

# Older people: choice and independence

## Report on a Joseph Rowntree Foundation event held in Belfast on 25 February 2009

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### Introduction

The Joseph Rowntree Foundation has been conducting research into the kind of support older people feel they need to maintain independence, dignity and quality of life. This event brought together key stakeholders, including policy-makers, practitioners, charities, service users and those caring for older people in Northern Ireland and elsewhere in the UK.

The event featured workshops, debate and input from influential speakers in the field of social care, including:

- Jeremy Harbison, Chair of the Northern Ireland Social Care Council;
- Michael McGimpsey, Minister for Health, Social Services and Public Safety in Northern Ireland.

# Opening remarks from Julia Unwin CBE

Julia Unwin, Chief Executive of the Joseph Rowntree Foundation (JRF) and Joseph Rowntree Housing Trust (JRHT), welcomed delegates and thanked partners for making the event possible. It promised to be a valuable opportunity to share experiences and insights into services for older people. The combined knowledge and experience of those attending represented a huge asset in terms of finding ways to ensure older people are fully engaged in debates about their care and treated with dignity and respect.

## **Drama performance by the Spring Chickens**

'Spring Chickens' is a unique outreach programme run by the Big Telly theatre company to promote creative expression and engagement within Northern Ireland's older population. The programme uses a variety of workshops and performances to challenge perceptions about older people.

Members of Spring Chickens used poetry, drama and monologue, interspersed with the collective refrain 'Don't write me off' to provide the audience with an entertaining but poignant insight into the lives of older people. The drama 'How are we today Mr Wakefield?' captured the lack of autonomy and dignity experienced by some older people in residential care. The monologue 'Living in terrifying times' described an older person's frightening experience of a house break-in. Other performances emphasised the importance of individual expression and a collective voice for older people.

## **Michael McGimpsey, Minister for Health, Social Services and Public Safety in Northern Ireland**

The Minister began by emphasising the importance of independence and choice for older people. He said these principles were at the heart of his Department's vision and that everyone had a role to play.

Moving on to discuss the comprehensive assessment of needs, the Minister described the Single Assessment Tool for Older People, developed to strengthen integrated assessment. Older people across Northern Ireland (NI) will be the first in the UK to be assessed with this tool, which is designed to ensure better outcomes and independence. The NI government is spending £1 million on design and implementation to ensure people receive care where and how they need it most.

The message being received 'loud and clear' by the Minister was that older people wanted to continue living independent lives in their own homes for as long as possible. Work with the

independent and voluntary sectors has focused on building more flexible and responsive domiciliary care services. The need for practical and targeted support for carers was also acknowledged.

Direct payments were cited by the Minister as an example of how services can offer greater choice and be tailored to individual needs. Since 2003, there has been a tenfold increase in direct payments in NI. The intention is to increase this by 50 per cent by March 2011.

The Minister described how he had opened Barn Halt Cottages in Carrickfergus in 2007 and said this was the type of development he would like to see across NI: providing independent housing with care whilst offering the reassurance that older people wanted. He expressed his commitment to mixed provision of services; public, private and voluntary partnerships dedicated to social care.

NI is spending over £630 million supporting older people and investing a further £60 million over the next three years to support an additional 1,500 older people in the community. Only acute services get higher funding than this.

The Minister mentioned recent work on the development of a service framework for older people to improve quality of service, reduce inequalities and improve partnership working. He concluded his speech with a commitment to continue his Department's hard work in ensuring resources are used efficiently and effectively, saying he looked forward to the invaluable contribution of the JRF in this area.

## **Dr Jeremy Harbison, Chair of the Northern Ireland Social Care Council**

Dr Harbison started by saying that NI was facing similar challenges to the rest of the UK and other industrialised countries. He outlined some of the demographic challenges, namely more older people and people living longer.

Between the years 2000 and 2040, the number of people aged over 60 will double. As this number increases, the proportion of older people in the population will increase further. At the same time, average family size is

decreasing, people are becoming more mobile and traditional support systems are shrinking.

