



All Party Group on Learning Disability

Priority issues for people with a learning disability in Northern Ireland

May 2018



All Party Group on Learning Disability




“We hope you listen to our views and take them on board and take them seriously as these issues affect our lives everyday as we live it 24/7 every day of our lives.”

A **learning disability** is a reduced intellectual ability and difficulty with everyday activities, which affects someone for their whole life. The level of support someone needs depends on the individual person and the extent of his or her learning disability. With the right support, most people with a learning disability in the UK can lead fulfilled lives.¹

¹ Mencap (2017) www.mencap.org.uk/learning-disability-explained/what-learning-disability

There are **42 000** people living in Northern Ireland with a learning disability,² including


31 000
adults


11 000
children
aged 0-17
years old


5 000
children
aged 0-7
years old

People with a learning disability are more likely to:³



Grow up in poverty



Have poor educational attainment



Experience social isolation & loneliness



Experience mental health difficulties



Have poor physical health



Have an average shorter life expectancy of 16 years⁴

² These approximate figures have been calculated using learning disability prevalence rates from Public Health England (2016) and population data from the Office for National Statistics (2017). Approximately 2.16% of adults and 2.5% of children in the UK have a learning disability.

³ For further information, see Webb, M A & Kelly, M (2018) Creating brighter futures: Early intervention for young children with a learning disability. Mencap, Belfast.

⁴ Heslop, P et al (2013) Confidential inquiry into premature deaths of people with learning disabilities (CIPOLD). Final report. Department of Health, London.

Introduction

Compared to their peers, people with a learning disability experience many health and social inequalities. Without appropriate support and intervention, they are at risk of a range of poorer outcomes. Reflecting the framework of standards set out in the United Nations Convention on the Rights of Persons with a Disability, the All Party Group on Learning Disability (APGLD) aims to:

- promote a better understanding of the issues facing people with a learning disability and their families; and
- influence policy, legislation and service development to improve the lives of people with a learning disability and their families in Northern Ireland, and ensure their full participation in society.

Set up in 2009, the APGLD is comprised of MLAs across political parties, and supported by a number of voluntary and community sector organisations, parents and people with a learning disability (see Appendix).

In order to effectively inform its programme of work for 2018 and beyond, the APGLD held a stakeholder round table event focused on identifying current priority issues for people with a learning disability.⁵ The 80 participants included a wide range of healthcare professionals, organisations, young people and adults with a learning disability, MLAs, parents and carers. Through facilitated table conversations, participants identified at least three key issues and discussed concerns, opportunities and potential action required by government in relation to these.

⁵ The facilitated event took place in the NI Assembly on 31st January 2018.

About this paper

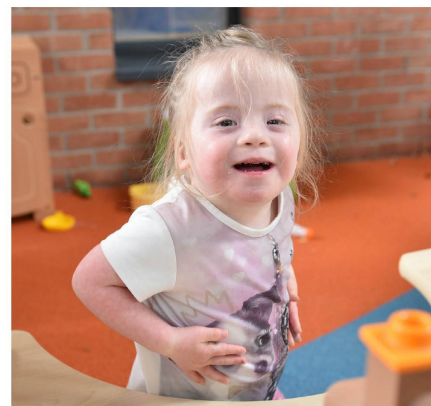
This paper presents the main priority issues relating to learning disability as identified by stakeholders attending the APGLD policy event. In doing so, it also suggests what needs to happen in each area to improve outcomes for people with a learning disability.



1 Policy Implementation

Significant targets and outcomes in key policy affecting people with a learning disability have not been achieved. Similarly, recommendations in research, evaluation and reviews relating to learning disability in NI are not being suitably considered / implemented. The absence of dedicated budgets and a functioning political system are significant barriers to implementation.

Most notably, the Bamford Review⁶ highlighted levels of unmet need, and advocated the need for investment in children and young people. However, many of the seventy-six recommendations in subsequent Action Plans to bring about positive change for people with a learning disability have not been completed. Although conducted in 2016, an evaluation of the most recent Bamford Action Plan 2012-2015 remains unpublished. Critical to ensuring people with a learning disability can lead fulfilled lives, the urgent need for whole systems change to transform and reconfigure health and social care support has also been identified.⁷



What needs to happen?

