



Department of
Health

An Roinn Sláinte

Mánnystrie O Poustie

www.health-ni.gov.uk

EXPERT ADVISORY PANEL

ON

**ADULT CARE AND
SUPPORT**

CALL FOR EVIDENCE

December 2016

Foreword

We are delighted to be asked to form an Expert Advisory Panel to advise the Minister of Health on future reforms to adult care and support in the North of Ireland.

Care and support services in the North, as elsewhere across the world, are coming under increasing pressures because of a range of factors: an ageing population leading to increasing demand; greater complexity of need; changing expectations requiring new and innovative approaches to services, all within a challenging financial climate.

We note and welcome both the Minister's and the Executive's commitment to change as outlined in 'Health and Wellbeing 2026: Delivering Together', which highlights the Reform of Adult Care and Support as a key part in the overarching reform agenda.

The Minister has set an ambitious target of consulting on potential reforms in April 2017. This Call for Evidence is intended to provide a mechanism to enable stakeholders to share examples and evidence as to how care and support can be improved to meet growing demand and changing expectations, and to provide suggestions as to how the care and support system can be sustainably funded to meet those needs.

Des Kelly OBE

John Kennedy

Setting the Context

Introduction

The aim of this paper is to seek evidence to inform future reforms to the current system of adult care and support. This document:

- Sets out our remit (Annex A);
- Outlines our assessment of the current system, including the opportunities and challenges it faces going forward; and
- Sets out the questions we would like addressed as part of this Call for Evidence (summarised at Annex B).

Format of your response

The Call for Evidence will be open until **midnight on 23rd January 2017**. Any responses received after this time may not be considered. All responses should be sent to reform.careandsupport@health-ni.gov.uk or via post to:

Reform of Adult Care and Support Team
Department of Health
Room D2.19
Castle Buildings
Stormont Estate
Belfast BT4 3SQ

Given the volume of responses we expect to receive, the main body of the report should be no longer than thirty pages. Where a submission is longer than five pages we ask that an executive summary is included. We are happy to receive supporting evidence as annexed documents.

We reserve the right to publish any of the responses we receive. **If you do not want your submission to be published or quoted, please state this clearly on the front of your response.**

For further information on the Panel and the Reform project, please see our website <https://www.health-ni.gov.uk/articles/reform-adult-care-and-support>.

Adult Care and Support

Adult Care and Support describes the activities, services and relationships that help us to live an independent, healthy, active and inclusive life. This includes both adult social care, which is the responsibility of the Department of Health, and services provided by other government departments which can support people to lead more independent lives, for example, benefits, help with housing, transport etc.

Adult Social Care

Adult social care supports include:

- Domiciliary care
- Residential care
- Nursing home care
- Day Opportunities
- Short Breaks
- Provision of equipment

At present, just under £900m per year is spent on adult social care services supporting vulnerable people in the community.

A System Under Pressure

As we look to the future, according to the latest NISRA population projections¹:

- the population aged **65 and over** is projected to **increase by 74.4%** to 498,500 people from mid-2014 to mid-2039, with the result that one in four people will be aged 65+;
- the population aged **85 and over** is projected to **increase by 157.3%** to 88,600 people over the same period, which will see their share of the population increase from 1.9 per cent to 4.4 per cent.

These changes will change the shape of our society, with the ratio of working age adults to older people shrinking and the proportion of the population aged 65 and over surpassing children (up to the age of 15) by mid-2028².

As people get older, they are more likely to need help and support, with rates of ill health and disability increasing dramatically: the rate of disability among those aged over 85 is 67% compared with only 5% among young adults³. Dementia is a growing issue for our older population, with 60,000 people projected to be suffering

¹ NISRA Statistical Bulletin: 2014-Based Population Projections (published 29 Oct 2015)

² NISRA Statistical Bulletin: 2014-Based Population Projections (published 29 Oct 2015)

³ Transforming Your Care, Health and Social Care Board, December 2011

from the condition by 2051⁴. In addition, the profile of older people requiring care is becoming more complex, with many people now living with multiple chronic illnesses. Similarly, advances in medical knowledge and practice mean that people with disabilities are also living longer, and more people with learning disabilities are living well into adulthood and old age.

At the same time, our society is experiencing huge change in terms of what people want from public services, with increasing demand for greater choice and control over how care and support needs are met.

The Reform of Adult Care and Support

The Department of Health is taking forward a three stage process to reform the adult care and support system in the North.

Having completed a large scale public consultation exercise in 2013 as part of stage one, the Department has now moved to stage two of the process which will see the development of proposals for change which will be the focus of a second period of public consultation.

