



Social inclusion and ageing with an intellectual disability

Introduction

More adults with an intellectual disability (ID) in the Republic of Ireland (ROI) and Northern Ireland (NI) are living to older ages. Social inclusion is vital for the health, wellbeing and quality of life of this group of adults as they age, and they often age without the family and social supports that other adults have.

A first step toward social inclusion is in better understanding what social inclusion means for older adults with ID and what these adults need from service providers and communities to achieve full participation. Martin & Cobigo (2011) propose that social inclusion should be understood in relation to five domains – **relationships, leisure, productive activities, accommodations and informal supports.**

This edition of the CARDI “Focus on” series examines social inclusion and ageing with an intellectual disability while assessing the current evidence on social inclusion in each of these five domains.

Key findings

- More adults with ID are living to older ages - in 1974 in ROI only 29% of people with ID were aged 35 or over but by 2013 this had risen to 49%. There are 3,600 people with ID over the age of 55 (Kelly & O'Donohoe, 2014).
- Among older adults with ID in ROI 99% are unmarried and just 2% of women have children. As a result, they are far more reliant on family for social participation especially as parents who are carers reach advanced ages (McCarron, et al., 2011).
- Adults with ID have very few meaningful relationships with people who do not have intellectual disabilities, are not relatives and who are not paid to support them (Robertson et al., 2001).
- Policy and services can combat social exclusion among older adults with ID through circles of support, peer-based approaches, training programmes and befriending strategies (Duggan & Linehan, 2013).
- There is a lack of data on older adults with ID in NI, with the most recent data coming from 2006 (Slevin et al., 2011). Census 2011 in NI did not include a specific question on ID (Murphy, 2014).

What we know about older adults with ID

In 2013 according to the National Intellectual Disability Database there were 16,000 men and 11,650 women registered as having an intellectual disability in ROI. 13% or 3,600 people in total were aged 55 or over (Kelly & O'Donohoe, 2014).

This population group is ageing – in 1974 only 29% of people with an intellectual disability were aged 35 or over but by 2013 this had risen to 49%. In 2013, the most populous age group was the 35-54 range with 28% of the people with an intellectual disability in that group. This indicates that there will be a large increase of people aged 55 and over with an intellectual disability in the next two decades. Among the population aged 40+ in ROI 24% have a mild intellectual disability, 46% have moderate, 24% have severe and 5% are profoundly disabled.

In Northern Ireland (NI), there is no equivalent to the National Intellectual Disability Database or the IDS to TILDA. As a result there is a dearth of information on older adults with an intellectual disability. The 2011 Census included a question on having a “learning difficulty, an intellectual difficulty, or a social or behavioural difficulty”. However, it is not possible to disaggregate the figures (Murphy, 2014). Slevin et al. (2011) notes that the most recent data on older adults with intellectual disability dates from 2006. In that year, there were 16,720 people in NI known to services with an intellectual disability. Of these, 14% (2,340) were aged 50 or over (Slevin et al., 2011).

Social inclusion of older adults with ID

In 2011, Martin & Cobigo assessed 1,341 adults in Canada with intellectual disabilities residing in institutional and community-based settings to better understand the nature of social inclusion among this group. They proposed five domains of social inclusion:

1. Relationships
2. Leisure
3. Productive activities
4. Accommodations
5. Informal supports

The researchers pointed out that “a clear definition of inclusion and its measurement is needed for decision-makers and service providers to define the nature of their responsibilities, set actions and assess their effectiveness in achieving inclusion” (Martin & Cobigo, 2011).

This section examines social inclusion of older adults with ID in ROI in terms of each of the five domains. The data shows social inclusion is at a low level in each of the five domains for older adults with ID.

Relationships

Family networks of older people with an intellectual disability are very different to that of the general population. As 99% of this group are unmarried and just 2% of women have children they are far more reliant on siblings and extended family to provide family networks and social participation, especially as parents who are carers reach advanced ages (McCarron, et al., 2011). Among adults with an intellectual disability over the age of 65, 9% have no family whatsoever (Burke, McCallion, & McCarron, 2014).

Analysis of data between Wave 1 and Wave 2 of the IDS to TILDA shows a fall in level of regular contact with family. Regular/monthly face-to-face contact had fallen from 54% in Wave 1 to 52% in Wave 2. Regular telephone contact had fallen from 50% in Wave 1 to 47% in Wave 2 (Burke, McCallion, & McCarron, 2014). Three out of four adults with an ID have never written, texted, emailed or used social media to contact family or friends. In addition, less than 60% of adults with an intellectual disability used the telephone to contact family and friends and this group were less likely to own a mobile phone (24%) than other adults in the ROI population (Burke, McCallion, & McCarron, 2014).