Dr Harbison also highlighted the challenge of protecting income post-employment. He said that NI was experiencing a cultural shift which had implications for everyone.

The increased number of older people can be viewed as a benefit and a resource in terms of contributing to society. The merger of Age Concern and Help the Aged in April 2009 provides a great opportunity. More older people means more older voters, and older people can make a positive contribution both to their own demographic group and society as a whole.

Dr Harbison set out the challenges ahead:

- maximising quality of life as people live longer;
- addressing inequalities in health and wellbeing in older age;
- improving the health and wellbeing of older people;
- capitalising on the lobbying pressure of older people.

These challenges have implications for the provision of housing, transport, lifelong learning and work-life balance. Best models in health and social care need to be identified to help assess what is best for individuals. New funding models need to be developed for people who need support and care.

The Northern Ireland Social Care Council (NISCC) has responsibility for governing the practice of 35,000 social care workers and social workers. As chair, Dr Harbison explained how the NISCC has to ensure these workers are best equipped to practise, through improved training and understanding and initiating discipline procedures where appropriate.

There is a need to support older peoples' rights to control their lives and make informed choices. Under the governance of NISCC, social care practitioners sign up to a code of practice. This provides a good model for what is needed to move services forward.

Dr Harbison was delighted that JRF had taken the initiative to look at evidence in this area. He said the key driver must be promoting choice and independence of older people and stressed the importance of learning from this event and developing an evidence base to inform policy.

## Panel discussion

The panel comprised Julia Unwin (chair), Jeremy Harbison and Claire Keatinge, director of Alzheimer's Society Northern Ireland.

**Mrs Pat Whyte** (Newtownabbey Senior Citizens' Forum) explained her situation as a retired 70 year old caring for her 92 year old mother, who was very well mentally but not physically. What happens when an older person has to look after another older person?

**Mr Paddy Joe McClean** (from Beragh, County Tyrone) said he came especially to hear from the Minister, Michael McGimpsey. He expressed dismay at proposed cut backs, such as older people being taken away from day care centres, saying they had a cruel effect on the lives of older people. How are older people going to cope in newly stringent economic conditions?

**Julia Unwin** (JRF) responded by saying she shared concerns about the impact of proposed policy changes on people who are already vulnerable and would have appreciated the opportunity to ask the Minister about this.

**Dr Brent Irvine** (School of Medicine, Queen's University, Belfast) felt that good cognitive ability was fundamental to choice and independence. He said dementia was treated as a Cinderella disease in terms of investment in research and development, likening the position of dementia to where cancer was twenty years ago. The ratio of investment in cancer compared to Alzheimer's disease is now in the region of 20:1. Recent focus on the need for research into prevention and cure for Alzheimer's disease has resulted from the interventions of high profile celebrities Terry Pratchett and John Suchet.

**Julia Unwin** challenged the notion that choice and independence were not possible where someone had cognitive impairment or dementia.

**Claire Keatinge** (Alzheimer's Society) backed Ms Unwin's point and went on to say that she was confident a person with cognitive impairment could 'exercise choice comfortably and happily'. There are currently 16,000 people with dementia living in Northern Ireland and by the middle of the century this number will increase to 47,000.

Supporting Mrs Whyte's earlier comments, Ms Keatinge reminded the audience that behind these figures was an army of 'older people providing care for other older people.' She also acknowledged that enormous efforts and investment into cancer research had produced 'real results'. The audience was invited to imagine the powerful insights and improved treatment that could be achieved if the same investment was put into dementia.

On the theme of promoting independence and choice for people with dementia, Ms Keatinge described how a recent dementia strategy had been sent out for consultation without any input from people with dementia. This situation is not acceptable. The Alzheimer's society in NI has carried out a range of interviews with people who have dementia, who are very certain about what they want from services.

Ms Keatinge cautioned against the 'ghettoisation' of older people and argued for an integrated society in which people with dementia are enabled to live as independently as possible.

