

Making Change
with Government



The AP / DSC Dementia Programme - Activity and Outcomes

April 2020



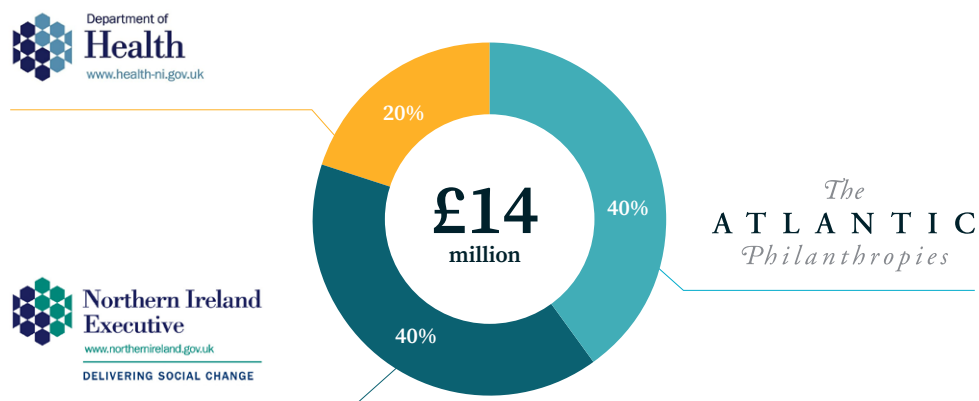
**SOCIAL
CHANGE
INITIATIVE**

1. Introduction

The joint Atlantic Philanthropies and NI Executive Delivering Social Change initiative on dementia (the AP/DSC Dementia Programme) aimed to transform the care and well-being of people living with dementia. Atlantic entered into the joint programme with government in order to encourage the development and embedding of good practices in publicly supported dementia expenditures, policies and services. It was one of three co-funded programmes under a £62m partnership initiative between philanthropy and government in Northern Ireland.

The initiative was delivered by the Health and Social Care Board and Public Health Agency, with oversight from a Project Board representing the funders: The Atlantic Philanthropies, The Executive Office and the Department of Health. The total investment secured for the initiative was £14m, of which Atlantic's contribution comprised 40%.

Figure 1: Total Programme Spend





The AP / DSC Dementia Programme involved two phases of work:

Phase 1

Dementia Together NI

(completed in March 2018) - focused on improving the care and support provided to people with dementia and carers, enhancing the skills of the dementia workforce, and tackling stigma around dementia among the general public.

Phase 2

Dementia E-health and Data Analytics Pathfinder Programme

(completing in 2020) - focuses on the introduction of technology-enabled healthcare systems to support people to live well with dementia, and the development of the capabilities necessary to make better use of data and analytics in dementia.



2. What Did the AP/DSC Dementia Programme Deliver?

The aim of the AP/DSC Dementia Programme was to make lasting improvements in services and support for people with dementia. The analysis below summarises, against the key themes of the programme, the immediate impact it made and how that was achieved. It also comments on progress made towards lasting system change, highlighting that continued government investment in dementia policy and service development is needed to realise improved outcomes for people with dementia in the longer-term.

**New Learning
& Development
Standards for
Dementia Care**

Developing the Dementia Workforce

Impact:

Dementia Together NI improved the knowledge and skills of the dementia workforce and created new standards and ways of working with potential to realise a lasting improvement in dementia practice.

Outputs:

