

Prepared to Care?

Modernising Adult Social Care in Northern Ireland

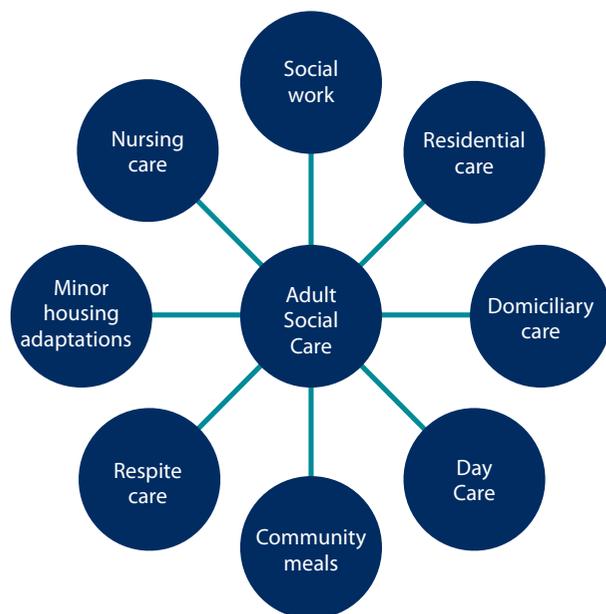
Adult Social Care
Care homes **Social work**
Provision of equipment **Respite**
Nursing and residential care **Independence**
Advocacy **Domiciliary care** **Laundry** **Carers**
Housing Adaptations **Support Services**
Home support **Community meals** **Day Care**
Rights and entitlements
Informed choices

Northern Ireland: Growing older

Northern Ireland is growing older, with life expectancy increasing faster than ever before. We are a better and richer society because more of us are living longer and healthier lives than ever before. One of the biggest challenges facing government today is the need to adequately prepare for ageing in a way which ensures that older people are enabled to live independent and dignified lives for as long as possible, as well as to ensure that necessary and appropriate support is available to those who need it. Adult Social Care is key to enabling older people to remain engaged and active. Engagement with older people has made it clear to the Commissioner that there is a lot of confusion around entitlements and access to these services. This report brings together a review of law and policy on Adult Social Care and sets it alongside the experience of older people making three key recommendations to government on the need to modernise Adult Social Care and support in Northern Ireland.

What is Adult Social Care?

Adult Social Care is vital for thousands of older people in Northern Ireland. It refers to services provided or secured by Health and Social Care Trusts for adults who need extra support, either to live their lives as independently as possible, who are vulnerable or who may need protection.¹ It comprises a number of services, ranging from residential and nursing care homes and the provision of aids and adaptations to domiciliary or home care support.



Role of the Commissioner for Older People

The Commissioner for Older People for Northern Ireland has a statutory duty to keep under review the adequacy and effectiveness of law and practice relating to the interests of older people. In her *Corporate Plan, Hope, Confidence, Certainty*, the Commissioner identified as a priority for action the need to review the effectiveness of law and policy in relation to entitlements to social care for older people.

¹ Department of Health, Social Services and Public Safety (DHSSPS), *Who Cares? The Future of Adult Care and Support in Northern Ireland. A Discussion Document*, 37 (Belfast: DHSSPS, 2012).

Current legislation and policy guidance

Adult Social Care law dates back over forty years. During this time, service development, technological advancements and changing lifestyles within society have continued to evolve. In contrast however, the law and policy surrounding Adult Social Care has not moved at the same pace.

Terminology and definitions contained within some of the oldest legislation are outdated, and there is unhelpful and confusing duplication as well as a lack of a coherent overarching rationale.

The tables opposite outline the key legislation and policy guidance which underpin the provision of Adult Social Care services and entitlements in Northern Ireland:

Key Adult Social Care legislation

- Health and Personal Social Services (NI) Order 1972
- Chronically Sick and Disabled Persons Act 1978
- Mental Health (NI) Order 1986
- Disabled Persons Act 1989
- Health and Personal Social Services (Assessment of Resources) Regulations (Northern Ireland) 1993
- Human Rights Act 1998
- Carers and Direct Payments Act 2002
- Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003
- Health and Social Care Reform Act 2009

Policy guidance

In addition to the legislation, a number of circulars and guidance which have been issued over the last 15 years direct practitioners in terms of how Adult Social Care services are assessed and delivered in practice. These include:

- Setting minimum standards for residential and nursing care homes;
- Setting levels of charging for residential and nursing care;
- Hospital discharge protocol;
- Care management, care assessment and provision of service.

Adult Social Care in practice

Many older people and their carers are unclear or unaware about their entitlements to social care and how to access these services. In addition, the ways in which Adult Social Care can be accessed, delivered and funded are also confusing meaning that many people in need of support may be missing out on services which could have a real impact on their quality of life. This can include a lack of availability of suitable high quality beds in residential or nursing homes, adequate rehabilitation support as well as timely access to aids and adaptations. The provision and availability of these services can vary from Trust to Trust, leading to a sense of “postcode lottery” at play in Northern Ireland.