In order to successfully create a supportive society, the public needs to be informed and educated about dementia. Local communities have knowledge and support mechanisms, which are crucial in supporting people with dementia to live independently. We need to build on these resources and enable communities to become more responsive and more 'dementia friendly'.

Ms Keatinge also argued for better and more responsive services to support people at the early stages of the disease, for example, those who are worried about their memory. GPs need to be trained so that they are better equipped to recognise the condition and make early referrals. Ms Keatinge concluded her remarks by reminding the audience that people with dementia have feelings, dignity and rights that cannot be taken away from them. 'Rights', she said, 'are not a movable feast'.

**Dr Jeremy Harbison**, responding to Mr McClean's question, stressed that while he was not there as an apologist for the Minister, the reality is that there are fewer resources available. The government has to recognise that we are moving into economically stringent times which will have different effects for older people. Older people are in a position to lobby, challenge and speak out to get what they are entitled to.

**Dr Harbison** reminded the audience that budget cuts had been decided by the Executive and that the Minister had limited choice. It is important to ensure efficiency savings do not impact on critical services. There is a need for genuine consultation with service users, not just using a 'tick box' approach. Dr Harbison stressed the importance of adherence to section 75, whereby policy-makers and service providers had to explain how and why negative impacts of changes would be ameliorated.

To illustrate the need for people to remain vigilant and become actively involved in lobbying, Dr Harbison quoted statistics on poverty from the Department of Social Development. One in seven older people in NI are living in severe poverty and one in three older people are living below the poverty line. Income inequality is a very real issue and one that is set to increase. Funding of pensions is not being faced openly and honestly by society. There is a great danger that the inequality between those people with comfortable index-linked public pensions and those dependent on the basic state pension will increase.

**Julia Unwin** concluded the plenary session by recognising that the sector was facing some very big challenges, but that those in the room were in a position to make a difference.

## Workshop 1: Prevention and early intervention

This workshop was led by Alex O'Neil from JRF Older People's Programme, Claire Horton from the Newcastle Quality of Life Partnership and Mary Nicholls of the Elders Council of Newcastle.

Discussion highlighted the following issues:

- It is important to engage older people at a level that is comfortable for them, e.g. informal networks and lunch groups.
- Older people have identified a need for 'that bit of help', including practical services relating to transport, home maintenance and personal services.
- Social stimulation and activity have a role in preventing ill health.
- There are both challenges and opportunities involved when older people live in rural rather than urban areas.
- Intergenerational issues need to be considered.
- Developing capacity to deliver this work requires committed funds.

## Workshop 2: Care costs

This workshop was led by Sue Collins from the JRF and Alison Bowes of the University of Stirling, Scotland. Discussion covered the following issues:

- Changes in UK population demographics, in which the older population increases while the number of people of working age decreases, can be seen as a real opportunity to encourage the contribution of older people.
- Options for improving older people's choices in funding care include:
  - increasing capital limits for care homes;
  - equity release from privately owned homes;
  - doubling the personal expense allowance for people in care homes;
  - extending 'free personal care' in nursing and residential homes.
- Local authorities in Scotland no longer charge for personal and nursing care for people over 65. This has led to a rise in people seeking personal care support, suggesting a previous unmet need, but also brought equity issues because people under 65 with disabilities or chronic conditions are not eligible.
- Direct payments can be complex and people need support to know what is available to them and how to make sense of the system.
- NI government has cut spending across all departments, including the Department of Health, Social Services and Public Safety.
- A lack of strategic thinking hampers investment in new developments and new models of care provision. There is a need to involve users, particularly in linking policy with implementation.
- While people have rights to receive benefits based on needs and personal circumstances, there are no rights to receive care according to a defined standard of need.