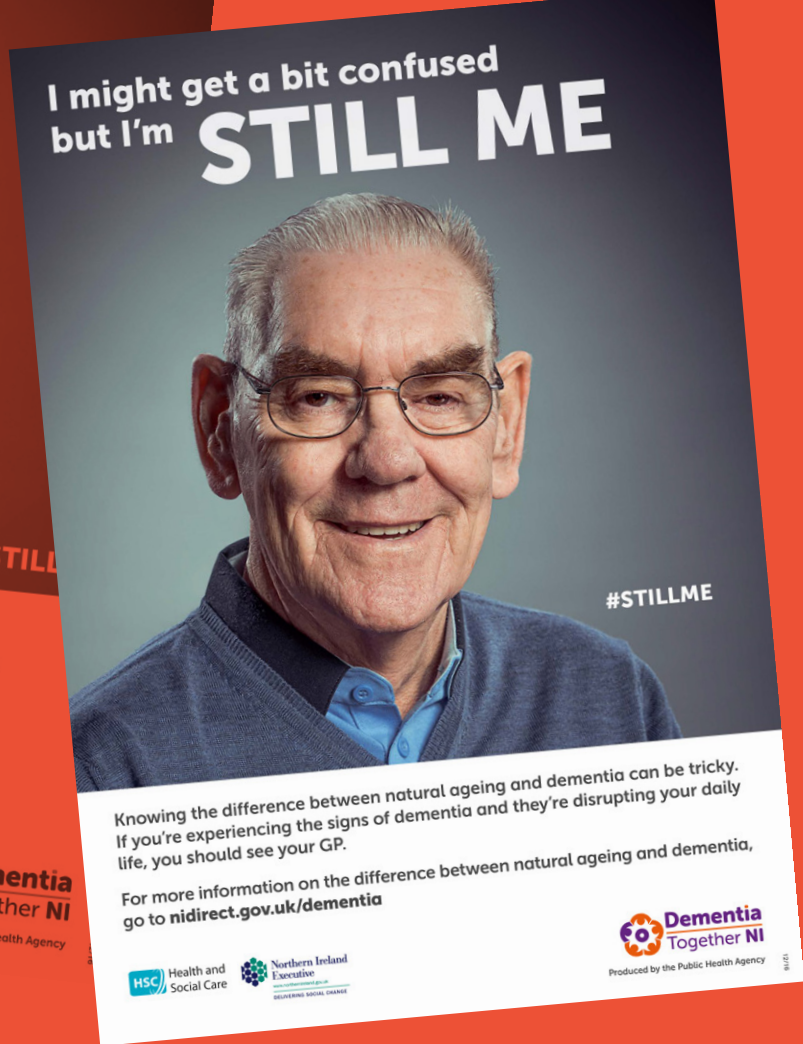
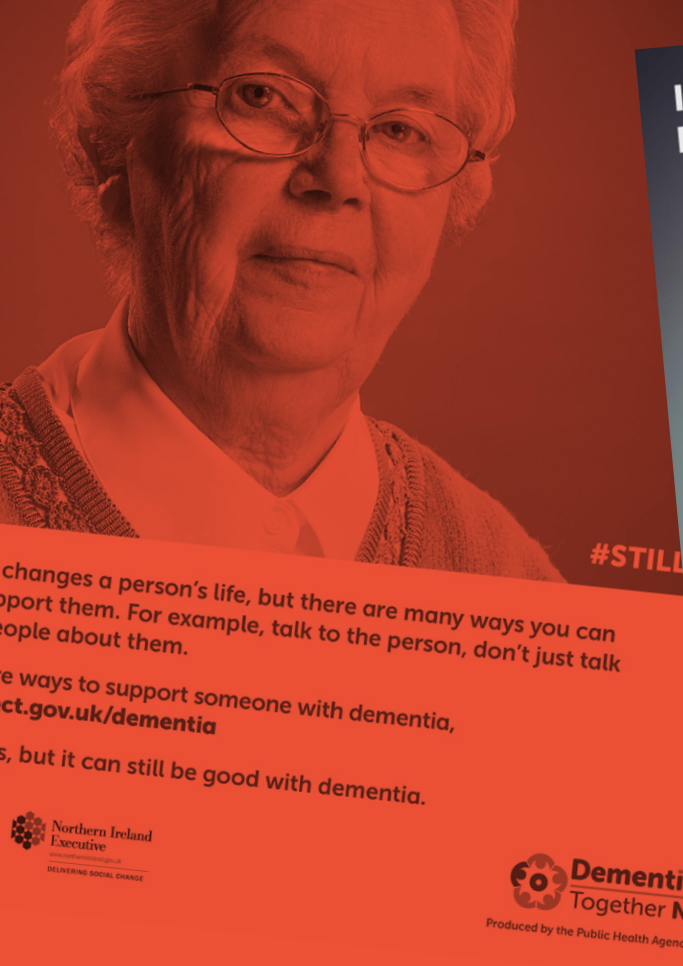
- Created a Learning and Development Framework defining the skills and knowledge needed by the dementia workforce in order to interact and respond sensitively to the needs of people living with a dementia, their families and carers.
- Took steps to embed the framework into pre-qualifying professional education and continuing professional development courses, the standards for workforce registration and inspection of care services, and employee appraisal and development processes.
- Trained the formal and informal dementia workforce including:
 - 1,850+ carers completed dementia training and reported a positive impact on their knowledge, confidence and satisfaction as a carer
 - 2,800+ hospital staff were trained to identify and manage delirium and 40 staff trained as trainers
- Mobile training apps and various training courses (on living with dementia, care practice and managing the behavioural and psychological symptoms of dementia) made available to day-centre, residential, domiciliary and community health and social care workers
- 250+ staff - working at all levels and disciplines - trained as Dementia Champions and completing improvement projects in their place of work.



