

Dementia Carer Voices - Rights and the Carer Voice The Policy Context

Introduction

Dementia Carer Voices recently published a report analysing the 14,000 pledges received over the three years of the project. In this report, Dementia Carer Voices laid out the key finding of our analysis and demonstrated key motivations and concerns among health and social care professionals and students.

Appendix 1 of [‘Dementia Carer Voices – Rights and the Carer Voice’](#) laid out a brief explanation of the policy landscape in health and social care, especially as it pertains to dementia. This document presents a more in-depth overview of this policy landscape to complement the full report. This policy context focuses especially on the key reports published over the last decade on the issue of dementia and health and social care policy that pertains most closely to dementia.

It presents the key messages of the following publications:

- Christie Commission on the Future Delivery of Public Services (2010)
- Realistic Medicine (2016)
- National Clinical Strategy (2016)
- The Health and Social Care Delivery Plan (2016)
- National Dementia Strategies one (2010), two (2013) and three (2017)

The Policy Context: Dementia policy in Scotland

The health and social care system in Scotland is currently undergoing a period of extensive changes. In light of challenges around supporting an ageing population, the prevalence of long term conditions and complex health needs, the Scottish Government has started the process of integrating health and social care. This process is intended to join up services, reduce repeated treatments and make the system more effective.

A predicted increase in mortality has led to an enhanced focus on issues relating to ageing and conditions that become more prevalent with age. As a result of this demographic change it is predicted that the number of people with dementia in Scotland will rise from around 86,000 people today to 164,000 people in 2036. Consequently, there is understandable concern amongst policy makers to address this in the years ahead.

There has been an explicit focus on tackling dementia in policy in Scotland. Since the publication of the first National Dementia Strategy there have been many

publications and policy proposals aimed at improving the quality of care for people living with dementia, their families and carers.

This section offers an overview of the ways in which key national policy documents have emphasised the importance of reforming the health and social care system to work more effectively in light of the upcoming demographic challenges. It then moves on to discuss the specific measures laid out by the Scottish Government in the three National Dementia Strategies.

Christie Commission on the Future Delivery of Public Services

In 2010, the Christie Commission's report on the Future Delivery of Public Services¹ set out the many challenges in supporting people in a system that is often fragmented and complex. The Commission identified four key objectives for a programme of reform:

- Public services are built around people and communities, their needs, aspirations, capacities and skills, and work to build up their autonomy and resilience;
- Public service organisations work together effectively to achieve outcomes;
- Public service organisations prioritise prevention, reducing inequalities and promoting equality;
- All public services constantly seek to improve performance and reduce costs, and are open, transparent and accountable.

The report called for transformative change in public service reform, identifying three priorities which relate to giving people a voice in the policy debate:

- Recognising that effective services must be designed with and for people and communities - not delivered 'top down' for administrative convenience;
- Maximising scarce resources by utilising all available resources from the public, private and third sectors, individuals, groups and communities;
- Working closely with individuals and communities to understand their needs, maximise talents and resources, support self-reliance, and build resilience.

It was the Commission's view that "unless Scotland embraces a radical new collaborative culture throughout our public services, both budgets and provision will buckle under the strain."²

The Christie Commission effectively, though indirectly, highlights how the upcoming challenges posed by dementia need to be addressed, and how addressing these

¹ Commission on the Future of Public Service Delivery, 2010, <http://www.gov.scot/Resource/Doc/352649/0118638.pdf>

² Ibid, p. viii

challenges effectively has an economic impact and can be a source of empowerment for individuals and communities.

Realistic Medicine

The Chief Medical Officer's annual report, 'Realistic Medicine' sets out the importance of co-production to the future of health and social care in Scotland, and the outcomes that co-production can achieve, with a focus not only on the design of services but also on the quality of individual interactions between professionals and people accessing their services.

The report argues that; 'there is an imperative for a system and values change that rebalances decision-making power, where the expertise of professionals is valued equally to the expertise that people have about themselves' and to move away from a paternalistic 'doctor knows best' model'.³

'Realistic Medicine' concludes that there is now a cultural and legal expectation on both professionals and people who access services to co-produce decisions suggesting that;

'Professionals will need to develop the personal capabilities, within an organisational system, that helps them to communicate with and support people to make the decisions that are right for them. Decisions that help them live well, and indeed die well, on their own terms.'⁴

National Clinical Strategy

Published by the Scottish Government in February 2016, the 'National Clinical Strategy' aims to provide clarity on the priorities for reform of healthcare in Scotland, making high level proposals for how clinical services need to change in order to ensure a sustainable model which is fit for the future.

The strategy aims to tackle a number of long established challenges, including disjointed and disease-focussed care for people with multiple conditions, and a growing number of system pressures in the form of financial and workforce limitations and under/over supply of services in some areas.

The importance of co-production, person centred care and an asset based approach is acknowledged throughout the Strategy, which identifies 'a need to increase coproduction with patients and carers' as a current challenge.⁵ This is one of the thirteen key current challenges identified facing NHS Scotland currently that are

³ Chief Medical Officer's Annual Report 2014 -15 , *Realistic Medicine*, <http://www.gov.scot/Resource/0049/00492520.pdf>, p.17

⁴ *ibid*, p.21

⁵ Scottish Government, 2016, A National Clinical Strategy for Scotland, <http://www.gov.scot/Resource/0049/00494144.pdf>, p.42

outlined in the strategy, emphasising the importance of co-production within the Scottish Government's agenda.⁶

The Strategy makes specific reference to the need to change the balance of power in health and social care between professionals and people accessing services, and invest in co-produced health and wellbeing in partnership with individuals, families, and communities. It also notes that advances can be made by harnessing technology, the use of 'big data' to inform service planning, and a future 'Patient Portal' where people would have access to health records and services to promote informed decision-making.

