



Commissioner for **Older People**
for Northern Ireland

Consultation on Who Cares? - The Future of Adult Social Care and Support in Northern Ireland

Department of Health, Social Services and Public Safety

Response submitted by the Commissioner for Older People for Northern Ireland

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Executive Summary

1. The Commissioner welcomes the opportunity to contribute to the public discourse on the future of adult social care and support set out in the Department of Health, Social Services and Public Safety's discussion document entitled Who Cares? The future of Adult Social Care and Support in Northern Ireland.
2. The Commissioner agrees that the current system of adult social care is under pressure and is in need of urgent reform. The Commissioner is of the view that reform of adult social care should address the legal framework underpinning social care and support in parallel with policy and funding considerations, to ensure that reform of adult social care is supported by an appropriate, unified and effective legal framework.
3. The Commissioner is of the view that the Department's vision of social care should be founded on a rights-based approach that is individually focused and clear to service providers, service users and the general public.
4. The Commissioner welcomes the inclusion of prevention, reablement, personalisation, community support and support for carers as key components of the system. It is the view of the Commissioner that prevention should incorporate early intervention measures that are crucial to promoting the independence and well-being of older people. In addition, personalisation in relation to living arrangements should support people to remain at home, where this is their preference.
5. The Commissioner is of the view that social care reform should recognise the contribution of informal Carers where informal care is provided and ensure that their needs are adequately assessed and that appropriate and flexible and responsive support is provided, where needed.
6. The Commissioner is of the view that the current system of funding is in need of reform and that greater investment is needed in high quality social care. The Commissioner is of the view that any future model of social care funding should be based on sound economic analysis using robust data and addressing issues specific to Northern Ireland. In addition the Department should consider models of funding used in other international jurisdictions where good practice in delivering adult social care is evident.
7. Older people constitute a significant proportion of users of adult social care services and are therefore more likely to be impacted by issues arising in the provision of these services. The Commissioner is of the view that any proposals for social care reform should, therefore, ensure the full participation of older people including those whose voices are traditionally not heard and should monitor the equality and human rights impact of its proposals on older people.

Introduction

1. The office of the Commissioner for Older People for Northern Ireland (the Commissioner) is an independent public body established under the Commissioner for Older People Act (Northern Ireland) 2011.
2. The Commissioner has responsibility for an extensive range of general powers and duties which will provide the statutory remit for the exercise of her functions. In addition the Commissioner may provide advice or information on any matter concerning the interests of older persons.
3. The Commissioner's powers and duties are underpinned by the United Nations Principle for Older Persons (1991) (see appendix A). The wide ranging legal powers and duties includes amongst others:
 - To keep under review the adequacy and effectiveness of law and practice relating to the interests of older people
 - To keep under review the adequacy and effectiveness of services provided for older persons by relevant authorities
 - To promote the provision of opportunities for and the elimination of discrimination against older persons
 - To review advocacy, complaint, inspection and whistle-blowing arrangements of relevant authorities
 - To assist with complaints to relevant authorities
 - The investigation of complaints against relevant authorities
 - The power to bring, intervene in or assist in legal proceedings
 - The conciliation of disputes
 - Formal investigations, evidence in formal investigations
 - Powers of entry and inspection for purposes of formal investigation
4. The Commissioner welcomes the opportunity to respond to the Department for Health, Social Services and Public Safety's (DHSSPS) document entitled "Who Cares?: The Future of Adult Care and Support in Northern Ireland" which aims to promote public discussion that will result in significant changes to future adult social care provision in Northern Ireland.
5. The Department has outlined a number of questions to which they would particularly welcome views. The Commissioner offers a limited response to these issues in seeking to confine her response within her core area of expertise.

Background

6. The Commissioner agrees that the current system of care and support is coming under pressure and is in need of reform due to predicted increases in demand for these services for the following reasons:
7. Northern Ireland has an increasingly ageing population, which may result in an increasing future demand for health and social care services. Between 2001-2011¹, the number of people of pensionable age (60+/65+) increased by 18% whilst, the number of people aged 85+ years, the group most likely to be in need of social care, increased by 35.4%. These changes have been attributed to in part to longer life expectancy due to better nutrition and advances in medicine and technology and should be welcomed in light of the net positive contribution older people make to the economy as a whole² and the opportunities this brings. However, significant challenges remain: population projections have indicated that the number of people aged 85 years and over is likely to increase by 83% by 2025³ and predicted increases in the levels of chronic illness (hypertension, coronary heart disease, stroke, diabetes, dementia)^{4 5} may further increase pressure on health and social care services.
8. In addition, recent research⁶ has raised concerns about the provision of social care provided to older people in Northern Ireland. Whilst many individuals in Northern Ireland appreciate and value the care they receive⁷, significant concerns have been identified in relation to quality and standards of domiciliary care⁸ and the care provided in nursing homes⁹. It has been reported¹⁰ that current models of social care focus on traditional ways of working that are complex, not rights-based, contain regional discrepancies and variability in the quality of care between care-providers and are based on a person's suitability for a service rather than the outcomes that will best promote their well-being.
9. Given these pressures the issue of reform within adult social care is particularly pertinent to the purpose of the Commissioner's work in safeguarding and promoting

