

C|A|R|D|I **GRANTS**
PROGRAMME

Research Brief

**Ageing and
Intellectual Disability**

Ageing in the general population: ROI

- At the 2006 census, there were 468,000 people aged 65+ (11% of the population).
- By 2041, there will be 1.4 million aged 65+ (22% of the population).
- Life expectancy is 76.8 years for men and 81.6 years for women.
- 95% of men and women aged 70+ rate their health as very good (19%), good (50%) or fair (26%).
- 9.1% of people aged 65+ are still in employment (Q2 2009).

Ageing in the general population: NI

- In 2008, there were 248,500 people aged 65+ (14% of the population).
- In 2041 the 65+ age group is projected to make up 24% of the population.
- Life expectancy is 76.3 years for men and 81.3 years for women.
- 66% of people aged 70+ rate their health as good (25%) or fairly good (42%).
- 9% of men aged 65 and women aged 60+ are still in employment (Q2 2009).

Intellectual disability policy: ROI

- The National Disability Strategy 2004 aims for equal rights for people with disabilities and establishes rights to assessments and services in the health and education sectors.
- The Health Bill 2006 established HIQA with a registration and inspection system for people with disabilities and older people.
- *A Vision for Change* (2005) is the government strategy on mental health and includes sections on provision of services for older people and those with an intellectual disability.

Intellectual disability policy: NI

- The Disability Unit in the OFMDFM has responsibility for developing anti-discrimination policy on disability.
- A Promoting Social Inclusion Disability Working Group reports to the First Minister and Deputy First Minister.
- *Equal Lives* (2005) was part of the Bamford review of policy and services for people with learning disabilities. This review made recommendations on future policy, strategy, service priorities and legislation, and was followed up by the Bamford Action Plan 2009–11.

Ageing and Intellectual Disability

Introduction

There are over 3,100 older people with intellectual disabilities in the Republic of Ireland (ROI) and nearly 2,000 in Northern Ireland (NI). However, the voices of this group of older people (and of those who care for them) are not regularly heard in debates about public policy or services, despite the fact that the numbers are steadily increasing due to rising life expectancy (McConkey, R. et al, 2011).

This research briefing is based on the study *Ageing and Intellectual Disability: a feasibility study in Northern Ireland* (McConkey, R. et al, 2011) led by Professor Roy McConkey. It was funded by the CARDI grants programme. The rationale for the study was that information on social, psychological and health issues for older people with intellectual disabilities is currently lacking. In ROI, there is an Intellectual Disability Supplement (IDS) to the longitudinal study on ageing (TILDA), but no equivalent in NI. The McConkey led study aimed to examine how these gaps in information on older people with intellectual disabilities in NI could be filled.

This briefing examines current facts and policies related to ageing and intellectual disability, and how policy relating to older people can most effectively take into account the specific needs of people with an intellectual disability.

Key findings

- Just over 26,000 people in ROI are registered as having an intellectual disability, representing a prevalence rate of 6.15 per 1,000 population. 12% of these are aged 55+.
- In 2003 in NI over 16,000 people had an intellectual disability. Of these, 14% were aged 50+.
- The lifespan of people with intellectual disability is increasing. In ROI, there are 789 more people aged 55+ now than there were in 1996.
- A UK study found that 89% of adults with learning disabilities live in the community, supported by unpaid members of the family. 25% of these carers are over the age of 70.
- Mainstream policy for older people fails to take into account the specific needs of people with an intellectual disability.

What is intellectual disability?

Intellectual disability is a broad concept which is used to describe a variety of intellectual deficits, including learning difficulties and impaired cognitive function. Like that of the general population, the life expectancy of people with intellectual disability is increasing. The numbers of older people with intellectual disability in the past were very small, but are set to increase significantly. Despite this, there is a lack of information on the health and well-being of this group of people in society.

As people age their support and care needs change, which places new demands on services. Traditionally, many people with intellectual disabilities lived with their parents but, as life expectancy increases, parents are now likely to pre-decease their offspring (McCarron and McCallion, 2007). Younger and middle-aged people with intellectual disabilities who may have been living independently may also become more dependent as they age. Understanding older people with intellectual disabilities is vital as it enables policy-makers to put the cost-effective care and support responses in place.