For many older people and their families, the first interaction with Adult Social Care is at the point of a crisis where, for example, an older person becomes ill and requires more support or care, often at short notice. Throughout the Commissioner's engagement on this project, many people said that they felt pressurised into making significant decisions around discharge from hospital to a care home. In such cases, older people and their carers often do not know what social care support they are entitled to, when, where and from whom they should make a request.

Of particular concern to the Commissioner is those older people who do not have family or carers who can advocate on their behalf.

The Commissioner considers that the current legislation and policy for Adult Social Care is in need of modernisation and reform, which should better reflect the changing needs of an ageing population and ultimately provide older people with the necessary information to make informed choices about their future.

The case for change

The level of debate on the future of social care has been growing internationally in recent years. New and innovative ideas have been proposed to enable governments to adequately plan ahead and meet the challenges of an ageing population across Europe. Modern approaches to the provision of health and social care have been proposed and implemented on an international scale, including new social care legislation which has recently come into force in England.

Adult Social Care is also undergoing strategic change in Northern Ireland. This change process is being led by the Department of Health, Social Services and Public Safety (DHSSPS) via 'Transforming Your Care' and 'Who Cares?' which focus on reshaping how health and social care services are to be structured and delivered in order to make best use of all resources available. The Commissioner understands that the ongoing reform of adult care and support project in particular should extend to legislation and guidance and it is therefore hoped that the Commissioner's research findings will be of assistance to the DHSSPS as it takes its project forward.

Transforming Your Care (TYC)

Introduced in 2011, TYC seeks to place the individual at the centre of their care, and to shift care from the hospital setting towards community or primary care. It is underpinned by 12 major principles for change:

- Placing the individual at the centre of the model by promoting a better outcome for the service user, carer and their family
- Using outcomes and quality evidence to shape services
- Providing the right care in the right place at the right time
- Population-based planning of services
- A focus on prevention and tackling inequalities
- Integrated care – working together
- Promoting independence and personalisation of care
- Safeguarding the most vulnerable
- Enabling sustainability of service provision
- Realising value for money
- Maximising the use of technology
- Incentivising innovation at a local level

These developments, together with **increasing pressures on the health service in Northern Ireland** have led to an increasing local **public awareness and recognition of the need to plan for an ageing population** to ensure that the integrated health and social care system is ready and able to fully meet this challenge.

The Commissioner believes that reform of Adult Social Care is essential and must reflect the changing needs of the most vulnerable in society. Shifting the focus of care, encouraging independence and enabling people to remain in their own homes for longer all reflect most people's aspirations for their care however, such changes must still be fully resourced and supported in the long term. Changing needs require equivalent changes to service delivery which must continue to be safe and resilient, yet must also be proactive and ready to offer innovative solutions to meet the challenges of modern society.

In Northern Ireland, the dual system of integrated health and social care has evolved over time in the absence of a clear and coherent legal framework setting out clear rights and responsibilities. Through engagement and casework, **the Commissioner is convinced that there is confusion and a disparity in the provision and practice of Adult Social Care throughout Northern Ireland.**

The research process

The Commissioner asked a team of leading academics in the field of Adult Social Care to review the current position in terms of law and policy in Northern Ireland and to compare its findings with international good practice with a view to developing a set of recommendations on how best to reform Adult Social Care for the future.

What the legislative review found

- Legislative reform is needed in Northern Ireland to benefit all adult users of social care.
- Such legislative and policy reform should be person centred and based on human rights principles.
- Northern Ireland has an integrated health and social care system. This carries both advantages and challenges in terms of service planning and provision.
- There is a lack of direct and reliable data available relating to current service provision and unmet need.
- There is an impression of regional and geographic disparities in service provision and development.

What the legislative review found

- Current legislation and policy guidance surrounding Adult Social Care is outdated, confusing and fragmented in Northern Ireland. Definitions and terminology used in the legislation need updated to fully reflect and meet the needs of modern society.
- The effect of the out of date legislation and policy position is to disadvantage older people in both understanding what social care services are available to them and in terms of how to access these services.
- Early intervention to assess need is key together with the provision of necessary support to enable older people to be fully involved in decisions about their future care needs. A preventative type of “Support Visit”, similar to that currently offered in Scandinavia, to all over 75 year olds, would enable information and support to be shared and assessments conducted in a more controlled, proactive and consistent way.

Following the work of the academic team, it was crucial to obtain real life experiences of older people in receipt of, or eligible to receive social care in Northern Ireland as well as to obtain the views of future users of Adult Social Care. For this reason an engagement programme was undertaken in collaboration with Age NI² to “test” the recommendations from the academic review against the real life experiences, concerns, and barriers identified from current users, carers and potential future users.

² Age NI's engagement report can be found at www.copni.org/publications

What engagement with older people found

Older people and their carers

Many older people and their families and carers do not know what they are entitled to under current law and policy in Northern Ireland, and this came through in engagement with them.