¹ Northern Ireland Assembly (2011). A demographic portrait of Northern Ireland: some implications for public policy. NIA: Stormont.

² e.g WRVS (2011) Gold Age Pensioners: Valuing the Socio-economic contribution of older people in the UK: WRVS: UK

³ NISRA (2011). Statistical report – 2010 based Population Projections. NISRA: UK

⁴ Institute of Public Health in Ireland (2010). Making Chronic Conditions Count. Institute of Public Health in Ireland: Dublin

⁵ DHSSPS (2010) Dementia Strategy. DHSSPS:Belfast

⁶ E.g. Patient and Client Council (2012) Care at Home: Older people's experiences of domiciliary care. PCC: Belfast; NIHRC (2012) In Defence of Dignity. NIHRC Belfast.

⁷ Patient and Client Council (2012) Care at Home: Older people's experiences of domiciliary care. PCC: Belfast

⁸ Ibid

⁹ NIHRC (2012) In Defence of Dignity. NIHRC Belfast.

¹⁰ AgeNI (2011) Social Care and Older People: A Briefing Paper for the HSC Review Team. AgeNI: Belfast

the interests of older people in Northern Ireland and upholding the UN principles for older people.

10. It is the view of the Commissioner that the Department must determine how best to respond to these pressures, in order to ensure that older people can be confident that the quality and volume of care they receive meets their individual needs and allows them to lead dignified and fulfilled lives.

Key Issues

Legislative Reform

11. It is the view of the Commissioner that reform of the future social care system should address the legislative framework that underpins social care. At present, the current legal system is complicated, fragmented and not fit for purpose. Current social care law in Northern Ireland consists of different statutes¹¹ enacted during the last 30 years with no clear unifying principles underpinning them. These include:

- Acts passed by Parliament or by the Northern Ireland Assembly
- Orders passed by the Secretary of State for Northern Ireland on authority delegated by Parliament, in articles:
- Regulations made by government ministers on authority delegated by Parliament, in paragraphs;
- Directions issued by government in accordance with primary legislation

12. In addition, guidance in the form of codes of practice, circulars and advice notes are provided by government departments to public authorities and/or social care providers. However, the legal authority and status of this guidance has been called into question as guidance does not generally impose legally binding obligations on public authorities and social care providers in relation to assessment and service provision¹².

13. Reform of the current fragmented system would provide greater clarity for authorities, service users, carers and the judiciary. In addition, it would present an opportunity to align social care legislation with the social model of disability and with the European and international human rights legislation. This is particularly salient, given that recent reports from GB¹³ and Northern Ireland¹⁴ have identified human rights and equality issues with social care practices and the treatment of older

¹¹ e.g. Health and Personal Social Services (NI) Order 1972, as amended, Chronically Sick and Disabled Persons (NI) Act 1978, Disabled Persons(NI) Act 1989, Children (NI) Order 1995, Health and Social Care (Reform) Act (NI) 2009

¹² Except in some instances where guidance made under legislation specifically requires authorities to act upon it.

¹³ e.g. ECHR (2011) Inquiry into Older People and Human Rights in Home Care. London: ECHR

¹⁴ NIHRC (2012) In Defence of Dignity. NIHRC Belfast.

people across care settings whereby service providers have failed to meet basic standards of care.

14. Recent developments in the reform of social care in England have sought to address the similarly complex and disparate law on social care in England¹⁵ with the Coalition government accepting recommendations for the creation of a unified legal framework arising from Law Commission's review of adult social care in England and Wales¹⁶. A draft Care and Support Bill relating to England is currently being progressed through Parliament.
15. Given the recent moves in England and in order to address the issues with the current legal framework in Northern Ireland, the Commissioner would encourage the Department to ensure that any reform of adult social care policy in Northern Ireland is similarly supported by an appropriate, unified and effective legal framework.