Sustaining the Outcomes:

A large number of people working in the field of dementia care are now better informed and have improved skills as a result of the AP/DSC Dementia Programme. Ongoing investment and strategic focus is needed in dementia education and training to continue to develop the existing workforce and harness their potential as dementia change agents, as well as ensuring that new entrants to the workforce have the required skills and knowledge.

The additional injection of funding that the AP/DSC Dementia Programme made available for workforce development cannot be sustained, so ongoing development of dementia knowledge and skills must be integrated into regular systems and funding streams for learning and development. Government has committed to continuing the work already done on embedding the Dementia Learning and Development Framework into systems of education, professional registration, recruitment, development and inspection for dementia. A dementia workforce development strategy is needed to guide this work and set appropriate milestones and outcome measures.



Tackling Stigma

Impact:

Dementia Together NI improved the public's understanding of and attitudes towards dementia and provided insights to inform future public health engagement on dementia.

Outputs:

- Delivered 'Still Me', a multi-media advertising campaign featuring local people with dementia communicating that while dementia brings substantial changes, the person with the diagnosis remains essentially themselves. The campaign had strong reach and recall, and its use of real-life stories resonated with the public.
- There was evidence of improved public knowledge of the signs of dementia and more positive attitudes towards people with dementia post-campaign, but levels of emotional resistance to help-seeking and fear of developing dementia increased.

Sustaining the Outcomes:

Public understanding of dementia in Northern Ireland has been improved but continued work is needed to build upon initial successes and support public conversations about the deeply held fears and negative attitudes associated with dementia. Public resources will not stretch to repeated large-scale public advertising campaigns on dementia, but the campaign media and resources will be used to support regular public health messaging and communications on dementia.

Meeting Information Needs & Supporting People Post Diagnosis

Impact:

Dementia Together NI helped address the demand from those worried about or directly affected by dementia for relevant, evidence-informed information. It instituted a common regional approach to providing guidance and support to people receiving a dementia diagnosis. These developments have gone some way to making dementia information and support services more consistent across Northern Ireland improving equity of service.

Outputs:

- New dementia information content created on the official government website for Northern Ireland and visitor traffic maintained throughout the programme - site visits peaked during the public advertising campaign.
- 12 printed information guides produced on aspects of dementia, from recognising the early signs, to planning ahead, communicating with a person with dementia, talking about risk, dental, vision and hearing care, and sexuality and relationships.
- 10 Navigator posts created (and sustained on a permanent basis) to provide information & signposting service to people affected by dementia.

Sustaining the Outcomes:

Information, Support and Advice are core elements of a draft Regional Dementia Care Pathway that describes the support (from government and communities) that should be available to people living with dementia across Northern Ireland. Processes for production, distribution and maintenance of dementia information resources are being developed to ensure they remain consistently available to people throughout Northern Ireland, and there will be further development of the Navigator model which now has recurrent funding. However, government must begin the implementation of the Regional Dementia Care Pathway if the improvements to core dementia support services made under the AP/DSC Dementia Programme are to be sustained.