Health and Wellbeing 2026: Delivering Together

The Minister's vision, 'Health and Wellbeing 2026: Delivering Together' was published in October 2016 and sets out a commitment to tackling the issues facing the health and social care system. As part of that commitment, the Minister has identified consultation on proposals to reform the adult care and support system as a key action to be achieved by April 2017.

Expert Advisory Panel

The Panel was established on 5th December. The Panel's role is to provide advice to the Minister of Health on the nature of reform needed to ensure that the future system of care and support in the North is both sustainable and designed to respond to individual preferences about how needs are met.

⁴ Dementia Strategy, DHSSPS, 2010

PRIORITY AREA ONE: EMPOWERING PEOPLE TO MAKE POSITIVE CHOICES AND PLAN FOR THE FUTURE

Men and women in the North have fewer expected years of living in good health than their counterparts in the UK: men in the North can expect 58.6 years of living in good health compared with 64.2 years in the UK, while women in the North can expect 61.9 years of living in good health compared with 66.1 in the UK.⁵

In order to further manage demand for care and support, public health messages can play a key role in encouraging people to make better lifestyle choices, thereby reducing potential risk factors such as obesity, alcohol misuse and inactivity.

Reducing health inequalities such as poverty and social deprivation is also key to improving the long term health of the population and managing future levels of need for social care.

Informing people through the provision of appropriate, tailored information can play a key role in empowering people to make positive choices. Yet research undertaken by AgeNI for the Commissioner for Older People points to a “serious” lack of knowledge among potential future users about the sort of help which is available.⁶

It is also recognised that the availability of suitable housing can play a key role in enabling people to plan for the future.

What we are looking for:

- a. Evidence of initiatives which can encourage people to make positive lifestyle choices and plan for their later years;
- b. Evidence of the most effective approach of providing information on the care and support system.

⁵ UK National Wellbeing Measures: NI Data (NISRA)

⁶ Adult Social Care in NI: Engagement with Older People (AgeNI/COPNI) 2015

PRIORITY AREA TWO: SUPPORTING PEOPLE TO REGAIN, RETAIN AND MAINTAIN THEIR INDEPENDENCE

Empowering people to make positive choices can help prevent care and support needs, but not all care and support needs can be prevented. They may arise from an unexpected crisis such as a fall or perhaps from longer term frailty.

We know the value that people place on their independence, and commissioners have responded with services such as reablement, which are designed to restore a person's capacity for independent living, reducing long-term dependency and potentially removing the need for care and support altogether.

We also recognise the role of local communities and voluntary groups in supporting vulnerable people within the community. Wider services also play a key role such as appropriate housing and transport to promote both social interaction and access to services.

Technology is a huge part of daily life today, used by most people to communicate with their family and friends, keep up to date with world news and manage home security. Many public services already use technology creatively to meet the needs of their customers, and social care should be no exception. Technology can support care in many ways, including education; promoting healthy living; preventing disease; improving clinical information and management systems; and monitoring patients.

What we are looking for:

- a. Examples of local initiatives which have had a positive impact;
- b. Ideas on how government can improve awareness of supports which exist in local communities which can help maintain independence;
- c. Ideas/evidence on how services can be redesigned to promote independence rather than fostering dependence;
- d. Ideas on how the care and support system can work more effectively with Housing and Transport to support people in the community;
- e. Views on how best to integrate the role of technology to support people to remain independent.

PRIORITY AREA THREE: SUPPORTING CARERS

Carers NI estimate that carers save the government some £4.6bn per year. Securing the continued support of carers is essential to ensure sustainability of the system. Research suggests that the combination of adult children living away from parents, smaller families and greater numbers of older people with no children will mean lower levels of informal care in the future, that a 'family care gap' will emerge for the first time in 2017⁷, and that government intervention should be focused on those providing 20 hours or more of care.⁸ Other concerns include limited support to enable older carers of adult children with a learning disability to plan ahead for the cared for person.⁹

Carers who participated in research undertaken by AgeNI indicated that they felt frustrated about a lack of clarity about what was available, what rights they had as carers and what rights their parents had as people who use services.¹⁰

What we are looking for:

- a. Evidence of effective interventions including respite care/short breaks which can support carers in their caring role, including increasing resilience;
- b. Initiatives which can encourage people to act as carers in the context of changing society (e.g. often greater distances between family members, increasing numbers of people working).

⁷The Generation Strain: Collective solutions to care in an ageing society (IPPR) 2014

⁸ Knowledge Exchange Seminar (NI Assembly) 2015

⁹ Future planning for carers of people with a learning disability (PCC) 2014

¹⁰ Adult Social Care in NI: Engagement with older people (AgeNI/COPNI) 2015

PRIORITY AREA FOUR: CHOICE AND CONTROL

We know that the expectations of people using services and their families have changed and are continuing to change. People, rightly, are no longer content with being offered a limited range of established services to meet a broad range of needs.