- Publication of the most recent Bamford Action Plan evaluation, including a departmental status update; and clear accountability and leadership in terms of implementing its' key recommendations by 2020.
- Progression of key policy proposals aimed at achieving transformational change in the way that social care services operate and deliver in Northern Ireland.
- Implementation of the Mental Capacity Act (Northern Ireland) 2016, and publication of the related Code of Practice.



⁶ Bamford review of mental health and learning disability (2005) Equal lives: Review of policy and services for people with a learning disability in Northern Ireland. DHSSPS, Belfast.

⁷ For example: Kelly & Kennedy (2017) Power to people: Proposals to reboot adult care and support in NI; Bengoa (2016) Systems not structures: Changing health and social care; HSC (2011) Transforming your care: A review of health and social care in Northern Ireland.

2 Advocacy

Many families have been campaigning for years, often unsuccessfully, so that their loved ones have access to vital services and support to help them make decisions about their own lives. Resources are limited; however, people with a learning disability and their parents / carers need more independent advocacy support to get their views heard, and to ensure they have equal rights, opportunities and choices. This would ideally include different types of advocacy such as 'peer' (when an advocate and the person receiving support share similar experiences) or 'professional' (usually paid to represent people during periods of major change or crisis).⁸

“Advocacy [that is] involving parents and family members and close friends who know the person well, but helping learning disabled person’s voice be loudest.”

In addition to advocates who will challenge on their behalf, many would also welcome regular and meaningful engagement with politicians and policy-makers.

“I think a lot of people with a learning disability are interested in what is happening in this department [politics] and think that a

3 Data

While it is vital to have a clear picture about the numbers of people with a learning disability in order to appropriately target resources and improve outcomes, there is a general lack of disaggregated data in Northern Ireland for this population. Across Health and Social Care Trusts (HSCT), information is not collected in a single regional common information system with agreed data sets.⁹

lot of politicians don’t really know how much it means for politicians to involve more people like us in their parties and maybe have them on your team as an advisor person. I think it would mean a lot to them.”

What needs to happen?

- Legislation in the form of a NI Carers Act that clearly recognises carers’ formal role and legal right to support, to ensure parity with the rest of the UK.
- Greater investment in and access to independent advocacy services for all individuals and families with a learning disability across NI.
- Learning disability champions across government to influence decision makers and policy processes about issues that affect the lives of people with a learning disability and their parents/carers.
- All political parties should develop mechanisms for regular and meaningful consultation with people who have a learning disability.

What needs to happen?

- Improved collection and data sharing across government departments and HSCTs about the learning disability population, including by age range, in order to strategically and effectively plan to meet the level of need.

4 Housing

“Everyone has a right to be happy and content in their own homes, we just need extra support to help us live a full life.”

People with a learning disability have varying housing and support needs. This includes those who require some additional support to live safely in their own home, and others with a more profound learning disability and complex needs who require access to intensive, 24-hour care.

However, adults with a learning disability in Northern Ireland do not always have an opportunity to lead fulfilled lives.¹⁰ Most still live in the family home because there is a lack of housing options / funding, and long waiting lists for suitable accommodation. There is also little evidence of forward planning – support is too often provided only when a crisis emerges (e.g. family carer goes into hospital or passes away).

The population of adults living at home also includes many older people with a learning disability, which poses a particular challenge as family carers’ age. Compared to elsewhere in the UK and ROI, there is a higher proportion of older people with a learning disability in NI being cared for at home by an ageing family carer.¹¹ Without a clear pathway in place, ageing carers frequently worry about what will happen to their son or daughter when they die. As their own health declines, some caring responsibilities may in turn fall on the older adult with a learning disability.

“I cannot get a suitable home at present. On waiting list for many years. I am 37 this year and desperately want to be independent albeit with support. It would give my family peace of mind to know that I am settled and happy before anything happens that might cause a crisis.”



