



WHO CARES?



The Future of
Adult Care
and Support in
Northern Ireland

Executive Summary



MINISTERIAL FOREWORD

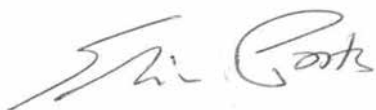
The care and support system directly impacts on thousands of people's lives every day in Northern Ireland, whether as people who need services, or as family members, friends and carers of those who do.

While there is much that is good about the current system, it is coming under increasing pressure and we need to react now to ensure that we are in a position to meet needs in the future.

This is not just an issue for those who use services now: none of us know if we or a family member or friend might need support at some point in our lives.

We want to hear your views on how care and support can be better, more effective, more efficient and deliver better outcomes: empowerment and independence, not dependence.

This is your opportunity to help shape how we support people in the future and I urge you all to participate in the debate and share your views and experiences.



Edwin Poots MLA
Minister for Health, Social Services and Public Safety



● **MINISTERIAL STATEMENT**

● My Department makes a significant contribution to the provision of services to vulnerable adults through the supporting people scheme, social security and disability benefits and the provision of supported housing and I wish to welcome the proposed discussion document and the DHSSPS approach being taken for the future of Adult Social Care.

● *Nelson McCausland*

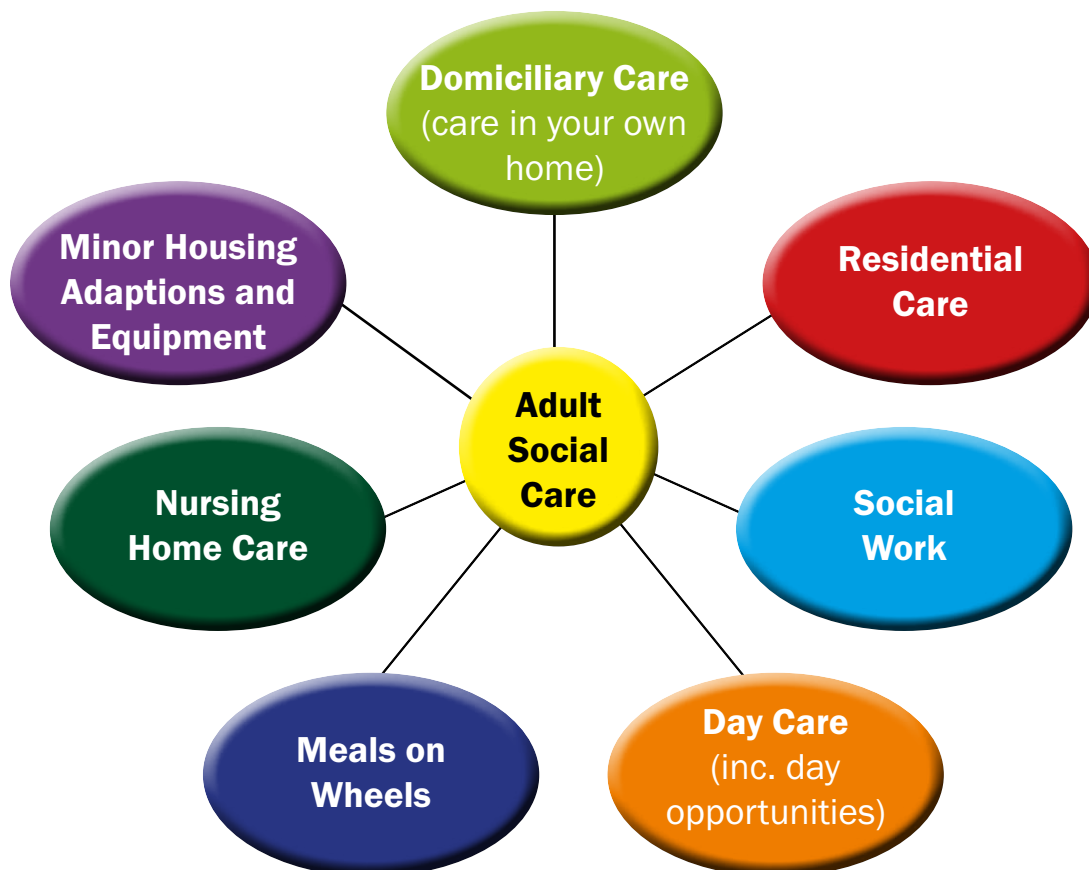
● **Nelson McCausland MLA
Minister for Social Development**

What is Care and Support?