A Vision for Care and Support

16. The Commission welcomes the Department's inclusion of dignity and respect, quality, independence, equity, equality and diversity, human rights, safeguarding as well as affordability / sustainability as core principles underpinning our future adult social care system.
17. The Department has indicated in the Who Cares? document that out of the 8 stated founding principles the most important core principle underpinning their vision for care and support is affordability and sustainability¹⁷. Whilst affordability and sustainability are important considerations, it is the view of the Commissioner that human rights rather than cost must be the most important principle underpinning social care reform.
18. In addition, a system which places cost as the over-riding consideration is unlikely to be value-for-money in the long-term as service provision is likely to be driven by how affordable any given service is and whether a person fits into that service. The key concern should be whether the service is meeting its core aims and objectives in meeting individual needs and delivering outcomes which promotes independence and improve well-being for older people.
19. The Commissioner is of the view that the vision for adult social care in Northern Ireland should be founded on a rights-based approach with the principles of quality, dignity and respect and human rights as core principles. A rights-based approach to social care that is individually focused and clear to service providers, service users and the general public will maximise delivery of services to older people that meet their needs and promote their independence, choice and well-being.

¹⁵ HM Government (2012) Caring for our future: reforming care and support. TSO:London

¹⁶ Ibid

¹⁷ See p20.

Key components of system: Right Support at Right Time in the Right Place

20. The Commissioner is in agreement that prevention, reablement, personalisation, community support and support for carers should be included as key components of the system. There are a number of issues, however, within these key components that need to be further addressed by the Department.

Prevention

21. The Commissioner welcomes the focus on prevention, including an emphasis that prevention will not only cover healthy ageing issues such as diet and exercise but early intervention with older people to prevent a loss of independence and that this ethos will also apply to residential and nursing care.

22. Recent research¹⁸ has indicated that there is a perception amongst older people that only “high level” care needs are met, particularly within domiciliary care, and that “low level” needs (such as “home helps”), that are necessary to maintaining independence, are no longer being provided for within the system. In one study¹⁹, older people indicated that the help offered to them within the social care system would not meet their needs and they struggled to get help with activities such as housework or getting into bed at night, areas which were vital to maintaining their independence.

23. Other “low level needs” including the provision of minor housing adaptations and older people’s active lifestyle programmes have also been identified²⁰ as having a crucial role in improving outcomes for older people. In a briefing paper to the Health and Social Care team, Age NI indicated that evidence from projects that promote early intervention have indicated that “the provision of that little bit of help” can result in significant savings and better outcomes for older people²¹.

24. It is the view of the Commissioner that any preventative measures should incorporate those early intervention measures and address “low-level” needs which are crucial to promoting the independence and well-being of older people.

Reablement

25. The Commissioner welcomes a focus on reablement and recovery services where unexpected incidences such as a fall or stroke, result in a loss of independence and the need to relearn skills for daily living. However, reablement should be used as a tool to assist people to regain independence rather than a motivation for “potentially removing the person’s need for care and support altogether”²².

¹⁸ Patient and Client Council (2012) Care at Home: Older people’s experiences of domiciliary care. PCC: Belfast

¹⁹ Ibid

²⁰ AgeNI (2011) Social Care and Older People: A Briefing Paper for the HSC Review Team. AgeNI: Belfast

²¹ Ibid

²² DHSSPS (2012) Who Cares?: The Future of Adult Care and Support in Northern Ireland. DHSSPS: Belfast

26. The Commissioner is of the view that any decision about a person's need for care and support should be made in full consultation with the person affected and their family and should focus on the psychological, emotional and social needs of the individual as well as their physical needs. In addition, where an older person is deemed to no longer require support after a period of reablement, it is crucial that the health and well-being of these individuals continue to be monitored and evaluated.

Personalisation

27. The Commissioner welcomes a commitment to greater personalisation of services and ensuring care packages are built around the needs of the individual rather than expecting the person to fit into standard services.

28. The Commissioner welcomes proposals currently being piloted to increase the uptake of Direct Payments by allowing people in receipt of care and support to choose what level of responsibility they want to take over how their budget is managed.

29. The Commissioner is of the view that where an older person asks the Health and Social Care Services to identify services to meet their needs and manage their budget, Health and Social Care Services should ensure that the older person remains fully involved in making decisions about their service provision.

30. The Commissioner welcomes a commitment to provide a range of options for people who can no longer be supported in their own homes, including a continued expansion of supported living schemes through the Supporting People Programme.

