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## Knowledge Exchange Seminar Series (KESS)

### Providing Supports to People with a Learning Disability Transitioning into Older Age

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**Introduction:** This KESS is a summary of a three-year Public Health Agency, Research & Development Office funded project that explored how Northern Ireland could develop age appropriate service supports for older adults with a learning disability and their family carers. The results of this research will help inform commissioners, policymakers and service providers on how to plan and develop specific services for this population in the future.

#### Background:

- People with a learning disability are now living longer and most are living with ageing family carers (i.e. mother, father, sibling). These numbers are continuing to rise, which will increase the demand for mainstream older persons services, learning disability services and services designed to specifically meet the needs of older people with a learning disability
- For people with a learning disability, it is argued that ageing begins earlier, from 50 years of age and for those with Down's Syndrome from 40 years. People with Down's Syndrome are also more likely to develop early onset dementia
- Northern Ireland has a higher proportion of older people with a learning disability living in the family home being cared for by an ageing family carer; than elsewhere in UK and Ireland
- Most family carers are female (i.e. mothers/sisters); but there are also growing numbers of males taking on the role of carer due to the death of a spouse/family member
- Despite 30 years of research into identifying the needs of ageing family carers, the needs of these family carers continue to remain unmet
- There is little evidence of forward planning
- Local communities do not plan for the inclusion of older people with a learning disability; and futures planning currently carried out by Health and Social Care Trusts (H&SCTs) involving people with a learning disability does not take place within a community context, leaving those with disabilities socially isolated
- Current models for supporting older family carers of people with a learning disability are no longer fit for purpose, nor are they a viable or sustainable option to meet increased demand
- Traditional service models for older people with a learning disability (i.e. buildings-based day centres, residential provision, respite) are unable to meet the current and future demands of the changing demographics of this population. There is a need for a rights based person-centred approach in order to provide age appropriate supports and services

# Knowledge Exchange Seminar Series 2015-16

- Commissioners, policymakers and service providers must urgently and radically rethink current family support and traditional service models, pool existing resources and place greater emphasis on “family-centred care and support” and create new community-based initiatives
- There is also a need to ensure that people with a learning disability are involved as co-designers, shaping the services they use and a need for greater emphasis on person centred, rights based models, which support people with a learning disability within a family context.

## Policy:

- The *'Equal Lives Report'* (2005) and the Bamford Action Plan (2009-2011) identified ageing as an area that required specific planning within learning disability services based upon Human Rights, Citizenship, Inclusion and Being Valued
- The *'UN Convention on Rights of Persons with Disabilities'* (2006) promotes the rights of all persons with a disability to 'live independently and be included in the community': freedom to make choices regarding their lives, including place of residence (access to range of in-home, residential and other community supports) to prevent isolation/segregation from community. The Convention also stresses the need to prevent age-related disabilities and promote the social inclusion of older persons
- The *'Caring for Carers' Report* (2006) advises that H&SCTs should pay particular attention to the needs of older people who are themselves providing substantial care to others
- Five years on from the implementation of *'Transforming Your Care'* (2011) and the development of population plans; which were to embody a joint commitment approach to improving the health and wellbeing of ageing family carers and older people with a learning disability, little change is evident
- The Northern Ireland Learning Disability Service Framework (2011a) recommended that all people with a learning disability aged 50 years and over should have:
  - The impact of ageing taken into consideration when assessing and managing their needs; and
  - The option to remain in their own home with their family carer for as long as possible with appropriate care and support to do so
- The Commissioner for Older People for Northern Ireland (2013-15) Corporate Plan outlined a number of themes and priorities including; *'that older people feel safe in the community; and that they are recognised as individuals who have made and continue to make a contribution to our society'*.

## What we set out to do:

- To identify appropriate services for people with a learning disability as they transition into old age
- To identify appropriate supports for older family carers to continue to care for adults with a learning disability into the future
- To identify policy and practice implications from local and international research.

## What we did:

- We undertook a **review of the international research literature on policy and practice** to inform the methodology of this study
- The study was conducted **across Northern Ireland** with participation from all five H&SCTs, voluntary and other stakeholder groups (i.e. Public Health Agency (PHA), Councils, Housing, Education), as well as adults with a learning disability and their family carers, and involved 4 Phases
- **Phase 1** involved meeting over 100 older people with a learning disability, their family carers and other key stakeholders (i.e. social workers, learning disability nurses, managers of day, residential, supported living and short break/respite services) to explore what constitutes ageing / retirement for this population
- **Phase 2** involved 15 interviews with senior managers from Learning Disability Services and the Older Persons Programme of Care across the five H&SCTs to explore what currently constitutes age-appropriate day activity, residential provision and respite services
- **Phase 3** involved the completion of a questionnaire with over 100 older adults with a learning disability and their family member or keyworker; to document the current use of services and family supports and calculate the costs associated with these options
- **Phase 4** brought together over 180 key stakeholders from across Northern Ireland (i.e. Department of Health, Health & Social Care Board, H&SCTs, Voluntary and Community sector, PHA, Councillors, Academics and

# Knowledge Exchange Seminar Series 2015-16

Researchers, Parent/Family Carers) to agree the way forward for the commissioning, development and delivery of services for this population in the future.