“Lots of our friends have severe learning disabilities who have specific behaviour issues that need special staff and living requirements. There is a lack of sufficient places. We do not know if this is money or training but we need more specialised care out in the community.”

What needs to happen?

- The development of a Northern Ireland strategy on housing for people with a learning disability, which includes:
- Key recommendations from the Bamford Review and relevant research in relation to accommodation and support.
- A joined-up approach to ensure the social care and housing needs of people with a learning disability are more closely aligned; and forward planning for their long-term future.
- Improved access to a more diverse and innovative range of housing options / solutions.
- Ring-fencing and further resourcing for initiatives such as the Supporting People programme and Self-Directed Support.

⁸ Social Care Institute for Excellence (SCIE) <https://www.scie.org.uk/care-act-2014/advocacy-services/commissioning-independent-advocacy/inclusion-empowerment-human-rights/types.asp>

⁹ Regulation and Quality Improvement Authority (RQIA) (2016) Review of adult learning disability community services: Phase II. RQIA, Belfast.

¹⁰ Equality Commission (2017) Statement on key inequalities in housing and communities in Northern Ireland.

¹¹ Taggart, L & Hanna-Trainor, L (2017) Supporting older adults with a learning disability and their ageing family carers: A family and community support model. PHA, Belfast.

5 Service provision

“...people are adults longer than they’re children; need to start planning in good time.”

In addition to limited accommodation options, wider service provision relating to learning disability lacks a joined-up, multi-agency approach that is suitably person-centred, individually tailored and focused on forward planning. Planning ahead, including recruitment and retention of a skilled workforce, is particularly important in respect of those with multiple and complex needs, and the increasing / ageing population of people with a learning disability. Workforce planning also needs to consider the potential impact on the health and social care workforce of the UK’s withdrawal from the European Union.

Across NI, there are also variations between the availability and quality of different services, with existing resources not always used as effectively as they could be. For example, the expertise of learning disability nurses who have the knowledge and skills to provide advice and support on a range of issues should be recognised and better utilised, particularly within the area of prevention.

Too often, services are provided in response to a ‘crisis’, rather than being planned and effective in meeting individual needs. Notably, transition planning into adulthood is generally poor for young people, both in terms of transitioning from school to further education, training or employment; and from child to adult health and social care services. Service response to ongoing and changing transitional needs throughout an individual’s adult life is also limited.

As well as offering opportunities for children and adults with a learning disability, respite arrangements provide essential breaks for carers, many of whom are caring for their family

member alone. However, service provision is often limited or not available where and when families need it. Too many ageing family carers are looking after people with a learning disability without any support or short breaks. In addition, while there have been improvements in access to a much wider range and choice of day opportunities, there is still scope for further development in this area.

“If I have no support then no support disables me.”

What needs to happen?

- Improved collaboration across government departments and between service commissioners and providers, to ensure joined up, equitable services leading to improved outcomes for people with a learning disability.
- A co-ordinated, multi-agency approach which is focused on early forward planning. This should be undertaken in partnership with individuals with a learning disability and parents/carers/independent advocates across key support areas such as employment, housing, transport and transitions.
- Social care workforce planning and development based on a review of the evidence about changing demographics and complexity of need in relation to people with a learning disability. The potential impact of the UK’s departure from the EU should also be considered.
- Provision of a wider range of respite and short breaks services, which are flexible and responsive to the needs of both individuals with a learning disability and their parents/carers.

6 Sleep-ins

Across the UK, various organisations provide a range of support and care to adults with a learning disability to enable them to live fulfilled lives. In some situations, this includes staff providing overnight support, whereby they sleep at the person’s house in case support is required.

Employment tribunals and a subsequent change from previously accepted practice and guidance requires that in the majority of cases ‘sleeping time’ is now considered as working time for National Minimum Wage (NMW) / National Living Wage (NLW) purposes. This has meant providers may have inadvertently paid staff less than NMW/NLW, as well as facing increases in the ongoing cost of providing support.