Responses to IDS to TILDA showed that 43% of older adults with an intellectual disability have no friends outside the home. 77% of older adults with a mild ID had friends outside the home compared to 58% with a moderate ID and 34% with a severe or profound ID. Place of residence also had an impact with 87% of those living independently or with family having friends outside the home compared to 60% living in a community group home and 41% in institutional care.

Older adults with severe and profound ID as well as those in the oldest age groups are much less likely to have purposeful contact with family, friends and neighbours (Burke, McCallion, & McCarron, 2014).

Leisure

Social inclusion in terms of leisure activities for older adults with ID is, in the majority of cases, limited to that provided by family or paid staff. Over 70% of respondents in Wave 2 of the IDS to TILDA were dependant on paid staff for participation in social activities (Burke, McCallion, & McCarron, 2014).

Bigby (2011) notes that IDS to TILDA findings show that older adults in ROI with ID have limited involvement in mainstream community organisations, retirement clubs, residents' associations or engagement with neighbours or other community members (Bigby, 2011).

Research from the Netherlands shows that high social participation among people with a mild or moderate ID within the domains of work, social contact and leisure activities does not necessarily indicate a high level of interaction with the community, because the majority hardly interact with people without ID (Dusseljee et al., 2011).

Older adults with ID and loneliness

The IDS to TILDA shows high levels of loneliness among older adults with an intellectual disability. Of the 390 people who self-responded to the question “Do you ever feel lonely?” 50% reported that they had experienced loneliness. Within this group, 19% also reported a doctor’s diagnosis of depression. Nearly half of respondents had not felt lonely and, of these, 16% had a previous doctor’s diagnosis of depression. In the general adult population, 5% of older adults reported a diagnosis of depression (McCarron, et al., 2011).

Women were more likely than men to report feeling lonely (53% versus 34%), feel left out (28% compared to 24%) and having difficulty making friends (28% versus 27%). Older adults with an ID living independently or with family have lower levels of emotional or mental health problems, are less likely to feel lonely and less likely to have difficulty making friends (Burke et al., 2014).

Productive activities

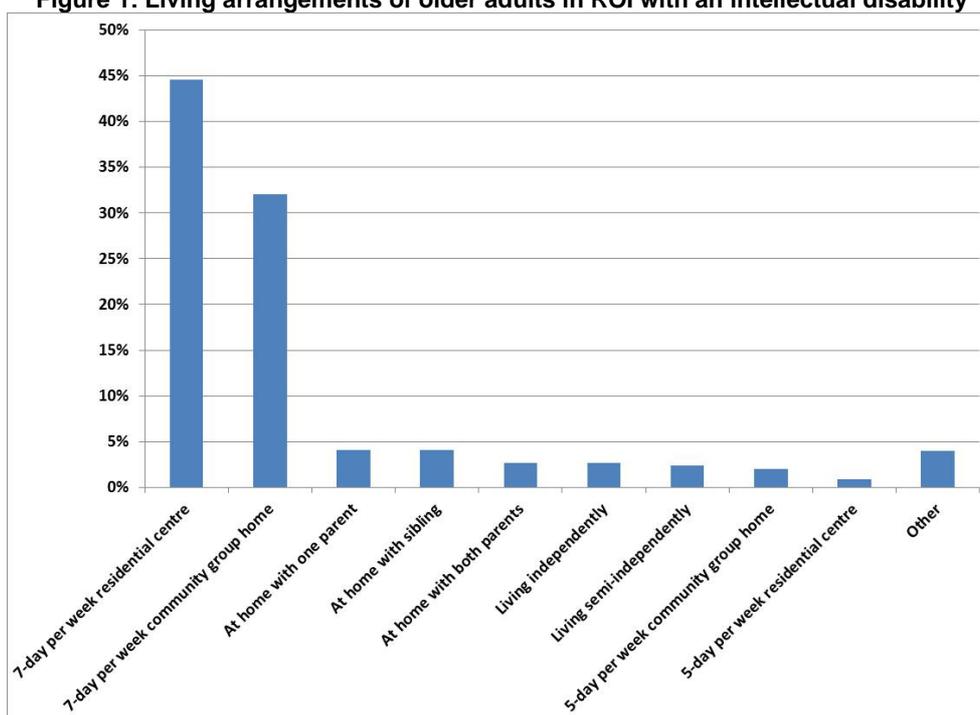
According to the IDS to TILDA, just 7% of adults in ROI with an intellectual disability are in paid employment. It was reported that 38% were unable to work due to permanent disability or sickness and 6% were retired. Of those in paid employment 44% received less than the minimum wage. Over half of respondents did not know how much money they received on a weekly/monthly basis (McCarron, et al., 2011).

The majority of older adults (62%) in the general population in ROI have achieved at least secondary education (Kelly & O’Donohoe, 2014). However, 32% of adults with an intellectual disability have no education and a further 31% have some primary education. The number of adults with a leaving certificate education is very low at 0.5% (McCarron, et al., 2011). In ROI 14% of older adults with ID participate in some form of education (Burke, McCallion, & McCarron, 2014).