The Health and Social Care Delivery Plan

The Health and Social Care Delivery Plan of December 2016 set out an ambition of integrated working 'so the people of Scotland can live longer, healthier lives at home or in a homely setting'⁷ and that there is a health and social care system that:

- Is integrated
- Focuses on prevention, anticipation and supported self management
- Will make day care treatment the norm, except where hospital treatment is required and cannot be provided in a community setting
- Focuses on care being provided to the highest standards of quality and safety, whatever the setting with the person at the centre of all delivery
- Ensures people get back into their home or a community environment as soon as appropriate with minimal risk of re-admission.

National Dementia Strategies

In an international context, Scotland is considered to be ahead of the curve in terms of policy measures around dementia. Scotland's first Dementia Strategy (2010-2013) was published in 2010 and sets out how the Scottish Government and partners in the statutory sector and third sector can work towards improving support and care for people with dementia, their carers and family.

National Dementia Strategy 2010-2013

The strategy identified five key challenges that needed to be addressed to improve the lives of people with dementia, their families and carers.⁸ The challenges were:

⁶ Ibid, p.43

⁷ Scottish Government, 2016, The Health and Social Care Delivery Plan, p. 3
<http://www.gov.scot/Resource/0051/00511950.pdf>

⁸ Scottish Government, 2010, Scotland's National Dementia Strategy,
<http://www.gov.scot/Resource/Doc/324377/0104420.pdf>



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- Fear of dementia that means people delay in coming forward for a diagnosis;
- Information and support after diagnosis for people living with dementia, their families and carers is poor;
- General healthcare services do not always understand how to respond to people living with dementia, their families or carers, leading to poor outcomes;
- People living with dementia, their families and carers are not always treated with dignity and respect;
- Family members and people who support care for people with dementia do not always receive the help they need to protect their own welfare to enable them to go on caring safely and effectively.

While this first strategy has set a strong foundation for ensuring a good quality of life for people with dementia, their families and carers, there is still a great deal left to do.

National Dementia Strategy 2013-2016

The National Dementia Strategy 2013 - 2016⁹ sets out the progress that had been made in the previous three years and what work was needed to improve support, care and treatment for people living with dementia, their families and carers.

The National Dementia Strategy 2013-2016 piloted the 8 Pillar Model of Community Support, which set out the responses that are essential to support people with dementia, their families and carers.

The 2013-2016 strategy highlights three key challenges over the lifespan of the strategy and sets out how the Scottish Government will seek to address these:

- Ensuring that all care and support to people living with dementia, their families and carers promotes wellbeing and quality of life, protects their rights and respects their humanity;
- Services and support from diagnosis, and throughout the course of the illness, including supporting the needs of carers, must continue to improve;
- This support must be person centred, and should understand care and support from their perspective, not the perspective of service managers or clinicians;
- The redesign and transformation of services to ensure that they are adequately supported to deliver service effectively and efficiently.

The second dementia strategy committed the Scottish Government to 17 headline commitments to improve standards of care for people with dementia, their families and carers.

⁹ Scottish Government, 2013, Scotland's National Dementia Strategy: 2013-2016, <http://www.gov.scot/Resource/0042/00423472.pdf>

The document included a 10-point National Action Plan to plan to make sure the current system of hospital care is working and maximise the impact of staff operating in those settings.

National Dementia Strategy 2017-2020

The third [National Dementia Strategy](#) was published on 28 June 2017, coinciding with a range of activity in the Scottish Parliament related to the ALLIANCE's Dementia Carer Voice programme, including a Member's Debate on dementia in the name of James Kelly MSP, a parliamentary reception and the launch of our latest report – [Dementia Carer Voices – Rights and the Carer Voice](#).

Dementia Carer Voices was represented on the National Strategy Group and welcomes the publication of the strategy. Below we have detailed a few of our initial views on the strategy. See the full briefing note [here](#).

- In general, the ALLIANCE welcomes the more flexible approach laid out in Commitment 1 of the National Dementia Strategy – that good quality care should not be prevented by time constraints and instead focus on increasing “personalisation and personal outcomes in post-diagnostic treatment”. Indeed, we argued for the need to move away from a time and task culture towards one defined by care and compassion in our recent publication.
- From information gathered in our [carer survey](#) and other engagement we know the value that carers place on accessing services locally. In light of this we particularly welcome Commitment 2 which focuses on testing and independently evaluating the relocation of post-diagnostic dementia services in primary care hubs. Not only does this serve to provide services locally, but also, in housing services within primary care it has the potential to decrease stigmatisation and improve awareness raising of issues faced by people living with dementia.
- The ALLIANCE is fully committed to the ‘What Matters to You?’ programme and over the last two years across a range of our projects we have supported the principle of constructive conversations which are person-centred and ask, “What Matters to You”. In light of this we welcome the focus given to conversations in the strategy and the highlighting of the House of Care model. It is worth noting that the House of Care Adopter Programme in Scotland, led by the ALLIANCE, British Heart Foundation, Year of Care Partnerships and Scottish Government, was initiated in September 2014 and works in partnership with five Adopter sites in Lothian, Greater Glasgow & Clyde, Tayside, Ayrshire & Arran and Lanarkshire.