



Executive Summary

Supporting older adults with a learning disability and their ageing family carers: A family and community support model

Dr Laurence Taggart & Dr Lisa Hanna-Trainor
Centre for Intellectual & Developmental Disabilities
Institute of Nursing & Health Research
Ulster University



Funded by HSC R&D Division, Public Health Agency, Northern Ireland

Contents

Evidence brief	3
Background	4
Aims	6
Methods	7
Findings	8
Policy and Practice	13
Conclusion	17
Policy recommendations	18
References	19

Evidence brief

Why did we start?

Governments worldwide are being challenged to develop more age-appropriate, evidence-based, efficient and cost-effective systems to meet the needs of an ageing population. This includes older adults with a learning disability. However, there have been few theoretically driven, robustly evaluated and coordinated models developed to support older adults with a learning disability and their ageing family carers to remain together within their family home. We carried out this study to develop a family and community support model.

What did we do?

This study involved 4 phases. Phase 1 comprised of focus groups with 87 adults with a learning disability, 34 family carers and 60 staff working across learning disability services. Phase 2 engaged in 16 1-1 interviews with senior managers from learning disability and mainstream older person services. Phases 1 & 2 explored the concepts of ageing, retirement and transitions. Phase 3 involved 97 1-1 interviews with adults with a learning disability and their carers to investigate health and social care service utilization and costs. Phase 4 used a roundtable methodology bringing together a range of over 180 stakeholders to develop a family and community support model.

What answer did we get?

- We found that the concepts of *'retirement'* and *'transitions'* were not clearly defined and therefore not proactively planned for by statutory service providers
- All the participants agreed that retirement for older adults with a learning disability was a *'meaningless term'*
- Professional staff reported being restricted by the lack of age-appropriate community options
- We found that those adults with a learning disability who resided in a residential facility cost on average £64,417 per annum compared to £25,553 for those adults residing with their families
- A number of practice and policy recommendations were identified and agreed by the stakeholders in order to develop a synchronized and enhanced family and community support model: planning for the older person, supporting family carers, reshaping services and inclusive communities.

What should be done now?

If this family and community support model is translated into practice, this model could be attractive to policy makers, service commissioners, learning disability services, mainstream older person services and community groups as this can clearly offer a low cost sustainable intervention. Using existing mainstream community social infra-structures rather than funding new retirement groups for this population, makes sense when promoting a human rights empowerment and social inclusion agenda, and in this manner, improves health and well-being of the service user.

Background

Globally ageing has been described as ‘a new public health threat’ (WHO, 2016).

Increased childhood survival with complex physical health needs, health and medical technological advances, greater recognition of autism and increasing life expectancy of the world’s population, have led to and continues to lead to a growth in the learning disability population. How age-appropriate, efficient and cost-effective services are therefore developed and delivered in the 21st century clearly concerns policy makers, commissioners and service providers across statutory learning disability and mainstream older person services: as well as public health (Bigby, 2010; Transforming Your Care: A Review of Health and Social Care in Northern Ireland, 2011; WHO, 2016).

Despite 30 years of research into identifying the ‘ageing, retirement and transition’ needs of older adults with a learning disability, and the needs of their ageing family carers internationally, it has been purported that the needs of this double population continue to remain unmet within many countries. There is little acceptance and preparation to support ageing and people with disabilities; and those with a learning disability are still not valued within their local communities.

It can be further claimed that current community models for supporting older adults with a learning disability to live with their ageing family carers are no longer a viable or sustainable option as we advance through the 21st century. Within the current financial climate, traditional service models (i.e. buildings based day-centres, residential homes, respite/short break, etc.) will be unable to meet the changing demographics and health and social care needs of older adults with a learning disability. Commissioners, policymakers and service providers need to be open to rethink traditional models, pool existing resources and place greater emphasis on supporting family carers and engaging with local communities. Current family and community service supports are no longer an efficient and cost-effective option.

Policy context

The ‘Equal Lives Report’ (DSPSSNI, 2005) from the Bamford Review identified ageing as an area that required specific planning within learning disability services: ‘the DHSSPSNI should produce a strategic plan to address current deficiencies in services and future service provision for older people with a learning disability and their families’ (Recommendation 52). To date, this recommendation has not been achieved.