## What the research found:

### Theme 1 – Current Service Provision

- There is a lack of age appropriate planning/service provision for alternative day opportunities/activities for older people with a learning disability
- There is a shortage of suitable residential/supported living provision that enable people to continue living in the local community
- There is a lack of appropriate and flexible respite options for older people with a learning disability and for their ageing family carers
- There is a lack of training for all staff on the health needs of older people with a learning disability and the needs of their ageing family carers
- There is a lack of communication and collaboration between Learning Disabilities Services and the Older Persons Programme of Care; they continue to 'work in silos'

### Theme 2 – Planning for the Older Person with a Learning Disability

- There is no regional database to identify details of older people with a learning disability and their ageing family carers
- There was no understanding of the concept of retirement by either people with a learning disability or their family carers
- There was no consensus amongst Learning Disability Services and the Older Person's Programme of Care as to how ageing and retirement should be addressed for people with a learning disability: this has led to a lack of proactive planning
- There was a lack of future planning
- Some people with a learning disability are also providing care for a parent
- There was a lack of planning or support for healthy ageing

### Theme 3 – Family Support

- The majority of staff reported that there was a lack of recognition that people with a learning disability's needs change as they grow older and this hasn't been recognised or resourced within statutory services
- Many families reported that they had no point of contact for practical information and emotional support, particularly at times of transition
- Few family carers had had a carers assessment and only a small number of families were availing of direct payments/self-directed support
- Few family carers had the opportunity to have support from other family members and their wider family circle
- There was a lack of use of assistive technologies and home adaptations

### Theme 4 – Inclusive Communities

- Many of the older adults with a learning disability acknowledged the important role attending a day centre/activity had for them; it was more than a day placement, it was the place where they connected with friends and enjoyed the company of their peers
- People with a learning disability welcomed the opportunity to engage in their wider community to develop new friendships with their non-disabled peers, however this was not common practice
- Although there were good examples of how some local communities have welcomed people with a learning disability, there are still many communities who are largely unaware and unprepared to engage with this population due to fear, lack of understanding, lack of contact with people with a learning disability, lack of opportunities to engage and discriminatory attitudes
- Community services rarely make the necessary 'reasonable adjustments' to enable people with a learning disability to engage with their communities (i.e. Councils, leisure centres, community groups, PHA (Making Life Better Report, 2014))

## Operational Recommendations

### Reshaping Services

- Review existing **day opportunity** provision to ensure that it is fit for purpose and meets the changing needs and choices of older people with a learning disability
- Develop more **housing options** beyond traditional residential and nursing options, such as supported living, home ownership, co-ownership and shared lives options by linking with relevant social care providers and where relevant different housing providers
- Develop more flexible day and overnight **short break/respite options** to include shared lives, adult family placements and short breaks that bring added value to older people with a learning disability
- **Provide training to all staff** within Learning Disability Services and the Older Persons Programme of Care, within H&SCTs and the Voluntary and Community sector, to improve their attitudes, knowledge and skills development to focus on the health needs of older people with a learning disability and their ageing family carers
- **Develop protocols and standards for inter-agency, cross-departmental communication and working**, which identify clear roles and responsibilities; facilitate the sharing of information; and hold individuals to account
- Each Trust should appoint a **Champion for Families of older people with learning disabilities** based across both Learning Disability Services and the Older Persons Programme of Care to bring a co-ordinating function to the H&SCT's services
- Revisit how services are **commissioned** for older people with a learning disability and their ageing family carers to ensure that all service users have access to supports which meet their needs and ensures their continued inclusion within their own communities.

### Planning for the Older Person with a Learning Disability

- A **regional electronic register/database** should be developed and disaggregated in line with UNCRPD, Article 31, to help identify the numbers and needs of all people with a learning disability and their family carers. This would predict the likely rise in numbers over the coming 10-20 years, as well as the potential for measuring community participation, health inequalities, access to services and morbidity levels
- Older people with a learning disability living in the community should be offered a range of meaningful day opportunities/activities that includes **tailored support to promote independence** in activities of daily living
- Older people with a learning disability living in the community should be offered where appropriate, environmental assessment and modification to aid independent functioning; and prescription of **assistive technology**
- All older people with a learning disability should have an **annual health check and a health action plan** should be developed so that their needs are identified early and appropriate prevention measures put in place to assist **healthy ageing**
- **Future Planning** needs to happen **early** and should include an **emergency plan**; taking into account **the contribution of siblings** (a family-centred approach); and establishing a **circle of support** for older people with a learning disability and their ageing family carers
- The needs of older people with a learning disability who develop **dementia** must be addressed within the Northern Ireland Dementia Strategy (2011b) (i.e. early screening and diagnosis, access to and accessibility of early interventions, clinical supports, environmental modifications, programme adaptations and specialised care) and addressed within individual HSCT's Implementation Plans
- People with a learning disability who become **carers** for their parents need to be recognised and supported and offered short breaks/respite in the same way as it is made available to other carers.