## Workshop 3: Vibrant communities for older people

This workshop was led by John Kennedy of JRHT and Karen Croucher from the University of York. Discussion focused on JRHT's approach to providing housing with care for older people and those with learning disabilities:

- Costs are shared so the state is not paying for everything.
- Choice and independence are key, as are prevention services.
- Flexible services support the equity principle, so that older people can draw on their housing assets whilst retaining something to pass on to their children.
- Hartrigg Oaks, a JRHT continuing care retirement community in York, has a cost sharing funding model where all pay a care contribution regardless of need. People in Hartrigg Oaks feel safe, have communal support and do not feel isolated.
- Hartfields, a JRHT retirement village in Hartlepool opened in August 2008, provides a different funding model of mixed tenure and mixed care needs.
- To avoid 'ghettoising' older people, JRHT tries to ensure an interface with local communities, for example through the external use of gym facilities.

## Conclusion

The event concluded with feedback from the four workshops and reflections on the issues raised during the event.

Participants were disappointed that the Minister had not stayed for questions and had wanted to hear more about his vision for the future, rather than costs. They pointed out that older people are often carers themselves and policy needs to be changed to avoid the current situation whereby the carers allowance stops at 65.

The key message emerging from older people was the need to focus on what was important to them not what was important for them. The lack of voice for people in residential and nursing homes contributes to their vulnerability. There was recognition that this exclusion also applied to workers in these institutions.

Julia Unwin brought the day to a close by acknowledging the wealth of expertise and experience in the room. Drawing on this collective knowledge had produced a rich articulation of needs, wants and desires. She thanked the partners for their support and reminded delegates that 'together we can really make a difference'.

# Appendix: Notes from workshops

## Workshop 1: Prevention and early intervention

Alex O'Neil (JRF Older People's Programme), Claire Horton (Newcastle Quality of Life Partnership) and Mary Nicholls (Elders Council of Newcastle)

### **Messages from the JRF Older People's Programme:**

- Services need to be led by older people.
- Quality should be defined as the retention of things that are important to older people.
- Families and communities are important as well as services.
- The lack of voice for older people represents a democratic deficit.
- JRF research into 'That bit of help' wanted by older people identified important recommendations covering intergenerational work, practical services and the importance of keeping older people as experts.

### **Features of the Newcastle Quality of Life Partnership:**

- The partnership was formed to strengthen work to support older people, including considering what should not be done and what older people want.
- Participation of older people is encouraged at a level that is comfortable for the individual, e.g. informal networks and lunch groups.
- The programme uses creative communication methods, e.g. drama workshops, to ask people what they would like in later life. Responses, such as 'wanting to look presentable' and 'being able to feel good' are taken on board when developing Health and Social Care Services.

- Services developed in response to the engagement of older people include a mobile hairdressing pilot and 'Hop to the shops' bus service. As well as providing practical support, these have a positive outcome in terms of building social capital.
- By setting up a unique public website, the partnership provides information in response to questions from older people on issues such as attendance allowance, DIY and complementary therapy.
- The central theme of this work is keeping older people at the core of activities.

### **Barriers and solutions to older people's involvement:**

- Accessing information – the need to use existing technologies to support older people's access to information.
- Practical help – concerns can be addressed using a trades register of people who have been checked.
- Coordination of information systems – the need for single point signposting.
- Older people having to fit the service – this should be the other way round, requiring older people to be persistent, informed and communicate effectively.

### **Key points from workshop 1 discussion:**

- *Organisation of transport networks.* Bespoke services have to consider timing and cost.
- *Health.* Keeping people active and interested helps reduce ill health. Social clubs and lunch groups are in danger due to a lack of resources.
- *Local initiatives in NI.* These include the Northern Ireland Housing Executive, Belfast

Healthy Cities and Belfast Housing Trust. The Care and Repair scheme (run by Age Action Ireland) has been very successful.

- *Rural areas.* There are different issues in rural as opposed to urban areas. There are pockets of good practice in Northumberland and Nottinghamshire, e.g. practical services and community transport. Home care is also affected. There is evidence of higher levels of volunteering in rural areas, showing that geography provides opportunities as well as threats. Age Sector Platform are lobbying for a single person in each local council area to be able to deal with older person's issues.
- *Intergenerational issues.* It can be difficult to develop a comprehensive, sustainable approach to intergenerational issues (as experienced by the Newcastle project). There can be benefits to sharing space, e.g. older people's homes and children's nurseries.
- *Funding.* Having the capacity to deliver this work depends on committed funds.

