budgetary system. At a time when public expenditure was being curtailed and dementia numbers were rising, Atlantic intervened to provide a stimulus to dementia care in Ireland, not only through the money it spent, but through its ability to leverage additional spending from government. Through persistent lobbying from the ASI, amongst others, and progress in Europe (e.g. the European Initiative on Dementia, 2009), the Irish government had already committed to developing a National Dementia Strategy in 2010. But, it was impossible to envisage how that commitment could be realised given the financial constraints that persisted at that time. If the National Dementia Strategy was to be developed, it was likely to be at no cost to the Exchequer. Atlantic, therefore, played a critical role in maintaining momentum by funding and bringing together a wide coalition of stakeholders in dementia and in commissioning the Creating Excellence research review which was undertaken to inform the content of the dementia plan.

Through its granting system, Atlantic built up a potent coalition of interests in the country that wanted more than the continuation of what had gone before for people with dementia. Many of its grantees sat on the Expert Working Group to the National Dementia Strategy and had a major influence on priority-setting within the new Strategy. Without Atlantic's intervention, both direct and indirect through its grantees, the official approach to dementia would not have changed much in terms of values or orientation. We would have most likely got more of the same in terms of service provision and coverage for people with dementia. And while this would have been welcomed at the time, in the sense that anything would have been judged better than nothing, it would not have been transformative in the lives of people with dementia and their families. Care would have continued to be provider-focused rather than person-centred with little or no emphasis on personhood

or the capabilities of people with dementia. Atlantic recognised that for real change to happen, the current policy frame would have to be nudged towards a new paradigm that recognised the narrowness of the prevailing official mind-set and the opportunity that existed to develop more appropriate counter-policy frames. That was its enduring contribution to dementia in Ireland, which will be elaborated upon in this chapter. While that process is far from complete, and the old model has not disappeared, Ireland, guided by an evidence-based approach, is on a pathway to a person-centred, personhood-oriented, biopsychosocial model of care for people with dementia.

The old model saw dementia in individual and biological terms. People got the disease and faced it, by and large, on their own within their families and, if they were fortunate, with the support of appropriate medical teams and the Alzheimer Society of Ireland. The model was reductionist and residual in terms of government support. Most people received no public services at all and muddled through with whatever support they could muster outside of the conventional system of care. They relied on their families and/or paid out-of-pocket for private care. When government did get involved it was mainly to support residential care for people with dementia. Policy makers tended to associate dementia with loss and risk resulting in a funding bias towards institutional care where people with the disease could be cared for in a safe and secure environment, not recognising that this approach sometimes contributed to a reduction in quality of life for some people. The consequences, whether intended or not, were that people with dementia tended to be excluded from mainstream society under this model, denied essential freedoms and left to face an uncertain and precarious future without much support from government, society or community.

Through the grant-making process, Atlantic has been able to influence the development of an alternative paradigm for dementia in Ireland. A desire for change already existed among stakeholders that had been building since the publication of the Action Plan for Dementia ten years previously. Consistent lobbying by

the ASI for a new model had also prepared the political establishment for change, making it more likely that they would accept outside support, if and when it was offered. A core principle, for Atlantic and its grantees, centred on the removal of the stigma and invisibility attached to dementia and instead to place people with the disease at the centre of decision-making in the midst of their communities, as net contributors to society. That core principle resonated with international evidence which identified personhood and person-centred care as key ingredients to any new approach in dementia. The new paradigm would be evidence-based in keeping with Atlantic's rational approach to priority-setting, but it would also have to be person-centred, based on the over-arching principles of personhood and citizenship.