31. It is the view of the Commissioner that the Department should commit itself to further investment in community care to enable people to maintain their independence in line with commitments given in Transforming Your Care. In addition, there is a need for further information and evidence in the document in relation to comparative spending on residential, nursing and domiciliary care, particularly where care needs are intensive.

Support for Carers

32. Carers are essential to the future success of adult social care reform outlined in the Who Cares? document. It is estimated that informal care of relatives, friends and neighbours constitutes a saving of £119 billion to the UK economy per year - more than total spending on the NHS²³. The Commissioner is concerned that pressures on the current system will have a significant impact on carers, given that the current care system is reliant on the presence of informal care.

33. In addition, much of this informal care is undertaken by older Carers. Many of these Carers have needs themselves, particularly given that caring has been shown to impact on the employment status, health and well-being of carers and can increase

²³ CarersUK (2012) Policy Briefing: Facts about Carers 2012. CarersUK

social isolation and poverty²⁴. It is, therefore crucial that the needs of these carers are adequately assessed and responded to by the social care system.

34. The Commissioner is concerned that whilst there is a statutory duty on the Health and Social Care system to offer Carers an assessment of their needs, the uptake of these assessments are low. During quarter ending December 2011, 56% of Carers in Northern Ireland declined an assessment compared to 9% in England in 2010/11²⁵. There is a need to establish why the uptake of assessments is low and action needs to be undertaken to address barriers to the uptake of assessments. The Commissioner welcomes the Department's commitment to further investigate the decline in uptake of Carers' assessments. The Commissioner plans to conduct work on the uptake of Carers assessments by older people.
35. In addition, under the current system there is a duty on health and social care services to offer an assessment, but no clear duty to meet a Carers' support needs²⁶. In England, the recent draft Care and Support Bill proposes to address this through the legal framework by extending the right to a carers' assessment to provision of an entitlement to public support²⁷. The Commissioner is of the view that this legal right to support for Carers should be part of wider legislative reform of adult social care in Northern Ireland.
36. The Commissioner is of the view that the social care system should recognise the contribution of Carers where informal care is provided, and ensure that needs are adequately assessed and that appropriate support is provided, where required. This will assist in promoting the health and well-being of Carers and preventing the social isolation and disadvantage that is often associated with caring. In addition, the presence of informal care should not be automatically assumed when an older person's needs are being assessed.

Support for Care Workers

37. The Commissioner is of the view that social care reform should address the status of care workers who are often on low pay with limited access to training and development. Recent research²⁸ has indicated that older people and their families have reported issues with quality and consistency of domiciliary care due to untrained and often inexperienced care workers.
38. Proposals for social care reform in England have acknowledged²⁹ the role of a properly trained and well-motivated workforce in delivering high quality care and support and have proposed that minimum training standards for adult social care

²⁴ Ibid

²⁵ DHSSPS (2012) Carers Statistics for Northern Ireland (Quarter ending 31 December 2011)
Revised.DHSSPS: Belfast

²⁶ Carers and Direct Payments Act (Northern Ireland) 2002

²⁷ HM Government (2012) Caring for our future: reforming care and support. TSO:London

²⁸ Patient and Client Council (2012) Care at Home: Older people's experiences of domiciliary care. PCC:
Belfast

²⁹ HM Government (2012) Caring for our future: reforming care and support. TSO:London

workers is introduced as part of social care reform³⁰. The Commissioner is of the view that in Northern Ireland investment in a good quality, well-trained and valued workforce of care-givers is vital to the success of social care reform in delivering high quality care. This training must include a focus on the needs of people with dementia.

Balance of Responsibility - Funding of Social Care

39. Currently in Northern Ireland, there is no uniform approach to charging for care and support services. Domiciliary care does not require the older person to make a financial contribution towards their care, meals on wheels has a flat rate charge and residential and care home provision is means tested.

40. Current funding of the social care system in Northern Ireland is perceived to be unfair³¹, expensive and to penalise those who save³². In Northern Ireland nearly two thirds of older people are homeowners³³, a significant proportion of whom may be “asset rich but income poor” and may be liable to sell their assets to pay for their care, particularly where care requirements are high. Whatever, the future balance of social care funding it is clear that the current system of funding is in need of reform and investment is needed in high quality care.

41. The Commissioner is of the view that any future model for social care funding should be determined on the basis of sound economic analysis using robust data and taking into account issues specific to Northern Ireland such as the relatively low income levels, property and wealth levels. In addition, the Department should consider models of social care funding used in other international jurisdictions where good practice in investing in and delivering high quality care is apparent³⁴. The priority for any future model for social care funding should be to protect those most vulnerable to poverty and to reduce negative adverse impact on those who are most in need of care.

