Age NI and ARK Ageing Programme
Annual Conference

Older People in Health and Social Care:
Getting the ‘Right’ Approach

22 October 2015

Participant’s Brief

Edel Quinn
Strategic Policy Adviser-
Citizenship
Age NI
3 Lower Crescent
Belfast
BT7 1NR

t: 028 90892622
e: edel.quinn@ageni.org
w: www.ageni.org
Conference Aim
The conference aims to bring together leading experts on older people, human rights and health and social care to:

- provide evidence based analysis of key issues affecting older people in order to identify solutions and recommendations
- improve outcomes for older people
- influence policy making and service delivery in Northern Ireland

We will hear directly from older people during the conference.

About Age NI
Age NI is the leading charity for older people in Northern Ireland. Our vision is a world where everyone can love later life, and our mission is to help people enjoy a better later life.

Our society is ageing. More than 350,000 older people live here today, and there are more people over the age of 50 than under the age of 19. In the next twenty years, the number of people over 50 will increase by more than 30%.

As we grow older we face new challenges, and may face difficult issues like illness, poverty or loneliness. We still want to laugh, love and be needed. We want to stay independent and keep doing the things we love. We all want a fulfilling later life. Age NI believes that living longer should be celebrated and that those who need help should be supported. We exist to support more people to love later life now and in the future. We want to make people think differently about what it means to get older, because age affects us all in different ways.

The charity provides a range of services across Northern Ireland including the Age NI Advice Service which deals with 10,000 enquiries every year; support for 11 sub regional older people’s networks to increase the voice and sustainability of older people’s groups at a local level; day, residential and domiciliary care to 1,200 clients every week in centres from Omagh to Castlewellan; policy and influencing activities to ensure that policy decisions made today will support more older people in Northern Ireland to love later life; a 1-2-1 service, First Connect, which supports older people who are in need of direct emotional and practical help in their lives at a time of crisis, perhaps through bereavement or illness; and products and services such as the Age NI personal Alarm, tailor made to support people over 50.

About ARK Ageing Programme
The ARK Ageing Programme is based within Queen’s University Belfast and Ulster University. Its aim is to support the use and development of research on ageing within the academic, voluntary, policy and practice sectors. For more information, see www.ark.ac.uk/ageing
Introduction

Our society is changing. Age NI believes that we need to change how health and social care delivers for older people. There is a growing consensus across Northern Ireland and indeed wider afield that radical change is needed, as governments respond to ageing populations, constrained resources and advancing technology. There is also a growing acceptance of the need to meaningfully promote and defend the rights and dignity of older people as important elements of the changes that are needed.

Age NI’s vision

Age NI promotes a rights-based approach to ageing – at its core this simply means we believe that people through all stages of their lives should be treated with dignity and respect. Nowhere perhaps is this more noticeable that in the area of older people and health and social care, the subject of today’s conference.

This approach is reflected in Age NI’s vision of what social care should look like for older people now and in the future – ‘quality integrated social care that recognises the rights, aspirations and diversity of us all, and is based on the right to live with dignity, independence, security and choice’. At the heart of our vision is a system that enhances wellbeing and independence, so that older people can continue to engage socially and maintain self-esteem, dignity and purpose.

To achieve our vision, Age NI has developed a new strategy, Making Later Life Better for 2015-2020 which aims to secure three key goals for older people, specifically that they have enough money to live comfortably and participate; the opportunity to stay well, and feel good; and the right to be equal and engaged citizens.

Statistics

The number and proportion of older people in Northern Ireland is steadily and consistently increasing.

The Chief Medical Officer for Northern Ireland has stated that:

“People are now living longer than they did 40 or 50 years ago and as a result the number of older people in our community is increasing. In 2013 there were estimated to be 279,000 people aged 65 and over with 33,000 of them over 85 years. These figures are projected to increase considerably in the next 20 years to 456,000 and 79,000 respectively”

Increasing life expectancy is not being matched by parallel increases in healthy life expectancy. Northern Ireland fares worst of all regions in the UK in this regard. We

---

1 Your Health Matters – Annual Report of the Chief Medical Officer for Northern Ireland 2014, Department of Health, Social Services and Public Safety, 2014
know that rates of disability and ill health increase with age. The rate of disability amongst those aged 85 and over is 67%, compared with only 5% among young adults. In addition the prevalence of the number of long term conditions, namely hypertension, coronary heart disease, stroke and diabetes among adults in Northern Ireland is predicted to increase by 30% by 2020. In Northern Ireland approximately 19,000 people are living with dementia, a number projected to rise to almost 60,000 by 2051, the fastest expected rate of increase in the UK.