Transforming Your Care: A Review of Health and Social Care in Northern Ireland (2011) recently reported that ‘the diversity and age appropriate nature of day services remains an issue for people with learning disabilities... ..a one size fits all service will be less attractive in the future’ (p. 95).

Moreover, the Northern Ireland Learning Disability Service Framework (DSPSSNI, 2015) proposed that:

- All people with a learning disability aged 50 years and over should have the impact of ageing considered in having their future needs assessed and proactively managed
- People with a learning disability should be enabled to remain in their own home with their family carer for as long as possible with appropriate care and support to do so
- People with a learning disability have the same needs for autonomy, continuity of support, relationships and leisure as other older people and
- All people with a learning disability should have access to dementia services at whatever age it becomes appropriate for the individual.

Bigby (2010) concluded that:

'The intellectual disability service system will have to reorient to incorporate knowledge and expertise around age-related support needs ... and take responsibility for the development of specialist age-related services. It may also give the disability sector a much clearer mandate to lead and adequately resource partnerships with existing services [older persons care programme] or organizations (p.11).'

Aims of the study

The research question that this study set to answer was:

‘What service supports need to be put in place to ensure an effective transition from adult services to ones geared to meet the needs of older persons with a learning disability living with their ageing family carers? What are the costs associated with different options?’

There were three aims of the study:

1. To examine how transitions within such services are best managed for ageing persons with a learning disability.
2. To provide an indication of the likely costs involved in providing services to older adults with a learning disability.
3. To document the most effective family and community supports (in particular day activity, residential, respite/short breaks and community programmes) for older persons with a learning disability and their ageing family carers.

Methods

The population under study involved adults with a learning disability in Northern Ireland aged 18 years plus and known to statutory learning disability agencies. This study involved four phases employing both qualitative and quantitative methods. Phase 1 comprised a series of focus groups with younger and older people with a learning disability asking them how they would like to spend their day and leisure time; these focus groups sought the service users' preferences and aspirations. Alongside the service users' voices, their ageing family carers and other stakeholders also explored their thoughts on how such aspirations could be achieved.

Phase 2 involved the use of a series of 1-1 structured interviews with senior managers from both learning disability and mainstream older persons programmes across Northern Ireland. Information was sought on current provision; their perceptions on what constitutes age appropriate day activities, residential accommodation, respite/ short breaks and community programmes for older people with a learning disability. Findings from Phase 1 and 2 were merged together to focus on the phenomenon, *'ageing, retirement and transitions'*.

Phase 3 involved undertaking 97 face-to-face structured interviews with adults with a learning disability and their family/paid carers, using the Client Service Receipt Inventory to investigate health and social care service utilization and costs. We compared this information with: where you live (residential accommodation versus family), age (18 – 30 years versus 50 years plus), gender and health (physical and mental health conditions).

Phase 4 used a roundtable methodology bringing together a range of over 180 stakeholders in order to develop a family and community support model for older adults with a learning disability and their ageing family carers. The Model for Evidence-Informed Decision-Making in Public Health (The Canadian Institutes of Health Research, 2004) provided the framework for the roundtable discussions and the actionable outcomes (in the form of recommendations) that were to stem from these.

Personal & Public Involvement

Conducting focus groups with older adults with a learning disability and their ageing family carers, greatly improved the outcomes of the study as it gave these participants the opportunity to contribute to the research and have their voices heard. Likewise, interviewing senior management across the five HSCTs from both learning disability and mainstream older persons programme of care, gave us a unique insight into the workings of these care directorates and afforded management the opportunity to have a say in how service provision should be managed in the future. By having ageing family carers present in the Research Steering Group, ensured that policymakers and those from statutory, voluntary and community sectors, heard directly from their service users and their family carers.

Findings

Phases 1 and 2

The focus groups and 1-1 interviews with the adults with a learning disability, family carers and statutory service providers in Phases 1 and 2 have highlighted a limited understanding of the concepts of ‘ageing’, ‘retirement’ and ‘transitions’.