Attendance Allowance and Disability Living Allowance

42. Attendance Allowance (AA) and Disability Living Allowance (DLA) are non-means tested benefits intended to meet the costs of a person’s personal care needs arising from a disability. The “Who Cares?” document suggests that, because domiciliary care is free in Northern Ireland, there may be a risk of duplication where people who receive domiciliary care also receive AA and DLA benefits designed to meet the costs of personal care.

³⁰ Ibid

³¹ Northern Ireland Life and Times Survey (2012) Attitudes to Social Care for Older People in Northern Ireland. ARK: Belfast

³² AgeNI (2011) Social Care and Older People: A Briefing Paper for the HSC Review Team. AgeNI: Belfast

³³ Evason E, Llyod K, McKee P and Devine P (2004). Older People in Northern Ireland. Report 1: setting the scene.

³⁴ Joseph Rowntree Foundation (2008). Rethinking social care and support: What can England learn from other countries. JRF: York.

43. Research³⁵ has indicated that AA and DLA make a positive contribution in maintaining the independence and well-being of disabled people. Although AA and DLA are not means tested they mainly support disabled people on lower incomes³⁶. In addition, disabled people face higher living costs due to their disability on top of care costs³⁷. Research by Age UK³⁸ has indicated that older disabled people often used these allowances to meet the cost of low level needs such as practical help and care services, heating and food that are not provided for by social care services.
44. Given the positive contribution of these benefits in providing additional assistance to disabled older people, the Commissioner is of the view that removal of these benefits from older people in receipt of domiciliary care could have an adverse impact on the ability of these individuals to maintain their independence.

Participation of Older People

45. The Commissioner is of the view that any proposals for social care reform should ensure the full participation of those people who are most likely to be affected by proposed changes. The Commissioner would like to know what plans the Department has made to ensure that the voices of those older people who are currently in receipt of domiciliary, residential and nursing care or who find it difficult to participate due to frailty, disability or illness including dementia are sought and considered.

Equality and Human Rights

46. The Commissioner is of the view that any proposals for social care reform should be subject to a full Equality Impact Assessment and should consider the degree to which proposals meet the requirements of national and international equality and human rights legislation including the European Convention on Human Rights, the United Nations Principles for Older People and the United Nations Convention on the Rights of People with Disabilities.

Monitoring and evaluation

47. Any proposed changes to adult social care legislation will require the collection of baseline data and future monitoring of the impact of change. Given the diversity amongst older people, there is a need for adequate disaggregated data on older people in social care to ensure that social care services are monitored and appropriately targeted to meet the needs of older people. The Commissioner is of the view that the Department should review its data processes to ensure that the data available is capable of disaggregation at an appropriate level to ensure appropriate monitoring of the impact of the provision of social care services on equality grounds, as set out in Section 75 of the Northern Ireland Act 1998.

³⁵ Hancock, Morciano and Pudney (2010). Attendance Allowance and Disability living Allowance claimants in the older population: Is there a difference in their economic circumstances?

³⁶ Hancock, Morciano and Pudney (2010). Attendance Allowance and Disability living Allowance claimants in the older population: Is there a difference in their economic circumstances?

³⁷ Ibid

³⁸ Age UK (2008) Transforming lives

Conclusion

48. The Commissioner welcomes the Department of Health, Social Services and Public Safety's document entitled Who Cares? The future of adult social care in Northern Ireland which has set a framework for public discourse on the future of adult social care in Northern Ireland.
49. Older people need to be confident that the quality and volume of care they receive meets their individual needs, allowing them to lead dignified and fulfilled lives. The Commissioner is of the view that future proposals for adult social care reform should be rights-based, individually focused, clear to service providers and the general public and underpinned by a unified and effective legal framework.
50. Older people constitute a significant proportion of users of adult social care services and are therefore more likely to be impacted by issues arising in the provision of these services. The Commissioner would urge the Department to ensure the participation of older people in the implementation, monitoring and evaluation of its proposals and address the equality and human rights implications of its proposals for older people.
51. The principal aim of the Commissioner, as set out in legislation, is to "safeguard and promote the interest of older people". Given her roles and responsibilities, the Commissioner will retain an interest in the development of proposals for adult social care reform.
52. Finally, the Commissioner would be grateful if the Department of Health, Social Services and Public Safety would include her in its consultation list for all further consultations. All future consultations should be sent to:

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