People who use services are increasingly demanding choice and control and government has responded with the introduction of Direct Payments and the roll out of Self Directed Support. But we also know that some people are reluctant to exercise this level of choice and control, and we need to understand the appropriate balance between promoting choice and control while also offering sufficient support to those who want it.

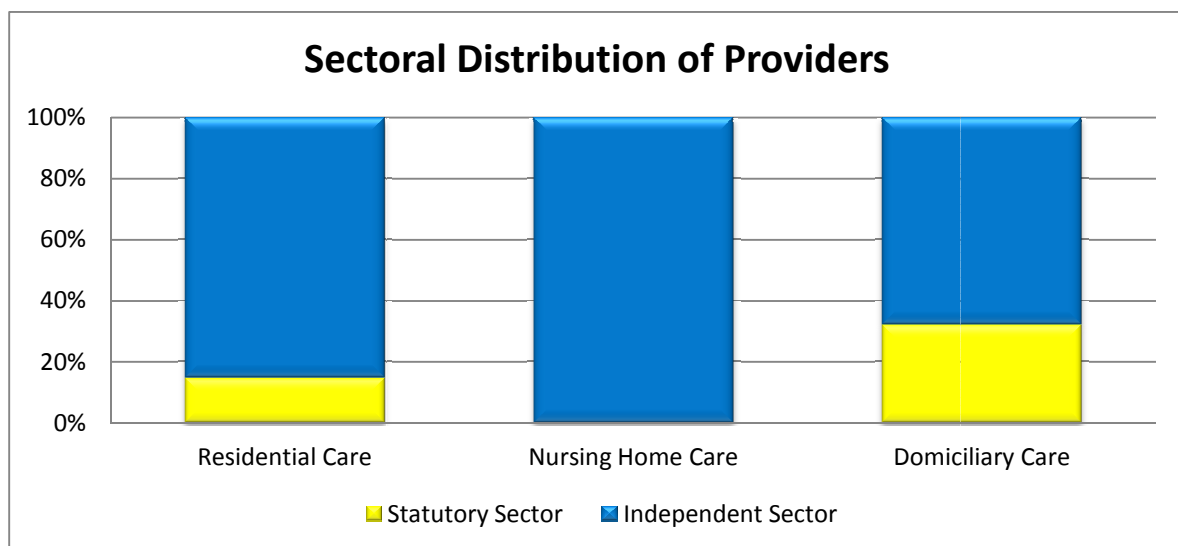
What we are looking for:

- a. Views on what barriers exist which restrict choice and control;
- b. Initiatives which can empower people to exercise choice and control when they may be reluctant to do so;
- c. Views on balance between recognising a service user's preferences about how their needs are met and potential additional risk to that service user as a result of the choice.

PRIORITY AREA FIVE: AN EFFECTIVE, INNOVATIVE AND RESILIENT CARE AND SUPPORT MARKET UNDERPINNED BY A VALUED SOCIAL CARE WORKFORCE

People First, the Department's community care strategy which dates back to the early 1990s, contains a commitment to a flourishing independent sector alongside good quality public services.

The independent sector now provides 100% of nursing home care, 83% of residential care and 68% of domiciliary care (against 51% of domiciliary care in 2008).



We know that there are some concerns about the current model of care provision:

- some members of the public are concerned about the perceived quality of care provided by the independent sector in comparison with the statutory sector;
- Providers have expressed concern about rising cost pressures and fees which are not increasing at the same rate;
- some concern among commissioners across the UK about the viability of some providers, with recent care home closures and domiciliary care providers handing back contracts which they are unable to fulfil.

Approximately 12,000 people are employed in the residential, nursing home and domiciliary care sectors.¹¹ Concern continues to grow about the availability of an adequate future workforce to meet growing demographic demand. In addition there are concerns about training, recruitment and retention and limited career development.

What we are looking for:

- a. Evidence outlining specific challenges to the care and support market and workforce in the North;
- b. Initiatives which can improve the functioning of the care and support market, including improving public levels of trust in the independent sector;
- c. Initiatives which can improve the experience of the care and support workforce and bolster recruitment and retention of the care and support workforce.

¹¹ Can we trust the trusts? (ICHP, UKHCA) 2013

PRIORITY AREA SIX: FINANCIAL SUSTAINABILITY

Almost £900m is spent on adult social care per year through the HSC in the North. People who use services contribute approximately £125m of that, mainly through charging for residential and nursing home care. We know that many people feel the current charging system is unfair: people in care homes can face huge costs depending on their ability to pay while those with lesser needs who are supported in their own home through the domiciliary care service are not charged.

We also know that, with growing demand, without significant additional funds the system will not be able to continue to provide support at the current level.