Back-pay: HMRC are indicating that, where under-payments have been made, providers will be required to back-pay all relevant ‘sleep-in’ staff, going back six years. The cost of this is estimated to be £400million across the UK.¹² The impact of retrospective payments presents a significant financial challenge to organisations who acted in accordance with the interpretation of the regulations at that time; and has the potential to undermine vital services for people with a learning disability.

Increased costs: Sleep-in shifts are likely to increase costs across the sector in the UK by over 4% every year, adding over £600 million to the wage budget by 2020.¹³ In Northern Ireland, some organisations are currently incurring the additional costs of the higher rate for sleep-ins from their own reserves, without being funded for this by commissioners.



What needs to happen?

- The UK government should publicly undertake to fund the back pay for the historical liabilities on sleep-in shifts.
- A commitment by service commissioners in Northern Ireland to fund the increased costs of sleep-in shifts.

¹² Figures supplied by Mencap.

¹³ As above

7 Social inclusion

Active participation in all aspects of society can make a real difference in reducing social isolation and helping people feel connected, happy, confident and healthy. However,

- Almost one third of young people with a learning disability spend less than an hour outside the house on a typical Saturday.¹⁴
- Older people with a learning disability can find it particularly difficult to participate in community life. Reduced social networks put them at greater risk of social isolation, exclusion, depression and ill-health.¹⁵
- Less than 10% of people with a learning disability are in any form of paid employment.¹⁶
- Young people with a learning disability are more likely not to be in education, employment or training (NEET) by age 19.¹⁷

Employment plays a critical role in promoting social inclusion. In Northern Ireland, the European Social Fund (ESF) is the main source for skills development, training and employment opportunities for young people most at risk of becoming NEET. It is likely that the UK's withdrawal from the EU will lead to the loss of vital European structural funding when the current round of funding ends in 2020, including ESF. Without this funding, the most vulnerable people in society will struggle to find opportunities to support them into paid work, potentially resulting in increased social isolation.

“A lot of companies will not take on people with a learning disability and they don't give people like us a chance and I feel we can do the job just as well as the other people can.”

Problems accessing public and specialist transport services can also lead to feelings of social exclusion. Common barriers include travel information which is difficult to understand or which is unavailable; inflexibility in provision to help enable independent living, especially in rural areas; and a lack of understanding from transport providers about the needs of people with a learning disability.

“A lot of timetables are hard to read....and when you ring to get a time they are rude or there is so many numbers to ring for different places.”



What needs to happen?

- Greater public awareness about learning disability, including amongst local businesses, front-line community services and leisure providers.
- More investment in initiatives that support access to local services, activities and social events for older people with a learning disability, including those with multiple and complex needs.
- Greater availability of accessible formats of information about local services, activities and events, including user-friendly (Easy-Read) public transport timetables.
- Clear links between learning disability and Community Planning processes in relation to tackling social isolation.
- More work placements, meaningful employment opportunities, and in-work support for individuals with a learning disability and their employers.
- Identification of alternative funding options (in addition to ESF); and a clear plan put in place regarding future funding for interventions currently delivered through ESF following the UK's exit from the EU.
- A joined-up approach to accessible transport provision to increase access by people with a learning disability to social, leisure, training and employment opportunities.



¹⁴ See www.mencap.org.uk/press-release/almost-1-3-young-people-learning-disability-spend-less-hour-day-outside-homes-survey
¹⁵ Turner, S; Bernard, C (2014) Supporting older people with learning disabilities: A toolkit for health and social care commissioners. BILD, Birmingham.
¹⁶ See www.mencap.org.uk/learning-disability-explained/research-and-statistics/employment
¹⁷ Tunnard, J; Flood, S; Barnes, T (2008) One in ten: Key messages from policy, research and practice about young people who are NEET. Forum 21, 3, 46-53.

8 Education

Children and young people with a learning disability may also have special educational needs (SEN) which can affect their ability to learn, and they may require extra help to achieve their potential at school. A SEN Statement sets out any additional support that a child should receive in school to enable them to make progress. In Northern Ireland, almost 5 per cent of the school population (17,000) has a SEN Statement. A recent review of SEN conducted by the NI Audit Office reported that 79% of new SEN statements were issued outside the statutory 26-week time limit.¹⁸ It further highlighted a general lack of monitoring and evaluation.