Many of us don't need any type of support to carry out everyday tasks like washing, dressing, shopping, cooking etc. But some people will need help with certain tasks because of events in their lives, illnesses, disabilities, or because they cannot protect themselves from harm. Equally, as people move into old age, it is likely that many will need assistance of some sort. It is in these types of circumstances that the care and support system steps in to provide that assistance.

Care and support in NI involves a wide range of services provided across government. These services include adult social care which is the responsibility of the Department of Health, Social Services and Public Safety (DHSSPS) working alongside benefits and help with housing which is the responsibility of the Department for Social Development (DSD).

The majority of care and support services are delivered through adult social care, part of the Health and Social Care (HSC) system provided by the Health and Social Care Board and Trusts. Some of the ways adult social care supports people are outlined in the diagram below:





Adult social care also includes services that are provided for those people who care for family members or friends, for example:



- information, advice and counselling;
- respite/short breaks;
- help with equipment;
- help with home adaptations;
- training in aspects of care;
- help with laundry;
- advocacy;
- helplines and carer support groups.

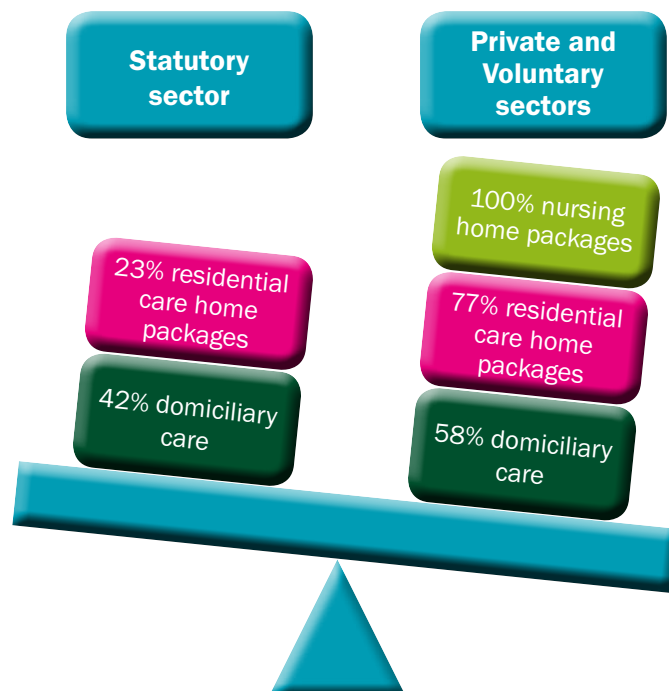


How is Adult Social Care Delivered?

The main providers of adult social care services are:

- **the statutory sector** (government agencies, e.g. Health and Social Care Trusts)
- **the private sector** (organisations and individual proprietors that own and run services for a profit)
- **the voluntary sector** (organisations, often registered as charities, which operate on a non profit-making basis, to provide help and support).

Over the last 10 years or so, adult social care services have been increasingly provided by the private sector and voluntary sector, while the proportion of services delivered by the statutory sector has fallen. We need to explore whether this is the best mix to provide adult social care in the future.



Source: cc7 31 December 2011, cc7b 2011 (DHSSPS)

Other government departments also provide services which can support people to lead more independent lives, and make up part of the care and support system. For example, services provided through the Department for Social Development (DSD) include:

- **Benefits** (Disability Living Allowance (DLA), Attendance Allowance and Carer's Allowance)
- **Housing Adaptations** (minor and major changes to the home such as rails or hoists)
- **Supported Housing** (support at home to help people live more independently)

Why do we need to Change the System?