So how is the new model taking shape in Ireland? What are its key features? And how has Atlantic's investment influenced its development? The qualitative analysis from our work has highlighted a number of key features of the new model namely: biopsychosocial framework, person-centred care, system development, citizenship, policy implementation and sustainability, all of which are inter-related in some way. Integrating the biological and the social within the biopsychosocial framework has encouraged greater discussion of the meaning of attachment, place, identity and relationships in dementia, thereby challenging families and communities to develop and maintain a communal approach to care that prioritises personhood, connectivity and mutual support systems. It has reinforced the need for, and benefit of, Dementia Friendly Communities. It has also helped to change the language of dementia from risk to capabilities, thereby allowing the potential of people with dementia to be realised during all stages of the disease, particularly in the early stages of the illness.

Atlantic has worked assiduously with the Health Service Executive, the agency that manages the public health system in Ireland, to put in place the building blocks that will be critical in recalibrating the balance between the biological and the social in the care of people with dementia. A key investment, jointly funded by Atlantic and the government, has been the

Health Service Executive/Genio demonstration project in personalised, locally based care for people with dementia across four different sites. This initiative involved reorienting care and services for some people with dementia, turning away from a primarily medical, institutional model toward one that encompasses community-based services, families, and home care. The demonstration project produced both superior outcomes for patients and families and reduced costs for the government (O'Shea and Monaghan, 2016). As well as being better for people with dementia, the intervention was more cost-effective. The results suggest that significant numbers of people with dementia could potentially be supported to live at home for longer as a result of the Health Service Executive/Genio Dementia Programme, thus resulting in savings to the exchequer when comparisons are made between public expenditure in the community and in residential care. Moreover, the lives of people with dementia and their family carers have been enhanced and enriched by a more responsive and socially-oriented community care system.

People with dementia have physical, emotional and spiritual needs that require nurturing, very often through psychosocial interventions, if the various dimensions of personhood are to be realised. Sometimes this means taking chances with care structures and care processes that allow people with dementia to live as normally as possible at home in flexible, accessible and familiar environments that allow capabilities to be maximised. For the most part, people with dementia should live in their own homes where images of self and identity are easier to preserve in the face of on-going cognitive decline. The challenge for the National Dementia Strategy is to incorporate some of the learnings from the HSE-Genio work into the roll-out of intensive home care packages for people with dementia. Already commitments have appeared in the planning documents of various Community Health Organisations across the country supporting and embedding some of key HSE-Genio initiatives. What is clear, is that simply giving people more of what they previously had is not good enough. People must get what they need and it must be provided in a personalised, person-centred manner in response to the stated preferences of the person with

dementia. That message is now feeding through to the planning documents of the Health Service Executive.

Atlantic have emphasised keeping people with dementia at home and ensuring that their social needs are met as much as their medical needs. Their grant-making has encouraged and supported new and innovative models of support for people with dementia that have emphasised citizenship and inclusion as fundamental to the caregiving process. Seeing people with dementia as assets to be cherished can be of enormous transformative value to the society within which they live. People with dementia are citizens with inalienable human and civil rights that must be protected. They continue to have roles and relationships within families and communities that serve to enhance overall well-being and preserve the integrity of the human spirit – their own and others. People with dementia are better off when treated with respect and dignity, but so too is society. Through a continuous focus on inclusion from Atlantic-supported projects, people with dementia have become more visible in Irish society, leading to greater awareness of the disease and an acceptance of the need for a public response in the form of improved services and community-based support systems.

The Alzheimer Society of Ireland's awareness campaign has influenced the way in which people with dementia are portrayed in society, giving them a voice and presence that they would not have had previously. Prior to Atlantic's investment, coverage of dementia in the national press was highly medicalised and the media engaged primarily with healthcare professionals on the topic. The coverage of dementia in various media now involves the direct participation by people with the disease, through the Dementia Working Group at the Alzheimer Society of Ireland, and their viewpoint is very much to the fore in any public conversation of dementia.