As such, older people’s reliance on a range of services, including health and social care services, to maintain their independence, will become paramount. Indeed, health and social care services are already considered the top concern for those aged 65 and over, with more than half (54%) stating that their health was a concern, followed by staying independent (40%) as Age NI’s survey of older people in 2014 showed.

**Ready for Ageing?**

In its report, *Ready for Ageing*, the House of Lords Committee on Public Service and Demographic Change warns that the Government and our society are woefully underprepared for ageing. The Committee highlighted the collective failure to address the implications of ageing. There is no evidence to suggest that the picture is any different here. Indeed Northern Ireland has been described as having ‘the most disjointed and limited approach to ageing issues in the UK’.

**Human Rights**

Set against this reality is the domestic and international human rights legal framework. Older people have a right to have full enjoyment and protection of their human rights. They have protection of domestic human rights and equality laws, including the Human Rights Act (1998) and section 75 of the Northern Ireland Act (1998) and a body of international human rights conventions and instruments.

There is also a body of international human rights conventions and instruments. International obligations to older persons are implicit in most core human rights treaties, such as the International Covenants on Economic, Social and Cultural Rights and on Civil and Political Rights, (the Convention on the Elimination of All Forms of Discrimination against Women, Convention on Elimination of Racial Discrimination and the Convention on the Rights of Persons with Disabilities). However, explicit

---

2 Transforming Your Care. DHSSPSNI. 2012
3 Making Chronic Conditions Count. Institute of Public Health in Ireland. 2010
4 Improving Dementia Services in Northern Ireland: A Regional Strategy, Department of Health, Social Services and Public Safety, 2011
5 Research carried out by Millward Brown on behalf of Age NI. August 2014
references to older persons in binding international human rights instruments are scarce. And they are largely invisible in monitoring and reporting processes.

There is currently no UN Convention on the Rights of Older People, although work is ongoing in this area and it is gaining momentum. Realistically however, it is likely that this will be some time off. In the meantime it is essential that we continue to challenge the invisibility of older people in existing international standards through ensuring that existing reporting processes include substantial information on the state of older people’s rights in Northern Ireland; and that we support older people to have their voices heard in the debate on a UN Convention, which currently neither the UK nor Irish governments support.

There also is in place a set of non-binding UN Principles for Older Persons which sets out 18 principles under the headings – Independence, Participation, Care, Self-fulfilment and Dignity – and which the UN ‘encourages Governments to incorporate into their national programmes whenever possible’.8

Age NI believes that the forthcoming Ageing Strategy should be set in the context of the UN Principles and that the NI Executive should commit to ensuring that these principles underpin the development of government policy for older people in Northern Ireland. We welcome the vision outlined in Transforming Your Care, with a focus on prevention, and supporting people to remain at home, which aligns with the UN Principles vision of care and prevention, however, as stated earlier, serious concerns persist with regards to implementation.

There is currently a lack of strategic and consistent rights based approach to policy development and ageing in Northern Ireland, despite the existence of human rights tools and the UN Principles for Older Persons. In order to address outdated and ageist perceptions of older age, a human rights approach needs to be mainstreamed in policies and services that relate to older people.

**Participation of older people**

Participation is an essential component in delivering dignity and respect for older people in health and social care. People have the right to participate in every area of their life, including inputting into all matters which affect them - from daily life through to policy decisions.

However, participation of older people is often tokenistic and piecemeal at best.