The current system of care and support is coming under pressure for a number of reasons:

Demographics

We have an ageing population. Similarly, advances in medical knowledge and practice mean that disabled people are also living longer, and more people with learning disabilities are living well into adulthood.

These developments should, of course, be welcomed and celebrated. Many older people and people with disabilities enjoy good health and play a significant role in their local communities, families, and society as a whole, whether that be as carers, learners, workers or volunteers.

However, an ageing population does of course also have consequences for the future. For example, rates of ill health and disability increase dramatically the older we get. And if our population is getting older and living longer with more complex health problems, it is to be expected that more people will need care and support services in the future.

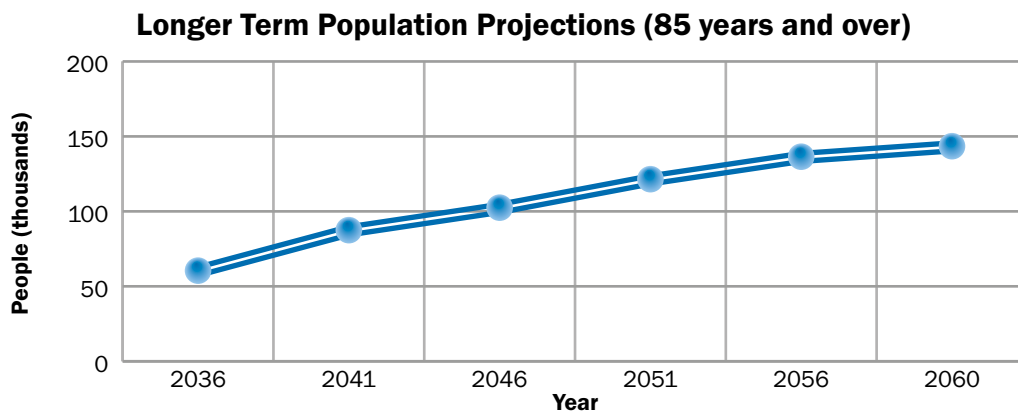
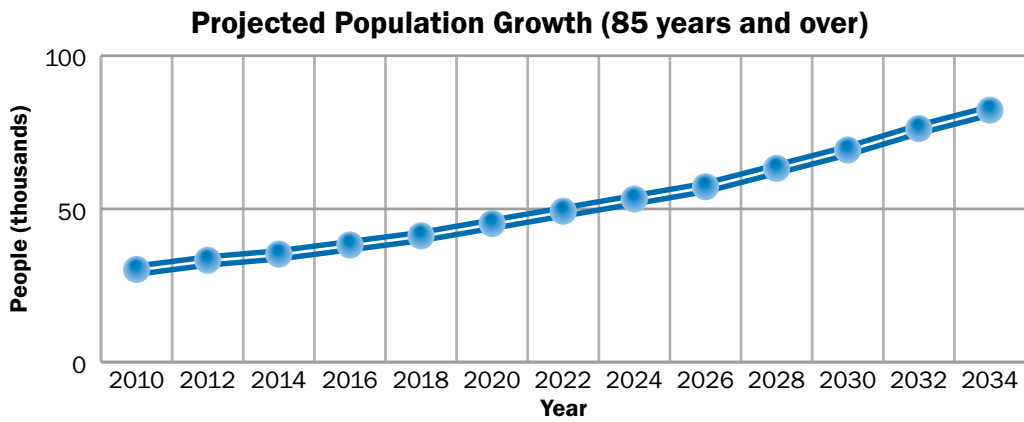
Some key facts

The NI Statistics and Research Agency (NISRA) has projected that, compared to 2010 figures, by 2025:

- the NI population will rise from 1.799 million to 1.951 million;
- the numbers of people aged 65 and over will increase by around 42%, or 110,000, whereas the working age population will increase by only 15,000 (1.4%);
- the number of people aged 85 and over will increase by 25,000, or 83%, to 55,000, of whom 62% will be women. The over-85 population will double by 2027 compared to 2010.