‘I think the term retirement is misleading in some ways... family don’t really, for want of a better word, push for planning for retirement’. (Staff Focus Group 7)

‘Retirement doesn’t really mean anything, certainly in terms of our son who is 51 years of age. As he gets older of course we have noticed changes in routine, but routine is very important... It just can’t be that he comes home and stays there, he has to get out and mix with the community and be part of that. I worry about how that is going to happen after we are gone’. (Ageing Parent, Focus Group 4)

This study found that ‘ageing’ was viewed by many adults with a learning disability as negative and only a handful of service users regarded getting older as a positive experience. There was no clear agreed age across all stakeholders when an adult with a learning disability was identified as ‘older’ and therefore the process of ‘retirement’ was not explored by the service user, carers and service providers: from what to what.

‘When you retire, you have to quit the service (day centre), I think it is a wee bit unfair because some people mightn’t want to quit and then they will have nowhere to go.’ (Person with a learning disability, Focus Group 4)

These findings indicate that ‘retirement’ and ‘transitions’ were not clearly defined and therefore not proactively planned for by statutory service providers. All the participants agreed that retirement for older adults with a learning disability was a ‘meaningless term.’

‘There is no exit strategy from TRCs (Training and Resource Centres). We (non-disabled adults) expect to retire at a certain age but I don’t think our people (with a learning disability) in our day centres, I don’t think that they have any expectation around retirement’. (Staff FG 1)

The question must be asked as to what are adults with a learning disability ‘transitioning into’ when they become ‘older’? Staff did recognise that ‘transition planning was needed’ but also reported they were restricted by the lack of available options. There were limited, if any, age-appropriate alternatives offered in terms of day provision, preparation for retirement and recreation / activity, and also short breaks / respite, that were bespoke for older adults with a learning disability and their ageing family carers.

'Traditionally learning disability services have been provided from birth to death and that is the traditional line of thought. It would require quite a significant change in the whole commissioning process through local collaboration to change that'.

(Senior Manager, Learning Disability Services, Interview 3)

There was little or no co-ordination of statutory learning disability and mainstream older person services: both services continued to work in silos. Likewise, there were few opportunities for older adults with a learning disability to engage within their non-disabled peers in their local communities.

'I think we can be working more closely with community groups such as churches, such as bowling clubs, such as bingo centres, that sort of thing where you are going to get older people there'. (Senior manager, Older People's services, Interview 2)

Phase 3

We found that many of the adults with a learning disability had on average three physical health conditions, with females experiencing more physical health conditions compared to males (see Table 1).

Table 1: Demographic details of the participants

	Family (N= 56)	Residential (N= 41)	Total (N= 97)
Age (mean= 48.7yrs)			
18-30 years	34%	10%	24%
50 yrs plus	66%	90%	76%
Gender			
Male	59%	41%	50%
Female	41%	61%	50%
Level of learning disability			
Mild	4%	10%	6%
Moderate	25%	59%	39%
Severe/Profound	70%	30%*	55%
Physical health			
Vision/hearing	55%	44%	51%
Chronic constipation	29%	46%	36%
Epilepsy	39%	24%	33%
Reflux / swallowing	32%	24%	29%
Digestive problems	11%	22%	16%
Arthritis	16%	17%	16%
Hypertension	13%	12%	12%
Circulatory Disease	11%	15%	12%
Diabetes	5%	20%**	11%
Respiratory problems	11%	7%	9%
Asthma	7%	7%	7%
Cardiovascular problems	7%	7%	6%
Osteoporosis	4%	5%	4%
Cancer	2%	2%	2%
Mental health			
Displays challenging behaviours	39%	46%	42%
Anxiety	38%	39%	38%
Depression	14%	39%***	25%
Dementia	5%	7%	6%
Schizophrenia	0%	5%	2%

*(chi sq = 15.1, p<0.001), **(t= 2.204, p< 0.05), ***(t= 2.204, p< 0.05)

More of the adults with a learning disability who resided in residential accommodation were found to have depression compared to those adults who resided with their families. Over 90% of this sample was taking prescribed medications, the average number of medications was 4.5, with older female adults with a learning disability residing in residential accommodation more likely being prescribed medications compared to the younger cohort living with their families.