"People should have their rights explained to them in simple language."

"There needs to be an understanding of family needs and use of common sense when organising care."

"Most people don't know how to use the law."

"It is important for older people to know their rights, if older people don't know they will never ask for them and won't get the help they need."

"I didn't know I could ask about other services."

Potential future users

Potential future users emphasised the importance of early intervention and preventative measures being in place to enable older people to take control of their future needs rather than responding to crisis points.

A support visit or regular “check in” with a GP or other health and social care worker was welcomed, particularly if this tied in with the provision of an information pack containing key contact points within health, social care, housing and benefits advice.

This group felt a greater effort should be made to ensure that older people and their families are made aware of their legal rights and entitlements.

“If I need to use it in my later years, I would need to know about it.”

When faced with numerous and outdated pieces of legislation, there was a definite preference for change:

“We need a set of rights.”

“How am I supposed to navigate these different statutes? It’s time for a modern single statute that is based on clear rights and entitlements.”

Adult Social Care and other support services

Bringing clarity to Adult Social Care is further complicated by the fact that some support services, such as housing and benefits support for adults are the responsibility of different government departments and these Adult Social Care entitlements and needs are accessed in different ways.

Often, older people and their carers do not know where to turn for information and advice when they need it to assist them with planning for their future.

Whilst it was not possible to also include the interfaces between social care and housing and benefit within the scope of this project, these were acknowledged as key areas which would require further discussion into the future.

Key findings

The research from the Commissioner's legislative and policy review, as well as from engagement with older people, point to an Adult Social Care system that is not fit for purpose and which is in need of reform, and resulted in three key findings which informed the Commissioner's Advice to Government. These are:

1. There should be a new single legislative framework for Adult Social Care with accompanying guidance for implementation.

This new framework could either be a new or consolidated legislation which would be based on human rights principles and specifically provide clarity on:

- Eligibility
- Entitlement and rights to services
- Assessment of need and unmet need
- Duties of Health and Social Care Trusts
- Overlap with existing frameworks for mental incapacity and adult protection
- Other support services including housing and benefits entitlement

2. Preventative support measures are key to better future planning. All older people in Northern Ireland should be offered a Support Visit upon attaining 75 years, by an appropriately trained health and social care worker.

3. Future funding arrangements must be equitable and must not discriminate against any groups including older people who may have higher levels of need.

Commissioner's Advice to Government

1. To The Minister of Health, Social Services and Public Safety:

- (i) The Commissioner recommends that the Minister prioritises the need for legislative change in Adult Social Care in the next Programme for Government.
- (ii) The Commissioner recommends the prioritisation of funding and resources to fully implement a new or consolidated legal framework for Adult Social Care in the next Programme for Government. This should be based on human rights principles and specifically provide clarity on:
 - Eligibility;
 - Entitlement and rights to services;
 - Assessment of need and unmet need;
 - Duties of Health and Social Care Trusts;
 - Overlap with existing frameworks for mental incapacity and adult protection;
 - Other support services including housing and benefits entitlement.

Commissioner's Advice to Government (*continued*)

(iii) The Commissioner recommends the provision of the offer of a Support Visit to all older people in Northern Ireland once they are 75 years of age.

2. To The Health and Social Care Board:

The Commissioner recommends that the Health and Social Care Board prioritise funding and resources to support the implementation of a new or consolidated legal framework for Adult Social Care.

3. To The Health and Social Care Trusts:

The Commissioner recommends that each of the five Trusts in Northern Ireland work together with the Health and Social Care Board to establish a regional approach to implementing the proposed new or consolidated legal framework for Adult Social Care.

Appendix – Case Studies³

Case Study 1

One carer gave their experience of looking after their 89 year old mother who has dementia. The carer has a background in social care policy and worked in the age sector for a number of years. Whilst this individual is very aware of Adult Social Care legislation she feels powerless in dealing with the system, showing just how complex the current legislation is.

Case Study 2

One case study, a female aged 75 who lives alone in rural Fermanagh, attended hospital for a knee replacement. Prior to going in to hospital, the lady called her local social services to arrange a care package for after her discharge, as she wasn't sure who was meant to organise this. As the lady neared discharge, the hospital staff called social services to put the arranged package in place but had no success. The lady felt extremely worried that nothing would be in place for her going home, and even called her GP to suggest a temporary stay in a nursing home but was told there was nothing he could do. Despite the hospital staff's best efforts the lady was discharged with no support arranged and her son had to stay overnight before returning to his international job the next day. Before leaving, her son made sure there was water, other essentials and a phone close to hand but as the door could only be locked from inside the lady spent the next few nights in bed with her home unsecured. The situation only improved when a friend called and by chance spoke to someone they knew personally within social services. This resulted in carers and a district nurse visiting but it was too little too late, leaving the lady feeling let down by the current system.

This report is available in other languages and formats on request.
Also available for download at www.copni.org.



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ISBN: 978-0-9930725-6-7