New
Information
& Signposting
Service for
Dementia



Improving Dementia Care in Hospitals

Impact:

Defined and trialled a new approach to preventing and managing delirium, which is beginning to be rolled out in care settings across Northern Ireland.


Outputs:

- Tool for delirium screening, diagnosis, prevention & management developed and piloted in selected care settings - pilot wards saw reduced falls and use of anti-psychotics and a shift in attitudes towards behavioural and psychological symptoms of dementia. More than 150,000 delirium information leaflets were distributed to patients and carers to improve their understanding of the condition.
- Audit of dementia care in acute hospital services completed and recommendations made to improve performance against key quality measures and realise optimum outcomes for people with dementia.
- New Dementia Companions role trialled and subsequently instituted on a permanent basis, to assist people with dementia in acute wards to carry out basic activities and help manage the behavioural and psychological symptoms of dementia.

Sustaining the Outcomes:

Progress in scaling up and rolling out the delirium approaches developed through the AP/DSC Dementia Programme has been variable across different areas. A regional strategy is needed to set priorities and objectives for improving dementia care in hospitals, including how delirium is identified and managed.





6 short break models
piloted, supporting

219
families

Supporting Carers

Impact:

The AP/DSC Programme demonstrated the transformative impact that a relatively limited amount of flexible, personalised support can have on families affected by dementia and its potential value in sustaining care relationships.

Outputs:

- 6 short break models piloted, supporting 219 families that had previously had inadequate short break support or none at all.
- Evaluation demonstrated a positive impact on carers' wellbeing and likelihood of accepting help and support.
- Receiving short breaks helped carers to sustain their caring role by maintaining satisfaction levels in the face of an increasing sense of caring difficulty over time.

Sustaining the Outcomes:

Short breaks for carers is a key feature of the model of care for people living with dementia described in the Regional Dementia Care Pathway for Northern Ireland, but implementation of the Pathway has not yet begun. Furthermore, the Reform of Adult Social Care and Support, which will determine the community support that will be provided in future, is making slow progress. A dementia short breaks strategy is needed to set objectives and an approach to transformation of short break support (taking account of broader system reform), so that the flexible, personalised type of short break support piloted through Dementia Together NI is made widely available to carers of people with dementia.

Dementia eHealth and Data Analytics Pathfinder Programme

Impact:

The Pathfinder Programme is laying the foundations in technical and capability terms for more data-informed planning and delivery of dementia services, and greater use of technology enabled solutions.

Outputs:

- Establishment of a new GP Information Platform (GPIP) to allow access - with appropriate controls and privacy protections - to data from individual GP systems. GPIP infrastructure has been built and data population will complete in 2020, enabling the creation of a virtual dementia register, bespoke dashboards for GP practices to support dementia care initiatives and significantly enhanced dementia analytics capacity for policymakers, commissioners and researchers.
- Creation of a multi-disciplinary Dementia Analytics Research User Group (involving people living with dementia, advocates, clinicians, service commissioners, researchers and analysts) overseeing a programme of impact-focused dementia data projects, building analytics capacity and changing ways of working so that data is routinely used to inform planning, evaluation and commissioning of dementia services.
- A new dementia e-health portal (in pilot mode) enabling people with dementia and their circle of care to see their records, appointments and prescribed medications.
- A new online library launched enabling people living with dementia to access reviewed and recommended dementia support apps.
- Two bespoke apps being developed – the InspireD app supports reminiscence and the CLEAR app enables carers to understand and respond to distress experienced by people with dementia.
- A process supporting GPs to add their patients' dementia diagnoses to their summary electronic records so it can be seen by other clinicians across health and social care, including in emergency hospital settings.
- Technology-enabled dementia learning sessions delivered to primary health care teams and hospital-based dementia specialists.

Sustaining the Outcomes:

The Pathfinder Programme is not due to finish until later in 2020 and there is still much to do to sustain and embed its work, and realise the system changes needed to improve the lives of people with dementia. This includes securing support for continued operation of the technical products (such as the portal and the GP Information Platform), and for further development of data-informed ways of working among the dementia community at policy, planning and delivery levels. Many of the technical products of the Pathfinder will roll out to the entire health and social care system in Northern Ireland, but the programme's immediate priority is to realise benefits for people affected by dementia.