Age NI places the voice of older people at the heart of everything it does. Over the past 6 years Age NI has supported a diverse range of older people to be informed about and directly engage in a range of public policy initiatives. This includes not only older people who access older people’s groups, but those who are considered hard to

---

reach or hard to hear, including older people living with dementia and those living in residential and nursing homes. Age NI is strongly committed to supporting the participation and voice of older people in all aspects of life. We have developed a range of expertise in supporting individuals, groups and networks to become informed and involved.

There have been a number of positive moves towards more meaningful engagement and consultation taken by the Health and Social Care Board, and the Department of Health, Social Services and Public Safety during 2014 which has meant that the opinions of residents in nursing and residential care settings have been heard. Their voices have had a significant impact on government policy in 2014 through the review of Minimum Standards in Nursing Homes, and the Making Choices consultation on proposed care home closures. This approach aligns with the need to show full respect for the dignity, beliefs, and rights of older people to make decisions about their care and the quality of their lives.

However there is as yet no systematic approach to ensuring that older people have a voice in regard to decision-making processes. Without a rigorous structure to ensure this inclusion, arrangements will vary from one area to another. Effective consultation with older people will require an appropriate structure plus investment in resources and infrastructure to encourage community links and build capacity for full participation. It also requires cultural change among decision-makers and indeed wider society.

**NI context**

➤ **Political context**

The ageing demographic is set against a backdrop of continuing austerity and welfare reform. Seventy-five per cent of older people are concerned that they will be affected by spending cuts. The fragility of the Executive and Assembly are a further cause for concern, with opposing ideologies and stalemates delaying progress on key matters that affect older people. This has resulted in a lack of priority being given to health and social care issues. The lack of political leadership over recent weeks and months has resulted in a growing concern as the human costs attached to unresolved problems mount – for example, the recent public debate about waiting lists. There are also major changes afoot in terms of the formation of 11 new super-councils through the Review of Public Administration.

---

9 Research carried out by Millward Brown on behalf of Age NI. August 2014
Policy context

• Age discrimination

Age is the only ground where it is still legal to discriminate in accessing goods, facilities and services in Northern Ireland. Ageism and discrimination challenges the dignity and rights of older people in Northern Ireland.

These prejudicial attitudes are at the root cause of inequality and disadvantage which range from abuse and neglect, to second-class services and restricted opportunities. Older people face discrimination in accessing cancer services, including screening services, mental health services, coronary services. Age NI believes that tackling age discrimination in health and social care is hugely important to improving the lives of older people, having campaigned on this issue with older people for over ten years.

We believe it is essential that the NI Executive keeps its Programme for Government promise to extend age discrimination legislation to the provision of GFS, within the lifetime of this Assembly.

Age NI further believes that the Department of Health, Social Services and Public Safety should undertake an Age Discrimination Review of all aspects of Health and Social Care in preparation for introduction of this legislation, similar to the wide-ranging review carried out in GB in respect of the Equality Act 2010. ¹⁰

• Ageing Strategy

Northern Ireland has been without an ageing strategy for almost 8 years. The previous strategy failed older people, presiding as it did over a reduction in a range of indicators of older people’s well-being, in areas such as poverty, fuel poverty, winter deaths and social care. OFMDFM is working to produce a new Active Ageing Strategy, which we understand is close to publication.

Age NI supported over 120 older people across NI to participate in the public consultation exercise and it was clear that expectations among older people are high. The new Ageing Strategy must be the high-level overarching driver which anchors all policy, planning, legislation, practice and service delivery that impacts on older people and ageing. It must be visionary and forward thinking, fully funded, outcomes-based, with SMART targets, indicators and baseline data.

• Transforming Your Care

The vision outlined in Transforming Your Care: Vision to Action, produced in January 2013, which focused on prevention and supporting people to remain at home, was

widely welcomed. The “Donaldson review”\textsuperscript{11} completed in December 2014 examined the application of governance arrangements for ensuring the quality of health and social care provision. However, almost three years after TYC we still urgently await implementation. We have yet to see evidence of serious planning for the promised ‘shift left’ and a move towards greater investment in low level preventative services and care at home. Instead we have seen a growing erosion of low level services – with for example, people with fewer needs who might once have received a few hours of ‘home help’ or visit to a day centre, often getting nothing. In addition, we have witnessed an increase in the use of 15 minute calls, and in some places 8 minute calls. There have also been concerns raised about access to services – for example, waiting lists for GP appointments and transport problems faced by older people living in rural areas.