## Workshop 2: Care costs

Sue Collins (JRF) and Alison Bowes (University of Stirling)

### **Evidence on funding long term care in the UK:**

- JRHT run care homes within north-east England. There are no JRF/JRHT care homes in Northern Ireland at present.
- There will be an 81 per cent increase in people over 65 by 2051, accompanied by a fall in the numbers of people of working age who will be able to support this age group. This can be seen as a real opportunity to encourage the contribution of older people.
- JRF has identified four options for improving older people's choices in funding care:

- increasing capital limits for care homes to benefit those on modest incomes, at a cost of £280 million;
- equity release from privately owned homes, supplementing personal income;
- doubling the personal expense allowance for people within care homes (currently £28 per week). This is also being advocated by Age Concern and Help the Aged through the 'Peanuts campaign';
- the extension of 'free personal care' in nursing and residential homes.

### **Overview of the Scottish experience arising from the Community Care and Health (Scotland) Act 2002:**

- Local authorities no longer charge for personal and nursing care for people over 65. Older people require assessment to be deemed eligible for free personal care.
- When the Scottish Act was introduced, there was a sharp rise in people seeking personal care support, particularly from those living in their own homes. This indicates unmet need prior to the introduction of the Act.
- The introduction of free personal care resulted in a change of behaviour in unpaid care givers. Many were pleased to get personal care support as it was an aspect of care with which they felt uncomfortable. They were able to focus on other aspects of care, which tended to enhance the quality of care provided.
- An unexpected consequence was development of equity issues in people younger than 65 with disabilities or chronic conditions, who are not entitled to free personal care. However, all people in hospital with medical conditions who require personal care do not have to pay.
- There are differences between health and social care provision within countries in the UK, but the benefits system is standardised throughout.

### **Key points from workshop 2 discussion:**

- Funding issues are key. Direct payments are a complex issue and people need support in order to make use of this system. People need to know what is available to them – there needs to be a supportive infrastructure to support decision making. Additionally, a ‘postcode lottery’ exists in terms of available resources.
- NI government has cut spending across all departments, including the Department of Health, Social Services and Public Safety. These cuts mean a reduction in money for local services and health and social service organisations becoming ‘sandwiched’ between lower financial resources and the needs of patients/clients.
- A lack of strategic thinking hampers investment in new developments and new models of care provision, especially in the present climate where, due to a transition into new structures, planning has become dislocated. Money should be ring-fenced for specific areas of need or improvement. There is a need to involve users, particularly in linking policy with implementation.
- While there are rights to receive benefits based on needs or personal circumstances or finances, there are no rights to receive care according to a defined standard of need. Care is provided in line with available resources. Should insufficient resources be unavailable, needs go unmet.
- Personalisation of needs should be based on a rights-based approach, so that clearly defined needs are met.

### **Workshop 3: Vibrant communities for older people**

John Kennedy (JRHT) and Karen Croucher (University of York)

#### **Features of JRHT’s approach:**

- JRHT has a tradition of putting research into practice through the provision of housing with care for older people and those with learning disabilities.
- Costs are shared so the state is not paying for everything.
- Choice and independence are key.
- Prevention services are vital.
- The provision of flexible services supports the equity principle, so that older people can draw on their housing assets whilst retaining something to pass on to their children.
- Hartrigg Oaks, a JRHT continuing care retirement community in York, has a cost sharing funding model where all pay a care contribution regardless of need.
- People in Hartrigg Oaks feel safe, have communal support, and do not feel isolated.
- Hartfields, a JRHT retirement village in Hartlepool opened in August 2008, provides a different funding model of mixed tenure and mixed care needs.
- Do such schemes ‘ghettoise’ older people? JRHT tries to ensure an interface with local communities, for example through the external use of gym facilities.



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