Over the coming years the funding available for care and support in NI is unlikely to increase enough to keep up with growing demand, and this will put intense and growing pressure upon the current system.



Changing Expectations

Our society has experienced huge change in terms of what people want from public services, what they value and what they expect. People today are better educated, more independent and more affluent than ever before, and want choice, control and change in all areas of their lives. In addition, people with care and support needs generally want to live independent, socially inclusive lives; they want to design their own care and support in a way that best meets their needs, rather than trying to fit themselves into existing services.

Our care and support system has to accept these changes in attitude and move with the times. However, we have to acknowledge that these increased expectations cannot be met through the current system and the funding available to it.

Lack of Understanding of the System

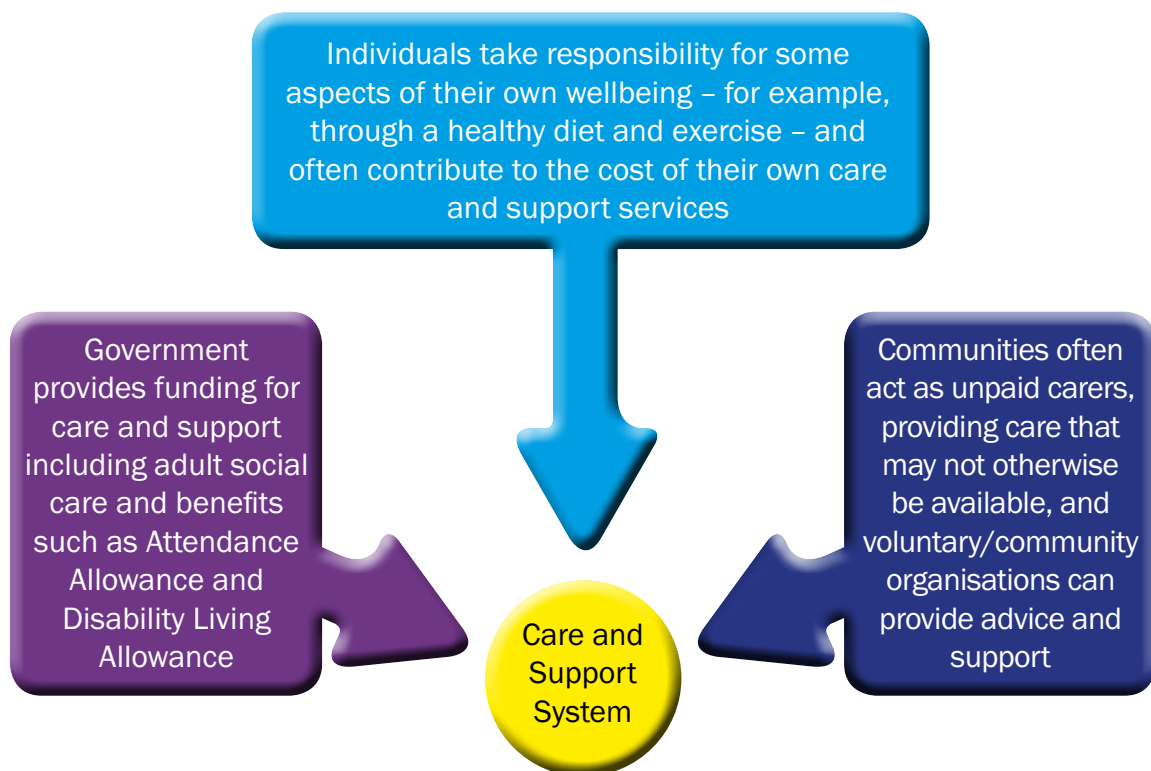
Another problem with our existing system is that people too often do not understand who is responsible for the provision of care and support. Many people think that care and support is the responsibility of government, and that all services are free at the point of delivery, like the NHS, which can mean that some people will make no

preparation for their future, as they believe the government will meet all the costs of their care. In reality, many services require the person using the service to make some contribution towards the cost.