A leading example of the success and impact of the Dementia Working Group is Helen Rochford Brennan, who was diagnosed with early-onset Alzheimer's disease in her late fifties. Through the ASI, and with the support of Atlantic, Helen and others have become teachers and agents of change dedicated to telling

the world the importance of not letting the disease define who and what you are. Helen believes that the silence surrounding dementia needs to be broken and argues that *"this can only happen when people with dementia are given a voice; a platform and put at the heart of that change. I thought my days of activism were over; I had packed away my hopes alongside my dreams, but as Desmond Tutu said: 'Hope is being able to see that there is light despite all the darkness'. Now I have hope; a small, budding flower that will continue to grow as long as I have a voice, as long as I am still Helen."* Helen Rochford Brennan, Dementia Working Group.

Collaboration has been an important part of Atlantic's dementia investment programme. Co-operation between different agencies was in-built into many of the Atlantic's grants and organic collaboration which developed across the various programmes further enhanced the value of the investment. The collaboration between the Health Service Executive and Genio was central to the success of local innovation in personalised community care and in relation to the hospitals care pathway programme. The Irish Hospice Foundation teamed up with the Alzheimer Society of Ireland to develop the Changing Minds project which involves the provision of end of life care for people with dementia and education programmes on palliative care. The Atlantic investment programme also allowed the Irish Hospice Foundation to work with clinicians in UCC to develop advance care directives suitable for people with dementia. Age Friendly Ireland collaborated with Home Instead and other local partners to establish the OPRAN project designed to keep people on the margin of residential care in their own homes. Third Age Foundation and the Health Service Executive are co-operating to develop an advocacy programme for older adults, including people with dementia in various care settings. Educational films produced by the Neuro-Enhancement for Independent Lives project have been used for a variety of purposes by a number of organisations, nationally and internationally, to change perspectives on dementia. The Creating Excellence in Dementia Care Report provided the research framework for the National Dementia Strategy. Education and training programmes developed by the Elevator programme

at DCU have provided dementia-specific education and training to healthcare professionals in the Health Service Executive and in private organisations delivering care and services to people with dementia. The LiD programme at Trinity College relentlessly focused on social aspects of care, personhood and the voice of people with dementia, thereby permeating the work of a large group of dementia stakeholders.

We are at the beginning in Ireland of a seismic change in how people think individually and collectively about dementia. This includes more enlightened personal attitudes and expectations about dementia, a new awareness and understanding of prevention, through various Brain Health initiatives, and recognition that dementia is one of the most important ageing questions that society will face in the coming decades. Atlantic's dementia programme recognised and anticipated this by bringing together many of the main stakeholders across the continuum of dementia. Accepting the personhood of people with dementia means that more attention is now focused on ensuring that people with the disease play a more formal role in decision-making at both the micro care level and the macro policy level. The education and training programmes organised through the Elevator programme at DCU and the ASI, including the Dementia Champions Programme, are all necessary ingredients in facilitating the recalibration of autonomy and power into the hands of people with dementia. So too is the work of SAGE through various advocacy programmes and the Irish Hospice Foundation in relation to end-of-life care. Embedding these programmes and others into mainstream thinking and provision are key to the sustainability of the Atlantic dementia project. The portents are good that embedding will happen, but only time will tell.

Dementia is competing for ever scarcer public resources at a time of increasing need. The allocation of resources to dementia is ultimately a political decision that can be influenced by stakeholders and public opinion. Even within such binding budget constraints, however, Atlantic have shown, through their grantees that the future is bright, provided resource allocation is based on an alternative policy frame for dementia that emphasises: the

biopsychosocial model, home-based care, capabilities, citizenship and social inclusion. The goal of Atlantic's investment strategy has been to provide people with dementia with an individualised, person-centred pathway of care from diagnosis through to end-of-life care, achieved through agreement and engagement with all relevant stakeholders. That is now available for some people, through the Health Service Executive-Genio programme and intensive home care packages funded through the National Dementia Strategy. At the macro level, the objective has been to make dementia a community-oriented public health priority, thereby placing people with dementia at the heart of local communities, comfortable and secure in their own place and time. We will know more through the various evaluations of the implementation of the National Dementia Strategy in the coming years whether these goals will be reached in the longer-term. For now, what we can say for certain is that Atlantic has been at the heart of all that has been good and transformative in dementia care in Ireland over the past five years. The speed of change has been remarkable and for the better, not just for people with dementia, but for the society within which they live.