Modelling Participation of People with Dementia

Impact:

People with dementia have been involved in the design and implementation of many of the workstreams of the programme. This has improved the quality and appropriateness of the products for people with dementia and demonstrated that this population has both the capacity and will to co-produce dementia policy and services.

People with Dementia were Co-Designers on the Programme

Outputs:

- People with dementia co-designed the dementia learning and development framework, the public advertising campaign and the information resources produced in the first phase of the programme.
- The e-health and Data Analytics Pathfinder has involved people with dementia in the commissioning and implementation of the dementia analytics projects and the design of the dementia apps library and patient portal.
- This programme has modelled some examples of good practice in participation - lessons were captured from the first phase of the programme to support involvement of people with dementia in the work of the pathfinder programme.

Sustaining the Outcomes:

Those involved in the DSC/AP Dementia Programme have developed useful knowledge and practice in the participation of people with dementia that can be further developed and applied in future. Despite this progress, feedback from people with dementia indicates that there is much more to do to ensure that their right to participation is upheld, through mechanisms that facilitate more continuous involvement in dementia policy and service development with opportunity for genuine impact.

Summary of Overall Impact

The DSC/AP Dementia Programme catalysed investment and focused attention on improving publicly supported expenditures, policies and services for dementia. It has produced numerous new products with potential to improve the lives of people with dementia, and there is evidence of emerging system change as regards the provision of information, advice and support, and the development of appropriate knowledge and skills within the dementia workforce. The value of and models for engaging people with dementia as co-producers has also been demonstrated.

While there is commitment at service planning and delivery level to continuing to embed and sustain these achievements, the long period of suspension of the devolved Northern Ireland government had a chilling effect on the development of strategies and policies needed to support ongoing improvements in dementia care. The Regional Dementia Strategy produced in 2011 has expired and while a Regional Dementia Care Pathway has been designed, implementation has not yet begun. Reform of adult social care is also making slow progress. In absence of these strategies and the political focus, accountability and leadership they could bring, the long-term impact of the DSC/AP Dementia Programme is at risk. Activating the implementation of the Regional Dementia Care Pathway would provide a vehicle through which regional dementia outcomes could be agreed and models of working could be established that involve people affected by dementia as active co-producers and enable the public and other stakeholders to hold the public health and social care system to account.



3. Lessons Learned About Transformation

The DSC/AP Dementia Programme aimed to transform dementia services by embedding new ways of working and improved service delivery models into mainstream dementia practice. Like many programmes it involved delivering a series of projects, but somewhat unusually it also provided resources and space to plan how the work would effect longer-term change and to evaluate its impact and lessons learned. Several generalisable lessons were identified about how to accelerate and support transformation.

Applying Evidence-Informed Models

In several cases the AP/DSC Dementia Programme adopted existing approaches and service models with evidence of efficacy, and worked with practitioners to apply them to local circumstances. This approach accelerated progress and gave some degree of confidence over outcomes, while building ownership among practitioners.

Finding Ways to Share Excellence

One aim of the Dementia Programme was to tackle the issue of variation in dementia services across Northern Ireland, spreading the best practices across the region. Information guides for people affected by dementia may not be a particularly innovative product but by taking a collaborative approach to developing them, the project was able to harness the experience and motivation of dementia practitioners and service users who worked together to agree best practice guides for adoption across the region.

Involving the People Most Affected by an Issue

The Dementia Programme engaged people with dementia and carers in many of its workstreams. Where this engagement provided opportunities for genuine collaboration and co-production it upheld the rights of people with dementia to define and realise the changes they need and produced better outputs. Involving real people and reflecting their stories gave a more authentic perspective and was effective in motivating and engaging people in change. For example, the Still Me public information campaign starred people with dementia (not actors) and their stories resonated highly with the public. The involvement of people with dementia as co-producers on other programme products like the Dementia Learning and Development Framework and dementia information guides provided a challenge function and was widely regarded as having resulted in a better product. The gap was in programme governance where insufficient steps were taken to involve people with dementia in scrutiny and decision making.