Intellectual disabilities and ageing in Ireland: key issues

The *Ageing in Persons with an Intellectual Disability* research was led by a steering group that included carers, policy-makers and other professionals. Part of the task of this group was to identify the main issues in NI for people growing older with intellectual disabilities, issues for their family carers and issues facing the support services. The issues are summarised in the table below. Many of them are also likely to arise in ROI.

Table 1: Key issues in ageing and intellectual disability

Person who is growing old	<ul style="list-style-type: none"> • Security and “feeling safe”. • Financial security. • Transport issues, particularly in rural locations. • Quality of access to services. • Additional caring responsibility. • Lack of support, e.g. respite and domiciliary care. • Lack of information and awareness of what is happening. • Moving from disability programmes to older people’s programmes, involving different care centres and the break-up of existing relationships. • Person-centred planning. • Retirement.
Family carers	<ul style="list-style-type: none"> • Isolation as the care burden increases. • Financial worries, e.g. the loss of the NI carer’s allowance at pensionable age. • Transport. • Safety and security. • Emotional element associated with placing the family member in residential care.
Support services	<ul style="list-style-type: none"> • Training and development strategy needed to ensure staff meet the needs of older persons with intellectual disability. • More structured inspection programmes required. • Specific training needed in dementia and palliative care. • Joint working to be encouraged between intellectual disability nurses and district nurses. • Links to be developed between services such as cancer and palliative care and intellectual disability services. • Lack of resources to be addressed in anticipation of the ageing population with intellectual disability. • Person-centred planning needs to target the older population. • Day centres for older people need to allow for the needs of people with an intellectual disability, such a quiet room. • Intellectual disability is an exclusion criterion for some sheltered accommodation. • Additional support is required for staff in mainstream residential homes and private nursing homes.

Caring for older people with intellectual disability

As the lifespan of people with an intellectual disability increases, new challenges will emerge in the future with regard to their care. A major challenge is that most people with an intellectual disability are cared for by their parents. But as their life expectancy increases, many older people with intellectual disability will outlive their parents.

One UK study showed that 89% of adults with learning disabilities lived in the community, supported by members of the family. Some 25% of these carers were themselves over the age of 70 and were virtually unknown to services until a crisis occurred (Robinson and Williams, 2002).

A study in NI of older parents caring for offspring with disabilities showed that 38% of the carers were over pensionable age. The average age of sons and daughters with disabilities was 33.5 years (Changing Ageing Partnership, 2009). Two-thirds of the participants (67%) relied on informal family arrangements in the event of the main carer falling ill. In 48% of cases, there were no adequate substitute care arrangements. Likewise a UK study of older carers (aged 70+) for adults with a learning disability showed that 55% of these carers were either unwilling or not ready to make future plans (Bowey and McLaughlin, 2007).

A lack of forward planning leads to people being admitted into full-time residential care that is not suited to their needs. As a report from the National Intellectual Disability Database (NIDD) notes: "Emergency or crisis admissions to residential care are a continuing resource problem for the health services. The large increase in the number of people aged 50 years and over accommodated in nursing homes over the five-year period, many as crisis or emergency placements, needs to be examined" (Health Research Board, 2009).

Intellectual disabilities and ageing in Ireland: key statistics

This section presents some of the existing data on the prevalence of intellectual disabilities among older people in Ireland, North and South. It also provides information on the carers of people with an intellectual disability.

Republic of Ireland

In ROI, the NIDD was established in 1995. The aim was to ensure that information is available to enable the Department of Health and Children, the Health Service Executive (HSE) and the non-statutory agencies to provide appropriate services designed to meet the changing needs of people with intellectual disability and their families.