Atlantic has played a key role in brokering change and pushing the reform agenda for dementia in Ireland. There is clear evidence that the vision and ideas of Atlantic grantees in dementia have directly impacted on the thinking of government and have led to changes in policy and practice. So much so, that Ireland is now in the vanguard of policy and practice innovation in dementia in Europe. The project is far from complete, but many of the ideals, objectives and person-centred models of dementia care espoused by the WHO, OECD and the International Alzheimer Associations are working their way into policy and practice in this country, as a direct result of Atlantic's support. The international consensus for action on dementia provided an important framework and backdrop for Atlantic's investment. But the progress achieved in Ireland is also now an exemplar for international agencies and other countries of what can be achieved when all of the relevant agents and agencies find a way of working together to achieve a common goal. This is not to forget or dismiss the role of ideas and support for change that existed

within stakeholders and policy-makers in Ireland prior to Atlantic's involvement. Atlantic built on existing capacity and collaboration among stakeholders to effect real change and then worked with government to help implement that change. There was no open door, but neither was there antipathy to change. Building connections between the worlds of policy, practice and research helped to smooth the transition between ideas and action. So too, of course, did the funding, which leveraged further commitments from government and elsewhere.

The lessons for other philanthropic organisations and countries who might want to replicate the Irish experience, is that investment in people matters. The grantees have delivered on the investment bestowed upon them by Atlantic. Therefore, the message is choose your grantees well and know the market place for ideas before you spend any money. Atlantic took time to understand the dementia landscape in Ireland. The experience, past record of achievement, reputation and credibility of grantees were important for all successful grants. The second important ingredient is that values matter. Clearly, Atlantic believed in putting people with dementia at the heart of decision-making and in developing care models that emphasised individualised supports at home in the community. Therefore, the major grants were designed to support personhood and community-based care in a reasonably coordinated and integrated manner. The third important factor is a close and credible relationship with government. Atlantic had already established its bona fides through its work in higher education in Ireland, but new relationships were forged within the dementia policy-making community, making it easier to get traction on some of its jointly funded projects later on. Having big ideas that fit the prevailing mood of government also helps, as evident by the partnership agreements reached on the National Dementia Strategy between Atlantic and the Department of Health. Finally, building in research and evaluation into the various grants provides the framework for evidence-based decision-making and is a powerful stimulus for on-going rationality in resource allocation for grantees and for government. An emphasis on evidence and evaluation is a long-standing trait of Atlantic's involvement in public

policy in Ireland and has been influential in overall public service reform in the country. A more rigorous approach to evidence, in terms of its production and use, is now accepted across all government agencies.

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10. CONCLUSION

Atlantic's commitment to dementia in Ireland has served to transform the landscape of care for people with the disease by pushing out boundaries in relation to knowledge, personhood and citizenship. The Atlantic dementia programme in Ireland has created a framework upon which to base new approaches in dementia care and demonstrated that with the right investment in the right people, great progress can be achieved. The investment in a variety of stakeholders has served to widen and deepen capacity and leadership in the dementia field. Atlantic came with big ideas and a belief that by supporting the right people these ideas would lead to sustained improvement in dementia care. The grantees that received support have justified that confidence shown them by Atlantic through their on-going work in influencing policy and practice. Taken together, their work is an impressive contribution to the dementia field, not only in a domestic sense, but internationally as well. Encouraging the grantees to work together, especially in support of the National Dementia Strategy, has created a powerful collaborative force for good in the country that will lead to real change for people with dementia in the longer-term. Working with government has provided the opportunity to disseminate the benefits of the investment beyond the local and will lead to lasting change. Building research and evaluation into the granting process has made a major contribution to evidence-based practice and policy in dementia, as well as to on-going public sector reform in Ireland. The counterfactual to Atlantic's investment in dementia in Ireland is difficult to determine, but it is clear that even if one took the position that change was coming anyway, a proposition for which there was little evidence, Atlantic ensured that it came much faster and in a more coherent manner.