Accommodations

In the IDS to TILDA findings most participants lived in out-of-home placements. Adults with ID living with families and in the community tended to be younger with a mild or moderate range of intellectual disability. Those living in residential accommodation tended to be older with more severe to profound levels of disability. However, there were still a substantial number of people in the younger age cohorts living in residential centres. 27% of participants had lived in their current residence for less than five years but 41% had lived there for more than 20 years.

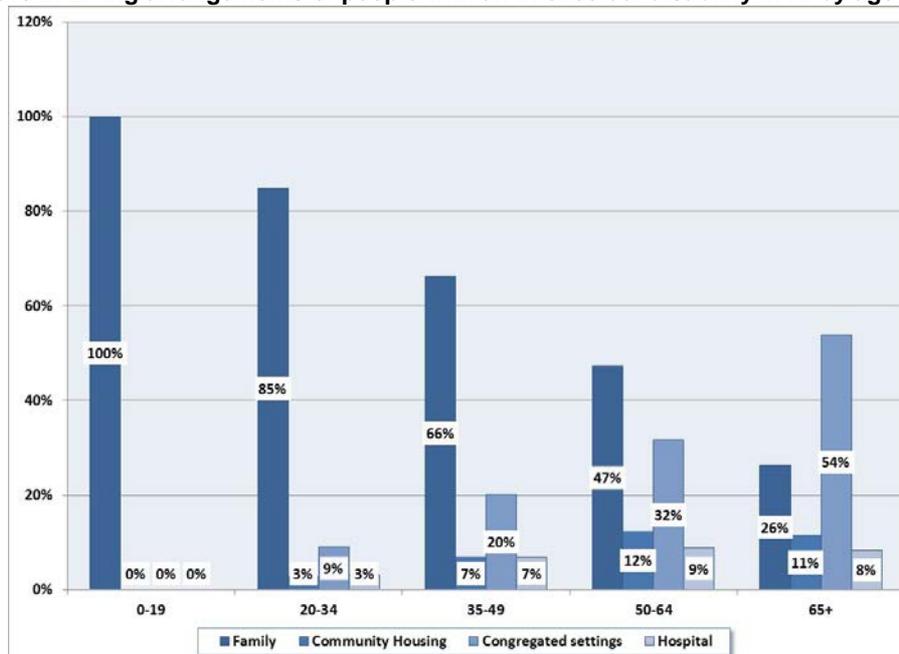
Figure 1: Living arrangements of older adults in ROI with an intellectual disability



Source: (McCarron, et al., 2011)

In NI, the number of people with ID who live at home with family declines with age. Among the 65+ age group, 26% are estimated to live with family, 11% live in community housing, 54% in congregated settings and 8% in hospital (Slevin et al., 2011).

Figure 2: Living arrangements of people with an intellectual disability in NI by age group



Source: Slevin et al. (2011)

In the IDS to TILDA, 75% of respondents reported having no choice in relation to where they lived and 86% reported that they had no choice in relation to who they lived with. Almost half of respondents said they had no choice in relation to the time at which they went to bed (McCarron, et al., 2011).

Informal supports

Informal supports for adults with ID tend to reduce as they age. Older parents who have cared for a child with ID into late middle age develop their own health and social support needs and many carers at this stage are widowed mothers (Walker & Walker, 1998). Family and social networks tend to reduce or become inactive when people age. Households in which there are older parents, or one surviving parent, and an ageing son or daughter with ID, are likely to become increasingly cut off from sources of informal support from family, friends and neighbours (Maggs & Laugharne, 1996). Adults with ID lack the two key providers of informal support in later life, namely children and a spouse. As a result, building an informal network of support earlier in life is a vital part of social inclusion as adults with ID age (Bigby, 2010).

Policy challenges

Robertson et al. (2001) summarised the challenge in terms of the development of social inclusion for adults with ID - people with intellectual disabilities have very few meaningful relationships with people who do not have intellectual disabilities, are not relatives, and who are not paid to support them (Robertson et al., 2001).

Social inclusion has a positive impact on physical and mental health and well-being as well as quality of life. It has a cumulative effect which builds over time so policy and practice interventions need to be implemented at all stages of the life cycle (Butler & Watt, 2007). Interventions focusing on assisting people with ID to develop meaningful relationships and exercise control over their lives are important from an early age (Kelly, 2010).

Policies of social inclusion for adults with an ID tend to focus on paid work and independent living. However, for many people with IDs this is either not desired or not possible (Hall, 2010). Bigby (2011) notes that for older adults with ID, there is a difference between “community presence”, *i.e.* living and functioning independently in the community, and “community participation”, having a network of personal relationships that includes people without ID as well as family members, peers and paid staff.