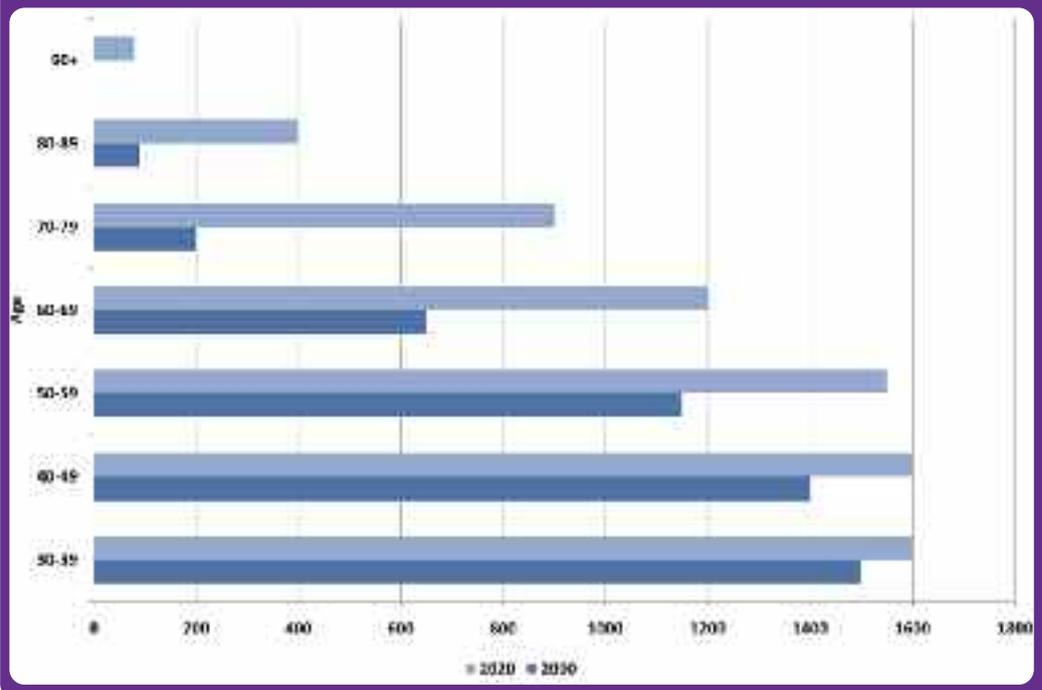
There were 26,066 people registered on the NIDD in December 2009, representing a prevalence rate of 6.15 per 1,000 population (Health Research Board, 2010). Some 12% of these are aged 55+. The lifespan of people with an intellectual disability in ROI has increased. For example, the proportion of people with an intellectual disability who were aged 35+ rose from 29% in 1974 to 38% in 1996 and to 49% in 2009. There has been an overall increase in the 55+ age group; the prevalence rate in 2009 was 2.54 per thousand of population. The number of people in this age group registered on the NIDD increased by 789 between 1996 and 2009 (Health Research Board, 2010).

Northern Ireland

In NI, relatively little research has been undertaken into ageing and people with intellectual disability. The *Equal Lives* report from the Bamford Review (DHSS and PS, 2005) stated that “the review had found limited evidence of strategic planning, specific policy or changing practices that will meet the emerging needs associated with increased numbers and needs of older men and women with a learning disability or their family carers in Northern Ireland”. There is no equivalent to the ROI database on intellectual disability.

About 16,400 people had an intellectual disability in NI in 2003. Of these, some 2,200 were aged 50+ (DHSS and PS, 2005). Figure 1 shows that the number of people with an intellectual disability over the age of 50 in NI is expected to increase markedly by 2020. The projection is that by then there will be 4,100 people aged 50+ with an intellectual disability, while the general population of this age group is estimated to grow to 617,000.

Figure 1: People with intellectual disability in NI, by age, 2000 and 2020



Source: McConkey (2011)

ROI intellectual disability longitudinal study

In ROI, an intellectual disability supplement to the landmark TILDA (the Irish longitudinal study of ageing) research was created in 2008 with Professor Mary McCarron, TCD as Principal Investigator. The study involves approximately 800 people with intellectual disability aged 40 years and over, charting their health, social, economic, environmental and psychological status as they age over a 10-year period. It is the first longitudinal study of ageing in people with intellectual disability in Europe.

The first results from the study were presented at a seminar in September 2010 (IDS-TILDA, 2010). The initial results show both positive and negative features. The positive related mostly to physical health: 45% of the people in the study

viewed their health as excellent or very good. The results also indicate that people with an intellectual disability are a population with a low prevalence of disease (although 33.9% had high cholesterol). However, 55% of the sample suffered from an emotional, nervous or psychiatric condition. Interaction with other people also emerged as a problem, as 80% of social interaction was with staff or family in the place of residence and 52% of respondents said they felt lonely. The level of employment among participants in the study was also very low.

Extending the study to NI

In 2009, CARDI funded a feasibility study to examine the possible extension of the TILDA intellectual disability supplement to NI. The research was led by Professor Roy McConkey of the University of Ulster. It set out to gather information in NI about older people with intellectual disabilities and older family carers and to test the potential of developing an all-Ireland module on intellectual disability that would be part of a long-term study of older people. The feasibility study concluded that extending the intellectual disability study to NI would be of great value, although adaptations from the TILDA sampling strategy would be required to increase recruitment rates in NI.