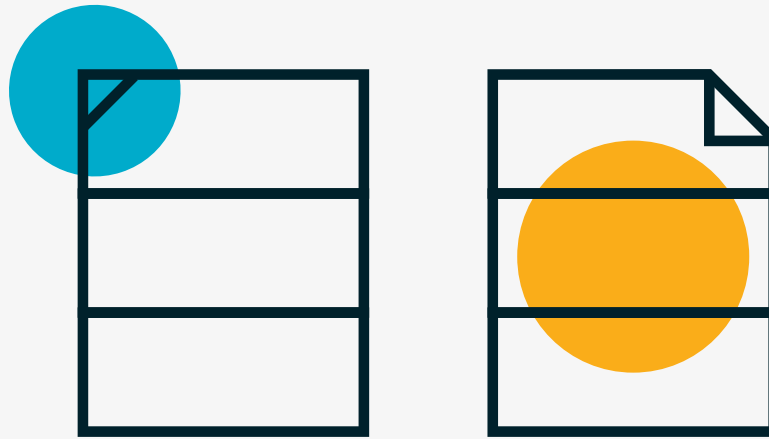
Working Collaboratively

Some of the Dementia Programme's products were pre-crafted during the programme design phase, while others had more design input from people in the system. The areas relying on 'command and control' worked less effectively. Where people were involved in the change from the outset it seemed to stick more easily and provide greater incentive among practitioners to work on sustaining it.

Planning for Impact and Sustainability

The partners in the Dementia Programme agreed on the long-term outcomes they wanted to achieve and made commitments to sustaining new products, services and ways of working. The funding package included continuation funding for elements of the programme requiring recurrent funding support. However, there wasn't always a clear strategy or approach to achieving sustainability and with attention on programme implementation, practical sustainability planning started late. This resulted in the first phase of the programme ending without a confirmed sustainability plan having been adopted for all of its work. This had variable impact.

Some areas of the programme used improvement methods that built in commitment to change from the outset. For example, the delirium service improvement project adopted a collaborative approach engaging practitioners from across the region in testing, refining and scaling up an evidence-based delirium management support tool. Sustainability was effectively built into the approach. While other areas of the programme relied more on demonstrating new models from first principles and there was reluctance to progress sustainability planning in advance of end-of-project evaluation (and the end of the programme). Some of the work had neither an identified owner at the end nor a clear succession path (e.g. on learning and development). The lesson is that programmes seeking to transform public services need early planning and persistent focus on how change will be embedded, and formal commitments on leadership and ownership of the ongoing change process.



4. Legacy

In seeking to partner with government, Atlantic recognised that the state had potential to realise the systemic and population-wide changes needed to better support people living with dementia. Philanthropic funding leveraged public resources into the dementia policy area, which had previously been poorly supported despite the existence of a regional strategy for improvement. New tools, capacities, services and ways of working were developed through the programme.

Investment in the programme – though small by public sector standards - had a catalytic impact on dementia services and support, resulting in additional, system changing activity that would not otherwise have happened. There is much to build upon from the AP/DSC dementia programme and there exists a capable and committed community of practitioners and people living with dementia. However, leadership and attention from policymakers are now critically needed if the programme is to result in longer-term system change and better outcomes for people with dementia.

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The A T L A N T I C *Philanthropies*

Atlantic Philanthropies is a global philanthropic foundation that aims to advance opportunity and tackle the root causes of inequity. Over its lifetime it awarded grants of more than 8\$bn in 8 countries. Atlantic operated in Northern Ireland for 25 years, investing 570\$m of grants to cement peace, improve public services, and protect and promote human rights. Among its final investments in Northern Ireland was a collaborative initiative with the NI Executive that aimed to improve services and outcomes for citizens – focusing on shared education and services for children, young people and families, and people with dementia - and develop more collaborative, effective and outcome focused ways of working.

Social Change Initiative collaborates internationally with activists, policy makers and funders to deliver lasting social change. Established in 2015, it took on responsibility for Atlantic Philanthropies' remaining commitments in Northern Ireland and has a particular interest in extracting and sharing the lessons from its partnership with government. This report is one of a series exploring how this experience can support broader social change efforts.



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