Disability services play a key role in linkage to community activities and contact with friends as older adults have little social contact outside of family and formal programmes (Bigby & Knox, 2009). Duggan & Linehan (2013) have identified four potential strategies for disability policy and services:

1. **Circles of support** engage family and friends in a formalised structure to support a person with intellectual disability to achieve personal goals.
2. **Peer-based approaches** facilitate people with disabilities to support one another, sharing experiences through peer counselling. They are typically facilitated in “drop in” centre environments.
3. **Training programmes** assist development of social skills to enhance social inclusion opportunities.
4. **Befriending strategies** are when volunteers in disability organisations form friendships with people with disabilities (Duggan & Linehan, 2013).

Case study: 3D Community Support, The Circles Network UK

The Circles Network UK is a national charity that promotes social inclusion among vulnerable and lonely people, using information, knowledge and practice to help those people to live improved, self-determined lives. The charity works in partnership with individuals, families, services and local authorities to provide personalised support.

3D Community Support is a system designed specifically for individuals and their families to take as much control as they would like over the running of their day-to-day lives. It is aimed at adults, young people and children who may be disabled, have learning difficulties, mental health issues, have acquired brain injury, people with autism and/or people who are at risk of exclusion. Each individual gets a tailored support plan that includes life coaching, building a circle of support and the opportunity to develop social networks and participate in local community activities (Circles Network, 2014).

The importance of the service is in the emphasis placed on personalised supports for building social networks and relationships. The service is provided in partnership with local authorities and trusts. Supports are paid for using direct payments, private funds or through direct purchase from local authorities depending on the individual circumstances (Warwickshire Direct, 2014).

Policy in ROI

In ROI, current policy for people with ID addresses social and community participation by emphasising deinstitutionalisation and moving people with ID into community group homes and more independent settings.

The *National Disability Strategy* published in 2004 represented a fundamental shift towards social inclusion and full citizenship for people with disabilities. It made specific legal provision for the mainstreaming of access to public services. The central objective of the Strategy was that people with disabilities should be supported to be active and contributing members of society (Department of Justice and Equality, 2013).

The *National Housing Strategy for People with a Disability* published in 2011 promotes independent living and individual choice for all people with a disability. This involves moving from congregated settings to community living (Department of the Environment, Community and Local Government, 2011).

The *National Positive Ageing Strategy* in ROI notes that “fewer social networks are associated with a number of adverse health outcomes” and that lower levels of social integration are comparable in their adverse effects to smoking or obesity. One of the strategy objectives is to promote opportunities for participation of people in their communities and society, but there are no specific mentions of older adults with ID (Department of Health, 2013).

The Health Service Executive (HSE) has primary responsibility for the provision of specialist disability services to all eligible persons with disabilities in ROI. Where HSE are unable to provide these services at regional level, primary responsibility is transferred from HSE to locally-based voluntary, non-statutory organisations. Services include residential services; adult day care services; disability allowances; multidisciplinary teams; personal assistant services; respite services; rehabilitation; aids & appliances; placements requiring revision and early intervention teams (Linehan, et al., 2014).

Services in ROI are currently in transition to a more personalised model of supports for people with intellectual disabilities. The process to date, however, has been characterised as a “slow and tentative drift” (Linehan, et al., 2014).

Policy in NI

There are large gaps in data which contribute to a poor understanding of older adults with ID in NI. There is no equivalent to the IDS to TILDA in NI and many existing sources are now outdated.

A *Strategy to improve the lives of people with disabilities 2012-2015* was published in NI in 2012. One of the central goals is to provide the appropriate support so that people with disabilities can exercise choice and control over their own lives. While there is a focus on early years and transitions to adulthood, there are no specific provisions for older adults with ID. As in ROI government policy, independent living is a key focus of the strategy (OFMDFM, 2012).

A housing-related support strategy for vulnerable people was published in NI in 2012. The strategy calls for better responses for people with learning disabilities at community and primary care level, which focused on a transition from institutional settings to varying levels of supported accommodation (Northern Ireland Housing Executive, 2012).

Conclusion

Across the five domains of social inclusion proposed by Martin & Cobigo (2011) and analysing the IDS to TILDA data there appears to be low levels of social participation and social inclusion among older adults with ID.

Those adults who live with family or independently in communities fare better in terms of social inclusion, so the move toward deinstitutionalisation in ROI and NI policy is a positive one. However, older adults with ID are now often outliving parents and siblings, and are highly unlikely to have spouses or children of their own (the main source of care and inclusion). Given the many barriers to social participation faced by this group of adults, initiatives to promote independence should be accompanied by others to foster meaningful relationships and social networks. Older adults with ID are also a diverse group with a complex array of needs and requirements for support. Individualised social inclusion measures would allow for increased levels of social participation and help adults with ID to age positively and actively.

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