There is a need therefore to take action to address both these issues: fairness to those using services when it comes to the application of charges, and the need to ensure the system has sufficient levels of funding to ensure future care levels are not at risk.

What we are looking for:

- a. Evidence of efficiencies within the care and support system which could release funding for investment in additional services;
- b. Factors unique to the population in the North which should be considered in the context of charging for care and support services;
- c. Evidence of the impact of charging on people who use services and care provision;
- d. Measures which could be adopted to address the perceived unfairness of charging for residential care.

Expert Advisory Panel on Adult Care and Support:

Terms of Reference

The Expert Advisory Panel will supplement the work of the Core Team in developing proposals for change in the following areas:

- Steps which can be taken to empower people to encourage positive lifestyle choices and planning for the future;
- Supporting people to regain, retain and maintain their independence through, for example, a focus on preventative services and technology;
- Supporting carers in their caring role;
- Facilitating choice and control over how care and support needs are met;
- Ensuring an effective, innovative and resilient care and support market underpinned by a respected, quality social care workforce; and
- Measures which can be taken to ensure the financial sustainability of the care and support system.

In this context, the Panel will help shape proposals through:

- A call for evidence inviting stakeholders to share ideas on potential reforms;
- A review of evidence and international best practice in these areas;
- The identification of further areas for potential reform which could contribute to a better system of support; and
- Assessing impact of reforms on balance of responsibility between government, people who use services and carers.

The Panel will report directly to the Minister.

Summary of Questions

We are interested in your suggestions on the future of adult care and support given the challenges and pressures facing the current system. Below are the questions we would like addressed.

We understand that this is a complex area and you may not feel able to answer all the questions set out below.

The Call for Evidence will be open until midnight on **23rd January 2017**. We ask that you provide a summary of your response if longer than five pages, and that the body of your response is no longer than thirty pages. We are happy to accept supporting evidence as annexes.

Please remember to note on the front cover of your response if you do not want your response or part of your response to be made public.

Please email your responses to reform.careandsupport@health-ni.gov.uk or post to:

Reform of Adult Care and Support Team
Department of Health
Room D2.19
Castle Buildings
Stormont Estate
Belfast BT4 3SQ

Questions:

PRIORITY AREA ONE: EMPOWERING PEOPLE TO MAKE POSITIVE CHOICES AND PLAN FOR THE FUTURE

What we are looking for:

- a. Evidence of initiatives which can encourage people to make positive lifestyle choices and plan for their later years;
- b. Evidence of the most effective approach of providing information on the care and support system.

PRIORITY AREA TWO: SUPPORTING PEOPLE TO REGAIN, RETAIN AND MAINTAIN THEIR INDEPENDENCE

What we are looking for:

- a. Examples of local initiatives which have had a positive impact;
- b. Ideas on how government can improve awareness of supports which exist in local communities which can help maintain independence;
- c. Ideas/evidence on how services can be redesigned to promote independence rather than fostering dependence;
- d. Ideas on how the care and support system can work more effectively with Housing and Transport to support people in the community;
- e. Views on how best to integrate the role of technology to support people to remain independent.

PRIORITY AREA THREE: SUPPORTING CARERS

What we are looking for:

- a. Evidence of effective interventions including respite care/short breaks which can support carers in their caring role, including increasing resilience;
- b. Initiatives which can encourage people to act as carers in the context of changing society (e.g. often greater distances between family members, increasing numbers of people working).

PRIORITY AREA FOUR: CHOICE AND CONTROL

What we are looking for:

- a. Views on what barriers exist which restrict choice and control;
- b. Initiatives which can empower people to exercise choice and control when they may be reluctant to do so;
- c. Views on balance between recognising service user's preferences about how their needs are met and potential additional risk to that service user as a result of the choice.

PRIORITY AREA FIVE: AN EFFECTIVE, INNOVATIVE AND RESILIENT CARE AND SUPPORT MARKET UNDERPINNED BY A VALUED SOCIAL CARE WORKFORCE

What we are looking for:

- a. Evidence outlining specific challenges to the care and support market and workforce in the North;
- b. Initiatives which can improve the functioning of the care and support market, including improving public levels of trust in the independent sector;
- c. Initiatives which can improve the experience of the care and support workforce and bolster recruitment and retention of the care and support workforce.

PRIORITY AREA SIX: FINANCIAL SUSTAINABILITY

What we are looking for:

- a. Evidence of efficiencies within the care and support system which could release funding for investment in additional services;
- b. Factors unique to the population in the North which should be considered in the context of charging for care and support services;
- c. Evidence of the impact of charging on people who use services and care provision;
- d. Measures which could be adopted to address the perceived unfairness of charging for residential care.