There have also been a number of important inquiries, inspections and reports into a range of issues concerning the health and social care of older people.

- **Adult Social Care Legislation**

  The Commissioner for Older People has produced two reports in the area of adult social care. The first report\textsuperscript{12}, dealing with adult safeguarding, highlights that older people in NI are not afforded ‘adequate’ legislative protection from potential abuse and consequently may not obtain justice if they are the victim of abuse. The Commissioner has called for the creation of a single Adult Safeguarding Bill for Northern Ireland, a call which Age NI supports. The second report\textsuperscript{13} highlights that current adult social care legislation is in need of modernisation and reform. The Commissioner has called for a new single legislative framework for adult social care with accompanying guidance for implementation. It further highlights that any new legislation should be based on human rights principles.

- **Regulation and Inspection**

  A Regulation and Quality Improvement Authority (RQIA) review in 2014 into actions taken in relations to concerns about care delivered at Cherry Tree House, revealed the repeated failure of the Northern Ireland care home to fully comply with regulations, and to meet minimum standards of care.\textsuperscript{14}


The report also highlighted the inadequacy of regulation and inspection procedures adopted by the RQIA to adequately ensure that improvements were made, and that residents were protected. Despite complaints from staff and relatives relating to case of abuse and neglect of residents, the report found that the necessary improvements and changes were not made or adequately sustained from inspection to inspection. Age NI is calling for regulation and inspection processes in NI to be made more rigorous and with more significant and timely enforcement action. Robust and responsive regulation and inspection processes are necessary to ensure that minimum care standards are maintained and that residents are protected from abuse and neglect. This is about delivering quality of life as well as quality of care for older people. Age NI believes that older people in all health and social care settings must be meaningfully engaged in all aspects of their care and support. The Review’s recommendations included using pre-inspection intelligence and Lay Assessors to ensure that user voice is more centrally and effectively ascertained during inspections.

The Northern Ireland Human Rights Commission has produced two important reports in the recent past regarding the health and social care of older people.

In 2012 the NIHRC’s ‘In Defence of Dignity’ investigation report found that ‘there is a risk of multiple forms of human rights abuse’ in nursing homes here.\(^\text{15}\) They made recommendations around quality of life, personal care, eating and drinking, medication and healthcare and restraint, finding that there were ‘significant structural barriers to the implementation of the human rights of older people in nursing homes’.\(^\text{16}\)

The Northern Ireland Human Rights Commission has noted in its report, *In Defence of Dignity*, that in areas of participation and autonomy, ‘residents are not given adequate opportunity to be involved in making decisions that impact on them.’\(^\text{17}\)

In 2014, the NIHRC undertook an Inquiry into Emergency Health Care found human rights violations which did not amount to systemic abuse. There was evidence that raised breaches of human rights including unnecessarily prolonged waits without medical reason for pain relief, food, or fluids, people placed on trolleys in circumstances that exacerbated existing conditions, patients unsupported and as a result unable to get to the toilet or have their other care needs met, and treatment and care which did not respect dignity or privacy. Issues also arose in regards to inappropriate transfer from nursing homes to Emergency departments, information and participation including consent, long waiting times, lack of time and appropriate care of dementia patients, evidence of discrimination including de-prioritisation of

---


\(^{16}\) Ibid, Page 74

\(^{17}\) In Defence of Dignity: The Human Rights of Older People in Nursing Homes. Northern Ireland Human Rights Commission. Page 70
older people, discharging older people with dementia to nursing home alone at night by taxi.

A review by the Equality and Human Rights Commission (EHRC) in England, Closer to Home: An Inquiry into Older People and Human Rights in Home Care, highlighted practices that raised dignity, human rights and equality issues. The Inquiry raised some very poor practice involving physical and emotional wellbeing, including support with food preparation, eating and drinking, physical abuse, neglect of personal care, financial abuse, lack of autonomy and choice, inflexibility of services, lack of respect for privacy, lack of personal security and insufficient attention to diverse needs.\(^{18}\)

**ENDS**