People will also often underestimate the likelihood that they will have a need for care or support in the future. About a third of all men and half of all women will, upon reaching 65, need long-term care and support at some time as they age¹.

What is the balance of responsibility for Care and Support?

Government, individuals and communities all contribute to the care and support system:



Government currently spends **over £811m** on adult social care and a further £947m on Attendance Allowance and Disability Living Allowance. People receiving services contribute a further £101m. And Carers NI have estimated that the support provided by carers would cost £4.4bn if it was instead to be provided by government. Many people think that this current balance is unfair because:

- People are required to contribute to the cost of services such as residential and nursing home care which they believed had already been paid for through taxation;

1 Caring for the Very Old: Public and Private Solutions, H Glennerster, 1996

- There is no consistent approach to charging across all adult social care services. For example, personal care provided by the domiciliary care service is completely free, while people who need residential or nursing home care contribute up to the full cost of their care. This can mean that, depending on your means and the service you need, your service could be free or you could face very high care costs – the cost of an average stay in a residential care home is in excess of £100,000;
- People with assets such as a former home find it unfair that they often have to sell those assets to pay for their care while those without assets receive financial support from government to ensure their care needs are met;
- While many carers give their time willingly, they can feel isolated, taken for granted and unsupported.

The central aim for a future funding system of care and support must therefore be a fair settlement between people who use services, carers and wider society who help fund care and support through taxation.

Vision

Recognising that the care and support system in Northern Ireland is coming under increasing pressure and that changes must be made to ensure it remains sustainable and capable of meeting the needs of the people who rely on it, we have identified a number of core principles which we think should underpin how we design our system of care and support in the future:

- **Dignity and Respect** – for everyone who uses services, their carers and the staff who provide care;
- **Quality** – care and support services must meet recognised validated standards;
- **Independence** – our efforts should be directed to keeping people living independently in their own homes for as long as possible;
- **Equity** – of access to, and eligibility for, care;
- **Equality and Diversity** – everyone, regardless of circumstances, should be treated fairly and equally;
- **Human Rights** – protection and promotion of everyone's human rights should be built into how our care and support systems work;

- **Safeguarding** – zero tolerance of abuse, wherever it occurs, whoever is the victim and whoever is responsible; **and, importantly,**
- **Sustainability and Affordability** – of our care and support system into the future.

Care and support is a collective responsibility for us all. We need to work together, across both government and sectors, and in partnership with the individual, to ensure a more joined-up approach in planning and providing care and support.

Care and support has often focussed too much on doing things to or for people, and not enough on helping people to do things for themselves. We need to consider how best we can empower people to help themselves. This could be, for example, through advice and information on how to look after ourselves, how the care and support system works, how it is funded and how to access it when we need it. Advocacy services can also play a role, ensuring that those who are not being heard are supported to say what they want and have their views heard.

Building on the principles identified on the previous page, we have developed a draft vision for the future of care and support in Northern Ireland:

Draft Vision

Working across government and in partnership with people who use services, carers, providers and communities:

- every person should be treated with dignity and respect, and should as far as possible be supported to lead the life they freely choose, safeguarded against harm from abuse, exploitation or neglect;
- for all of us, care and support should recognise, foster and promote the preventative role we can all play as individuals in maintaining our own wellbeing and that of those around us;
- for people with a care need, care and support should be personalised to individual need, providing the right support at the right time in the right place, with a focus on early intervention to protect and restore independence wherever possible.