There is also continued serious underfunding in special needs education and a lack of investment in specialist early intervention. Children with challenging behaviours, for example, would benefit from additional support in schools at an early age. Ensuring appropriate levels of support for children with SEN from educational psychologists is also important, especially given the vital role they play in ensuring children's successful learning and participation in school activities.

9 Early Intervention

Compared to their peers, children with a learning disability are at greater risk of experiencing poor outcomes. However, access to high quality, early support is more limited for children with a learning disability and their families; and they are generally under-represented in early intervention policy.

What needs to happen?

- Development and implementation of an Action Plan to progress the findings and key recommendations of the NI Audit Office Review of Special Educational Needs; with a particular focus on both special schools and mainstream provision.
- A clear pathway for the SEN Statementing process needs to be widely promoted; and a review undertaken to resolve the significant delays in issuing statements.
- The serious underfunding in special needs education needs to be addressed, and specific investment made in specialist early intervention.
- A review of educational psychology support, particularly at Stage 3, to ensure that levels of provision are adequate to meet children's needs.
- An up-to-date evaluation of SEN provision in mainstream and special schools is critical in order to improve quality, effectiveness and overall outcomes.

What needs to happen?

- Every child with a learning disability should have access to early intervention services that support their development from birth.
- Families of children with a learning disability should have access to family support services in every Health and Social Care Trust.



¹⁸ Northern Ireland Audit Office (NIAO) (2017) Review of Special Educational Needs (Note: its' focus was on mainstream provision).

10 Personal Independence Payment

Recently introduced in Northern Ireland, the Personal Independence Payment (PIP) is a new benefit that is gradually replacing Disability Living Allowance (DLA). PIP assessments are intended to be functional rather than medical, in that they consider the impact an individual's health condition or impairment has on their everyday life. People have to be re-assessed in order to qualify for PIP, and many have had their benefits disallowed based on their initial assessment.

Experience in other parts of the UK suggests that assessment processes have not always taken sufficient account of individual needs and circumstances. An independent review of PIP (not including NI) was critical of the assessment system, including a lack of transparency in the process.¹⁹ A recent High Court ruling found that an amendment to PIP, which limited the amount of support people with psychological distress could receive for making journeys, constituted a breach of their human rights.²⁰

Due to complete in March 2018, the Department for Communities has commissioned an independent review of how the PIP assessment is working in Northern Ireland.

“[PIP] re-assessments causing stress and fear.”

“People who need PIP are not getting it and are being made to feel undervalued, belittled and like we are liars and we do not matter...”

What needs to happen?

- Any recommendations from the NI PIP Review to make improvements to the assessment process should be considered and implemented as a matter of priority.
- Access to specialist learning disability assessors should be available, and all PIP assessors should have general learning disability awareness training.



¹⁹ Gray, P (2017) The second independent review of the Personal Independence Payment assessment. DWP, London.

²⁰ RF v Secretary of State for Work and Pensions <http://www.bailii.org/ew/cases/EWHC/Admin/2017/3375.html>

Appendix – Membership of APGLD

MLA members

Chris Lyttle, Alliance (Chair)
Michaela Boyle, Sinn Fein (Deputy Chair)
Robbie Butler, UUP (Treasurer)
Mark H Durkan, SDLP (Secretary)
Patsy McGlone, SDLP
Gordon Lyons, DUP
Paula Bradshaw, Alliance
Kellie Armstrong, Alliance
Colin McGrath, SDLP
Steven Agnew, Green Party
Colm Gildernew, Sinn Fein
Pat Catney, SDLP
Christopher Stalford, DUP

Supporting organisations

Mencap NI (Secretariat)
ARC
Positive Futures
Caring Breaks
Compass Advocacy Network
Now Group
Orchardville
Kilcreggan Homes
Triangle

This paper was prepared by Mary Anne Webb (Mencap NI), with the APGLD Planning Group.

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