In undertaking the health economic analysis, costs were only available for 92 of the 97 participants: 58 participants with a learning disability lived with their families and 34 participants resided in residential accommodation (i.e. supported living scheme (N= 25), residential group home (N= 7) and a nursing home (N= 2)). The mean cost of residential care was £41,715.29 per annum (standard error: £1782.74; 95% confidence interval: £38,088.27 - £45,342.31). The main form of day activity was attending statutory day-centres/opportunities (80%): the total cost of this day activity per annum was £21,384. The total cost of primary healthcare was approximately £1,048 per annum, total cost for hospital healthcare was £1,230 per annum and total drug costs per annum were £411.

Significant differences were evident in drug costs between males (£207) and females (£615): males costing approximately £407 less per year than females (see Table 2). Each additional physical health condition is associated with an increase in primary healthcare care costs of £146. For each additional mental health condition this increased drug costs by £261.

Table 2: Difference of mean costs by group for those living in residential accommodation versus those with family carers

Mean of variable	Residential (N= 34)	Family (N= 58)	Difference	t-value	p-value
Drug cost	421.16	405.93	-15.22	-0.08	0.94
Hospital cost	657.78	1,565.82	908.03	1.21	0.23
Primary Healthcare cost	1,492.44	788.59	-703.86	-2.89	<0.00
Day Activity	20,130.16	22,120.26	1,990.11	1.02	0.31
Residential care	41,715.29	672.41	-41,042.88	-25.34	<0.00
Total health and social care cost	64,416.82	25,553.01	-38,863.82	-13.67	<0.00

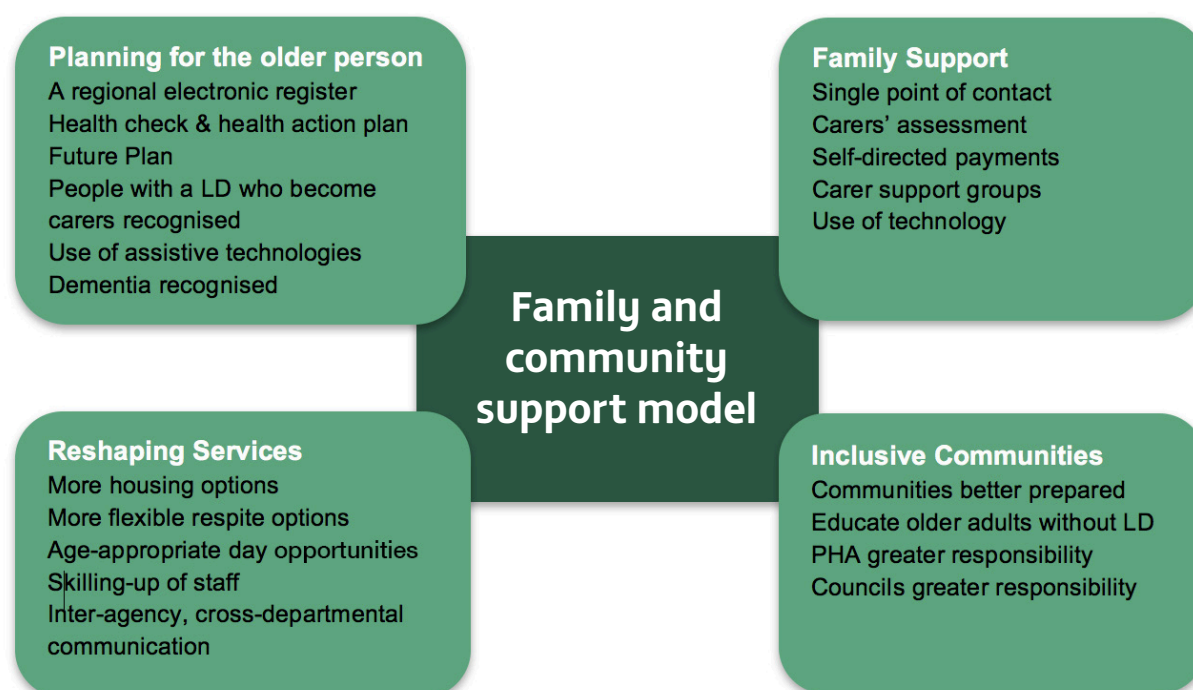
Marked differences were evident in respect of primary healthcare costs (£1,492 v £789: $p < 0.00$), and total health and social care costs between those who resided in residential accommodation compared to those living with families (£64,417 v £25,553: $p < 0.00$). Those who resided in a residential accommodation cost slightly under £39,000 more on average per year than those living with their families approximately (see Table 2). However, caution must be taken from these figures as this may not be a representative sample. We did not achieve the second part of objective 4, pertaining to projecting the likely future costs of services for older adults with a learning disability given a number of practical and methodological challenges we encountered.