We also need to look at the type of support available. Some of the main areas are:

<p>Prevention</p>	<p>For many people, their first contact with care and support will be in response to an unexpected crisis or illness.</p> <p>Of course a safety net in the event of a crisis or illness is one of the core purposes of care and support. But we shouldn't just focus on reacting to problems, we should work to try and reduce the likelihood of problems occurring in the first place and, where we can't, our aim must be to help people maintain or regain their independence.</p>
<p>Reablement/ Recovery</p>	<p>Linked to Prevention, services should be designed to actively restore independence and, where possible, potentially remove a person's need for care and support altogether.</p>
<p>Personalisation/ Self-Directed Support</p>	<p>People using services should be in charge of how their assessed needs are met. Care and support should be designed and moulded to individual need rather than expecting everyone to accept a standard service. Personalisation could take the form of Direct Payments where a person receives a cash payment to arrange their own support. Or it could involve the individual agreeing with a Trust how the budget for their care will be spent. In all cases, the individual should have the maximum choice and control in planning the services they receive and how they receive them.</p>
<p>Support for Carers</p>	<p>Carers have long been the backbone of care and support. We recognise the pivotal role that carers play in supporting many thousands of vulnerable people in our communities and the toll that this can have on the health and wellbeing of carers themselves. Carers know what works for them and for the people they provide care for, and so should be recognised as equal and expert partners in the provision of care and support.</p>

We also believe that we need a range of alternative options for people who can no longer be supported in their own homes, such as Supported Housing, which provides people with that little bit extra help and security, while at the same time enabling people to remain in as domestic an environment as possible. Residential care and nursing homes will continue to play an important role in supporting the most vulnerable in our communities.

The Future of Care and Support

We need to find a fair, sustainable and efficient way to fund and provide care and support in the future, sharing responsibility with the individual, to ensure that all those who need it have access to high quality, value for money care, at the right time and place.

Faced with increasing demand and limited resources, government needs to find a balance between responding to and meeting individual aspirations and wishes (such as to be supported at home) while also ensuring that limited resources are used efficiently to enable the maximum number of people to be supported with those resources.

If we fail to get to grips with these long-term issues, we run the risk of failing to provide appropriate levels of care and an acceptable quality of life for potentially large parts of our population.

How to get involved

With that in mind, we want to hear what you think about the issues we have raised. In particular we want your response to the following questions:

Q1:	Were you previously aware what care and support services are available to you, and where to go or who to ask to gain access to these services?
Q2:	Do you agree with our vision for care and support?
Q3:	Do you agree that care and support should continue to be provided on a partnership basis between the statutory, private and voluntary sectors?
Q4:	Do you agree that care and support should focus more on earlier intervention and prevention of loss of independence? Should savings made in hospitals be reinvested in preventative care and support services?
Q5:	Do you agree that people who need care and support should have control over how their assessed care and support needs should be met?
Q6:	Do you agree that we have identified the right areas for reform?
Q7:	Do you agree that there should be a balance between fulfilling individual preferences for how care and support needs are met and ensuring that resources are used efficiently to provide support to as many people as possible?
Q8:	Do you think that the current balance of responsibility between government, people who use services and carers is fair/right? If not, how should we change the role of: (a) Government? (b) People who use services? (c) Community and Carers?



You can send your answers to these questions either by post or by email to the Reform Team by **15 March 2013** at the address below.



A proforma is available to help you record your comments and views and can be downloaded from the DHSSPS website:

<http://www.dhsspsni.gov.uk/showconsultations?txtid=58501>



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Alternatively, an online questionnaire is available via:

<http://www.dhsspsni.gov.uk/index/hss/reform-cas-form.htm>

The full discussion document 'Who Cares? The Future of Adult Care and Support in Northern Ireland' can be downloaded from the DHSSPS website or contact the Reform Team to request a copy.

We are also holding a number of regional public consultation meetings where you can come and share your views on these issues. Check our website (<http://www.dhsspsni.gov.uk/index/hss/reform-cas.htm>) or your local newspaper for more details.

Please note that the Department will be unable to respond to individual responses to the consultation; however, a full summary of responses will be published following the close of the consultation period.

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