The chronology and rationale for the investment is worth noting. Early investment by Atlantic in neuroscience at NEIL in TCD was designed to counterbalance the nihilism associated with dementia in Ireland by supporting a scientific approach to dementia that was progressive and preventative in orientation. Support for the Alzheimer Society of Ireland ensured that advocacy and political lobbying were at the forefront of their activities, as they sought

to influence public attitudes about the disease and promote the case for dementia to be classified as a public health priority. The Alzheimer Society of Ireland also kept up the pressure for a National Dementia Strategy, pressure that eventually bore fruit with a promise to include a commitment to a Strategy in the Programme for Government of the incoming administration in 2010. The formation of the Dementia Working Group in recent years has been a major boost to personhood and social inclusion for people with dementia. The Alzheimer Society of Ireland have given a voice to people with dementia and demonstrated to the general public that people with dementia have a valuable contribution to make to society. The direct voice of people with dementia in the public policy arena is stronger now than at any other time.

As a crucial first step in the development of the National Dementia Strategy, and a sign that the issue was gaining traction in political circles, the government agreed to join with Atlantic in sponsoring what became a seminal report titled *Creating Excellence in Dementia Care*, authored by longstanding Atlantic grantees. This report provided the government with a critical baseline of research and policy analysis upon which it then proceeded to build its dementia strategy. Equally important, the government established a high-level Working Group, comprising public officials and several Atlantic grantees, to draft the promised Strategy. The grantees were powerful agents of change at a crucial stage in the development of the Strategy. The development of the National Dementia Strategy took place under the most testing of financial circumstances in Ireland. Dementia was competing for ever scarcer public resources at a time of increasing need. Without Atlantic's commitment to provide financial support for the new Strategy, and the ongoing lobbying by grantees, it is unlikely that any new resources would have been provided by government. Instead and for the first time, there was a strong commitment in the National Dementia Strategy to support community-based care through the provision of intensive home care packages, jointly funded by Atlantic and the government.

Atlantic also funded innovative, demonstration projects through Health Service Executive-Genio

that sought to deliver individualised and integrated community-based social care to people with dementia. These projects proved to be cost-effective and beneficial for people with dementia and their family carers. The Health Service Executive-Genio programme identified a biopsychosocial framework for the delivery of dementia care in the community that proved to be responsive to the needs and preferences of people with dementia. Its influence and sustainability in the future depends on how rapidly and effectively it is linked to the roll-out of the National Dementia Strategy. The HSE-Genio approach is consistent with the National Dementia Strategy reflecting a coherent approach to caring for people with dementia, promoting practices that have strong evidence of effectiveness, emphasizing early detection and intervention, and providing integrated responses to the physical, psychological and social needs of patients and their families. The social model and psychosocial care were also at the centre of the LiD project at Trinity College, influencing the next generation of research leaders in dementia. Not surprisingly, these themes correlate strongly with Atlantic's analysis of needs in dementia and they reflect its on-going advocacy with senior health officials working in the policy sphere. So too do the philosophical pillars of the National Dementia Strategy: personhood and citizenship, which have long provided the basis for Atlantic's engagement in the related areas of education, disability and human rights.