Phase 4

Using the findings from Phases 1, 2 and 3 above, we used the Model for Evidence-Informed Decision-Making in Public Health (The Canadian Institutes of Health Research, 2004) to provide a framework for the roundtable discussions in Phase 4. The stakeholders identified a number of shortcomings in existing family and community services across Northern Ireland. Using a consensus approach, we have proposed a synchronized and enhanced family and community support model for older adults with a learning disability and their ageing family carers based upon four core areas (i.e. planning for the older person, supporting family carers, reshaping services and inclusive communities).

A number of actionable outcomes were agreed across the stakeholders in the form of a series of practice and policy recommendations. The operational recommendations focused upon four core areas of the family and community support model (see Figure 1).

Figure 1: Family and community support model for older adults with a learning disability and their ageing family carers



Practice recommendations

Planning for the older person:

- Development of an electronic register
- Provision of an annual health check and health action plan (using the regional learning disability health passport)
- Tailored day activity and support programmes
- Early screening and detection of dementia
- Planning and use of assistive technologies
- Development of a future plan and a circle of support (see Box 1)
- Recognising adults with a learning disability as a potential carer for an ageing parent.

Box 1: Future planning

The Northern Ireland future planning resource and two-day workshop was based upon six core themes: exploring your own future plan; circles of support; person centred planning and emergency plans; signposting housing and support options; making sound financial and legal decisions; direct payments; and supporting a family carer to make a future plan.

See Taggart & Thompson (2015) report on Future Planning in Northern Ireland (<http://uir.ulster.ac.uk/38349/1/FuturePlanningReport%28WEB%29-12June15.pdf>)

Circle of Support

A Circle of Support is a group of people who meet together on a regular basis to help somebody accomplish their personal goals in life. The Circle acts as a community around that person. The focus person is in charge, both in deciding who to invite to be in the Circle, and also in the direction that the Circle's energy is employed, although a facilitator is normally chosen from within the Circle to take care of the work required to keep it running.

(Resource: http://www.circlesnetwork.org.uk/index.asp?slevel=0z114z115&parent_id=115)

Family support:

- Single point of contact
- Carers' support groups
- Sibling support groups
- Carers' assessments
- Self-directed and direct payments (see Box 2)
- Access to education and training and
- Early intervention and use of assistive technologies.

Box 2: Direct payments

As a carer you can use direct payments to buy in support/services that will help you to continue caring from an organisation or you can employ someone to provide you with help. Such as support that may help to have a break for a few hours, to supporting the person with a learning disability to go out of the home, etc. If you are assessed as needing domestic help, you may ask for a direct payment and buy the support services you need.

Centre for Independent Living NI is an organisation run by disabled people for disabled people. They work to promote the principles of independent living and, in particular, to provide a range of services for people using or considering using Direct Payments and/or Self-Directed Support.

T: 02890648546 | General email: info@cilni.org

Carers NI (Tel: 02890439843 | E: <http://www.carersuk.org/northernireland>) also provides support for carers.

Reshaping services:

- Each Trust to appoint a Champion for families of older people with a learning disability
- Develop more housing options (see Box 3)
- Review existing day programmes ensuring they are fit for purpose
- Provide training to all staff
- Develop protocols and standards for inter-agency cross-departmental communication and working
- Revisit how services are commissioned for this population (see Box 4).

Box 3: Housing options

Develop more housing options beyond traditional statutory learning disability 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.

*(Web resource: Housing and support for adults with a learning disability in later life
(<http://www.bild.org.uk/resources/ageingwell/housing/>)*

BOX 4: Bespoke family service model

The Better Futures Project was a 4-year Big Lottery Project (2012-16) in Northern Ireland which developed a bespoke array of family services (i.e. respite/short breaks, support groups, practical information, emotional support, knowledge, information sharing, signposting, emergency and future plans) that have clearly met the specific needs of the ageing family carers of adults with a learning disability, each of these families caring for a relative with a learning disability. Narratives from the family carers highlight that this project was a 'lifeline'.

