

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.