Through its audit of dementia in acute care, UCC highlighted issues for people with dementia in hospitals that were subsequently addressed in the National Dementia Strategy, including the importance of dealing effectively with delirium. UCC has also designed advance care directives for people in nursing homes reducing the amount of people being transferred to an acute care setting at the end of their lives. This combined with the palliative care services offered by the Irish Hospice Foundation to people with dementia has improved the end-of-life experience for some people with dementia. The Dementia Skills Elevator programme at DCU now provides a broad portfolio of education and training to people with dementia, their carers, public-facing services and health and social care professionals, where

the emphasis is firmly on personhood and person-centred care. The Dementia Champions element of that programme seeks to create strong leadership that will help shape policy and practice in the future. Measurement and evaluation has been supported through funding for the Health Service Executive Single Assessment Tool and for HRB grant-making activities in dementia. Grants to the Irish Hospice Foundation and SAGE reflected a desire to protect and support the most vulnerable with dementia and ensure that their voice is heard at critical stages of the disease, including providing them the opportunity to voice their preferences for the location of care.

The full dividend from the investment by Atlantic in dementia in Ireland will not be known for some time. Many of the grants are at an early stage and only a small number of them have completed internal or external evaluations. Moreover, the recent Global Brain Health Initiative is only beginning and it will take decades before the full implications of that grant bears fruit globally. What we do know from Ireland is that the dementia landscape has changed significantly in less than a decade. Where once there was pessimism, now we can be cautiously optimistic that dementia has gained some traction in government public policy. It is not that dementia care in Ireland is perfect. It remains under-funded and does not yet have the priority status from government that it deserves. But through careful support of grantees, who have risen to the challenge, Atlantic have succeeded in changing the narrative of the disease, not for everyone but for some, and more will follow. There has been a paradigm shift in policy towards personhood and the social model of care linked to evidence-based research. Now that Atlantic are leaving the stage, the challenge for their dementia grantees is to ensure that the gains made are capitalised upon and leveraged to continue the upward trajectory of care and support for people with dementia in the country.

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APPENDIX 1 - QUESTIONNAIRE

Evaluation of The Atlantic Philanthropies (AP) Dementia Programme

Focus and Objectives of the Project

1. With regard to the origins of your AP-funded dementia project, please outline the rationale and conceptual underpinnings of your project.

2. What are the key objectives of your dementia project (what is it that you are trying to achieve)?

3. What is the total level of AP funding for your dementia project?

4. Has there been any significant change in your budget expenditure relative to what was envisaged in your original application?

(a) If yes, please provide the rationale for this change and give details of any significant new spending.

Key Performance Indicators

5. What are the key performance indicators associated with your project?

Impact

6. What has been the overall impact, if any, of your project on practice in dementia care?

7. What has been the overall impact, if any, of your project on service delivery in dementia care?

8. What has been the overall impact, if any, of your project on policy for dementia care?

Obstacles and Learning

9. What, if any, have been the major obstacles that you have encountered in delivering your project?

(a) Have you managed to overcome these obstacles, if so, how has this been achieved?

(b) What were the main learning outcomes, if any, from dealing with these obstacles?

(c) Are there any upcoming obstacles that you anticipate and how are you preparing for this?

10. How do you currently communicate information and messages about your project to stakeholders and the general public?

Personhood, Awareness, Attitudes, Voice and Advocacy

11. Has your project **advanced the concept and practice of personhood** for people with dementia?

YES NO

(a) If yes, in what way?

12. Has your project **influenced awareness** in relation to dementia amongst people with dementia, family carers, practitioners, policy makers and the general public?

YES NO

(a) If yes, for whom in particular and in what way has awareness been influenced?

13. Has your project **influenced attitudes** in relation to dementia amongst the various stakeholders, including people with dementia?

YES NO

(a) If yes, for whom and in what way?

Integration and Collaboration

17. With whom have you collaborated in the formulation and implementation of your dementia grant, including other AP grant holders and government?