Policy implications

Mainstream policy for older people has ignored the specific needs of people with an intellectual disability. Disability, both physical and mental, will be an increasing feature within older people's policy and practice as the emphasis shifts toward inclusion and equality of opportunity. The McConkey study identifies three major policy issues with regard to people ageing with intellectual disability:

The *Equal Lives* report (DHSS and PS, 2005) provides a broad context for policy-making, with priority placed on person-centred planning and for older people to have the choice of "ageing in place".

Mainstream policy on older people must respond to the needs of older family carers and to those of people ageing with intellectual disability. Dementia policy and services need to recognise the specific needs of people with intellectual disability.

The study demonstrated that within the health and social care systems in NI closer working is needed between the programme of care for older people and the learning disability programme of care, particularly when people are "transitioning", i.e. moving from the care of disability services to the care of older people services. To this end, a multi-agency network on ageing and intellectual disability that embraces older people, family carers and relevant professionals would be advantageous.

An significant outcome of the study into extending the intellectual disability supplement to TILDA into NI is that cross-border initiatives on ageing and intellectual disability are lacking. It is important that research into intellectual disability be approached from an all-island comparative perspective in order to maximise the limited resources likely to be available in the foreseeable future.

Ageing and intellectual disability are perhaps perceived to be a future rather than present concern. However, policy preparations for an ageing population of people with intellectual disability need to be implemented now if value-for-money services are to be created.

Published by the **Centre for Ageing Research and Development in Ireland (CARDI)**
© Centre for Ageing Research and Development in Ireland. CARDI has produced this publication as a resource for researchers, policy-makers, older people and others with an interest in ageing research. To find out more about CARDI's grants programme please visit www.cardi.ie

This research briefing is based on information collated by CARDI and on the findings of a research report by Mc Conkey et al (2011) funded under CARDI's Grants Programme.

It may be cited as Ageing and Intellectual Disability, 2011. Belfast: Centre for Ageing Research and Development in Ireland.

This publication can be downloaded from www.cardi.ie Additional copies may be requested from:

Centre for Ageing Research and Development in Ireland
Forestview, Purdy's Lane,
Belfast BT87ZX
Tel: +44 (0) 28 9069 0066

Centre for Ageing Research and Development in Ireland
5th Floor Bishop's Square,
Redmond's Hill, Dublin 2
Tel: +353 (0) 1 478 6308

Email: info@cardi.ie

Our work has been made possible through funding by The Atlantic Philanthropies, augmented by grants from the Department of Health and Children in Dublin and the Health and Social Care Research Office, Public Health Agency, Northern Ireland. CARDI is hosted by the Institute of Public Health in Ireland.

Research team

Professor Roy McConkey, School of Nursing, University of Ulster

Dr Maria Truesdale-Kennedy, School of Nursing, University of Ulster

Professor Mary McCarron, School of Nursing and Midwifery, Trinity College, Dublin

Professor Philip McCallion, School of Nursing and Midwifery, Trinity College, Dublin

Dr Laurence Taggart, Institute of Nursing Research, University of Ulster

References

Bowey, L. and McGlaughlin, A., *Older Carers of Adults with a Learning Disability Confront the Future: issues and preferences in planning* (2007)

Changing Ageing Partnership, *What the Future Holds: older people caring for adult sons and daughters with disabilities* (2009)

DHSS and PS, *Administrative Prevalence of Learning Disability in Northern Ireland* (2003)

DHSS and PS, *Equal Lives: review of policy and services for people with a learning disability in Northern Ireland* (2005)

Health Research Board, *Trends in Demand for Services among those aged 50 years and over with an intellectual disability, 2003 –2007* (2009)

Health Research Board, *Annual Report of the National Intellectual Disability* (2010)

IDS-TILDA Ageing Conference 2010, Trinity College Dublin School of Nursing and Midwifery

McCarron, M. and McCallion, P., *Supporting Families who have Ageing Members with Disabilities* (2007)

McConkey, R. et al, *Ageing and Intellectual Disability: a feasibility study in Northern Ireland* (2011)

Robinson, C. and Williams, V., *Carers of People with Learning Disabilities, and Their Experience of the 1995 Carers Act* (2002)