(http://uir.ulster.ac.uk/38350/1/UUBetterFutures_Report-13June16.pdf)

Inclusive communities:

- Commissioning and delivery organisations (i.e. Public Health Agency and Councils) have a responsibility to reach out to support people with a learning disability to ensure that all mainstream community health programmes operate within their localities by making the necessary *'reasonable adjustments'* for this population and
- Older adults without a learning disability are recruited to mentor and support people with a learning disability to access and engage in mainstream community older people's activities (see Box 5).

Box 5: Transition to Retirement

'Transition to Retirement' (TTR) programme supports older adults with a learning disability (aged 45 years plus) to transition into retirement & engage in their local communities in mainstream older community groups. This program has been shown to be a viable low-cost option for developing a retirement lifestyle for older adults with a learning disability supported by trained mentors.

(Video: <https://www.youtube.com/watch?v=bcEjRQxG2Qs> and <https://www.youtube.com/watch?v=nQTfe-qVpFg>)

1. 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.

Conclusion

If the practice recommendations that we propose were fully translated into practice, this then will develop more age-appropriate, evidence-based, efficient and cost-effective systems, thereby achieving successful transitions for these adults with a learning disability and their family carers as they age (Equal Lives, DHSSPSNI, 2005; Learning Disability Services Framework, DHSSPSNI, 2013; RQIA's, 2016; Health & Wellbeing: Delivering Together, DHSSPSNI, 2016).

We acknowledge the organisational, cultural, leadership, attitudinal and financial obstacles in translating knowledge/evidence into practice, therefore in order to fully operationalise these recommendations this report concludes by providing a series of policy recommendations that clearly addresses these barriers.

BOX 6: Carers' Charter for Northern Ireland



(see https://www.positive-futures.net/cmsfiles/downloads/corppublications/PF_Carers-Charter_v2.pdf)

Policy 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 a Carer's Bill; Direct Payments and Entitlement Legislation, etc.

- Develop a **Carers Bill for Northern Ireland** aimed at promoting the rights and requirements of family carers (see Box 7).
- 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 commissioning and delivery organisations (i.e. HSCTs, Councils, Public Health Agency, HSCB, DoH) and the Trust' Carers Champions 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.
- 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.

If this synchronized and enhanced family and community support model is translated into practice, this model could be attractive to policy makers, service commissioners, learning disability services, mainstream older person services and community groups as this can clearly offer a low cost sustainable intervention. Reshaping learning disability services and utilising existing mainstream community social infra-structures rather than funding new retirement groups for this population, thereby makes sense when promoting a human rights empowerment and social inclusion agenda, and in this manner, improves health and well-being of the service user.

The recommendations from this study, which has included regional engagement and support from statutory, voluntary and community sectors, clearly identify both the policy and practice directions for how commissioners, policy makers and service providers should plan and develop specific services for older people with a learning disability and their ageing family carers in the future. These policy and practice recommendations should act as the catalyst for commissioning and delivery organisations to plan and develop services fit for purpose and for the 21st century.

References

Bigby, C. (2010): A Five-Country Comparative Review of Accommodation Support Policies for Older People with Intellectual Disability. *Journal of Policy and Practice in Intellectual Disabilities*, 7 (1) 3–15

Canadian Institutes of Health Research (2004): Model for Evidence-Informed Decision-Making in Public Health. (accessed: <http://www.nccmt.ca/uploads/media/media/0001/01/9e2175871f00e790a936193e98f4607313a58c84.pdf>)

DHSSPS (2005): *Equal Lives: Review of Policy for People with Learning Disabilities*. Belfast: DHSSPSNI.

DHSSPS (2011): *Transforming Your Care: A Review of Health and Social Care in Northern Ireland*. Belfast: DHSSPSNI.

DHSSPS (2015 revised): *Learning Disability Services Framework*. Belfast: DHSSPSNI.

DHSSPS (2016): *Health & Wellbeing: Delivering Together*. Belfast: DHSSPSNI.

RQIA (2016): *Review of Adult Learning Disability Community Services Phase II*. RQIA: Belfast. (access: www.rqia.org.uk)

WHO (2016): *The Global strategy and action plan on ageing and health*. Accessed: <http://www.who.int/topics/ageing/en/>