Name

Organisation

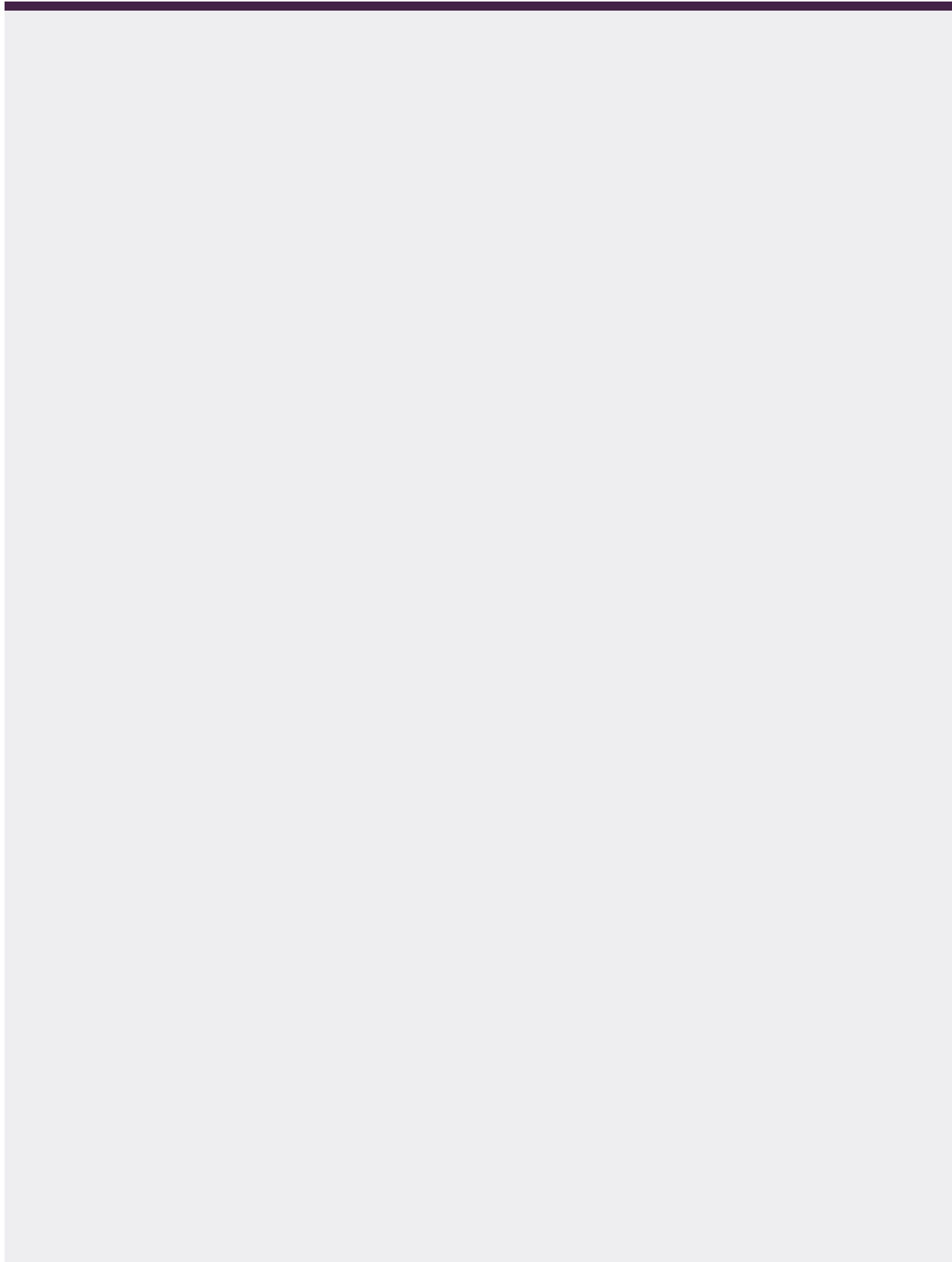
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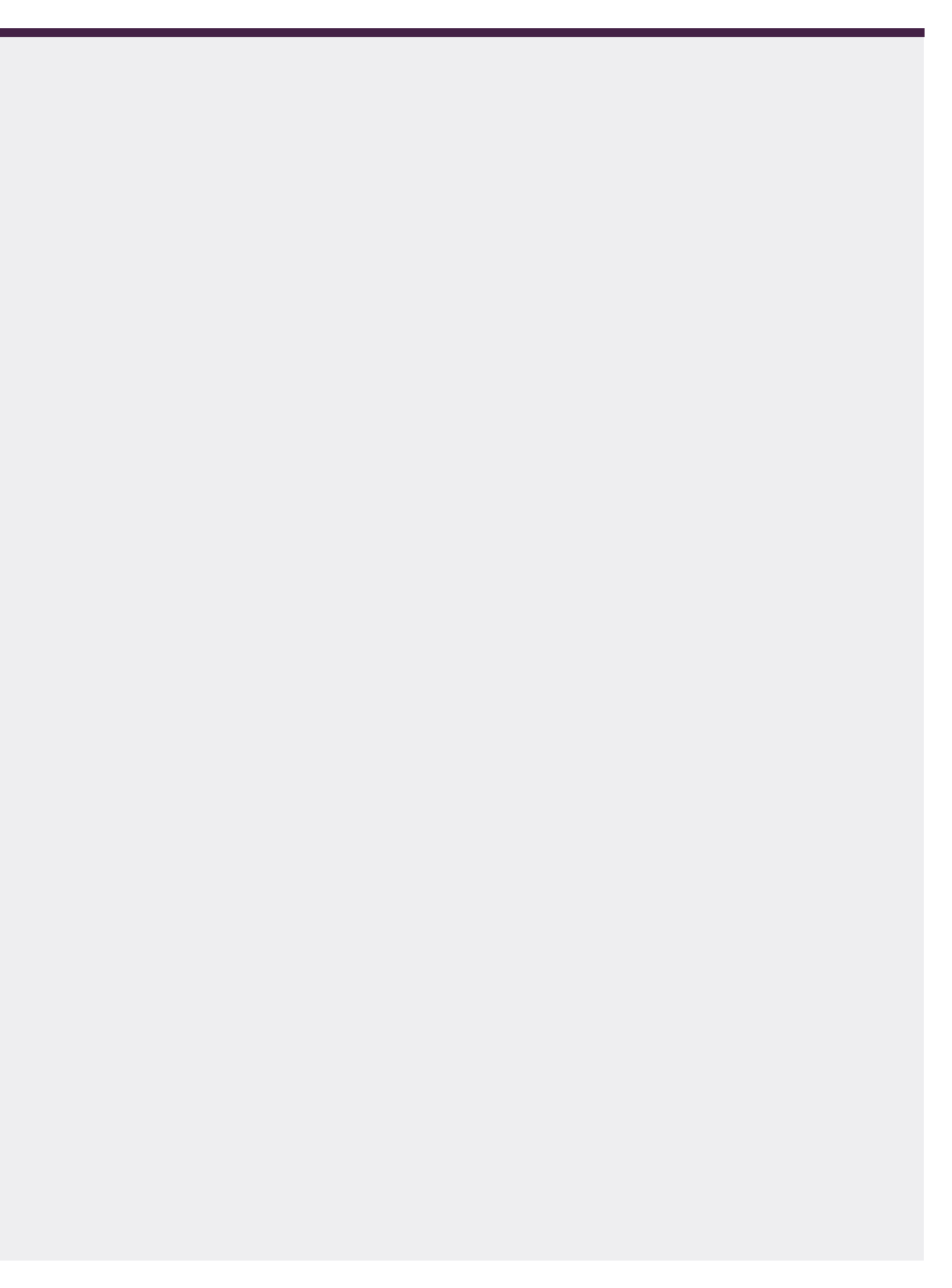
(a) Describe this collaboration for each of your main collaborators and what role they had in your project?

Sustainability and Legacy

18. How sustainable is your project when funding from AP comes to an end?

19. What do you see ultimately as the key legacy of your AP-funded dementia project?







PAYING DIVIDENDS

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