### Family Support

- There needs to be a **single point of contact** where families can access practical information and signposting about all service/support opportunities within their area/community
- All family carers should be offered an enhanced **carers assessment** that also includes an assessment of the needs of the family unit: a 'family centred assessment'
- Families should be encouraged and supported to use **self-directed support and direct payments** to ensure that their family member with a learning disability continues to have a 'meaningful day' and that they have access to the support they need to remain within the family home

# Knowledge Exchange Seminar Series 2015-16

- Carers and families (including siblings) should have **access to education and training** designed to provide support and optimise their ability to provide care for the older person with a learning disability. This should include counselling, information on future planning and advice on statutory/voluntary learning disability and older peoples' services
- Family support programmes of support should be **individualised, multi-faceted**, focused on early intervention and delivered over multiple sessions
- Develop appropriately resourced family **carer support groups** providing family carers and siblings with practical information, emotional support, signposting, empowerment and the opportunity to engage with other family carers (i.e. face to face groups, online format, message board and lists of local resources)
- Develop **sibling support groups** in order to provide them with practical information, emotional support and build the resilience needed to become future carers
- Identify **assistive technology** solutions that promote continued independence and monitor and support the family carers' health, in order to enable them to maintain their caring role within their own home (i.e. tele-health, home adaptations).

## Inclusive Communities

- Ensure and promote the health and well-being of older people with a learning disability and their ageing family carers; the **Public Health Agency** has a responsibility to reach out and support people to access these services, by making the necessary '**reasonable adjustments**'<sup>1</sup> to all their mainstream **community health programmes** to ensure that they are accessible to this population (i.e. healthy living, health promotion, health education, vaccinations, health issues (men's health, women's health, mental health))
- Local Councils have a responsibility to reach out to support people to ensure that all mainstream **community programmes** operate within their localities by making the necessary '**reasonable adjustments**' for this population, (i.e. learning and education, employment support, sports, leisure and recreation, the arts, travel and access to transportation, home safety, benefits, planning your retirement and wellbeing)
- Recruit older adults without a learning disability to mentor and support people with a learning disability to access and engage in **mainstream community older peoples activities** (e.g. Bowling, Volunteering, Men Utd, Men's Sheds, Gardening Clubs, Photography Groups, University of the Third Age)
- Co-ordinate the Statutory and the Voluntary and Community sector to work together, to inform the relevant local community organisations of the needs of older people with a learning disability and their ageing family carers, so that they are better prepared to understand and support the needs of this population and include them in local activities/opportunities.

## **Strategic Recommendations**

- Establish a **Family Manifesto / Charter** to protect the rights of both older people with a learning disability and their ageing family carers, overseeing and guiding on issues such as Carer's Bill; Direct payments; Entitlement Legislation (Make the Call Campaign, COPNI, 2015)
- To develop a **Carers Bill for Northern Ireland** aimed at promoting the rights and requirements of family carers
- A cross-departmental working group should be put in place to oversee the establishment and operational management of an '**Expert Committee**' to advise on how services can be developed to meet the needs of ageing family carers and older people with a learning disability given the recommendations listed above. This committee should have the authority to hold these organisations (i.e. H&SCTs, Councils, PHA) and the Trust's Carers Champion accountable
- All family carers and people with a learning disability should be supported to access the **Equality Commission** and the **Law Centre** if their needs are not being met
- All service providers (statutory and voluntary) need to evidence **leadership** and share responsibility to build the **relationships** required to ensure that existing service models are reshaped and co-designed with people with a learning disability to create new cost-effective solutions

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<sup>1</sup> Under section 49a of Disability Discrimination Act 1995 (as amended by the disability discrimination (Northern Ireland) Order 2006), public authorities when carrying out their functions must have due regard to the need to 1. Promote positive attitudes towards disabled people. 2. Encourage participation by disabled people in public life.

# Knowledge Exchange Seminar Series 2015-16

- New solutions ('best practice') must be proactive and require a **change of mind-set** on the behalf of all stakeholders, to enable older people with a learning disability to become actively involved within their communities ('positive risk-taking')
- Everyone has a **responsibility** to ensure that our communities are welcoming and inclusive of all and that older people with a learning disability are provided with opportunities to have their contribution valued and have a real role within their individual communities
- The recommendations from this executive summary should be the outcomes under which leadership are held accountable.

## Conclusion

The recommendations from this study, which have been regionally endorsed by both the statutory voluntary and community sectors, clearly identify both the strategic and operational direction for how commissioners, policymakers and service providers should plan and develop specific services for older people with a learning disability and their ageing family carers in the future. This document should act as the catalyst for Trusts to plan and develop services to support active aging moving forward.

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