

Epilepsy Action Northern Ireland response to Northern Ireland Assembly Committee Inquiry into Post Special Educational Need Provision in Education, Employment and Training for those with Learning Disabilities

Responder and contact details

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Why we are responding

Epilepsy Action Northern Ireland is the leading charity, supporting the needs of people with epilepsy in Northern Ireland. Around 20,000 people living in Northern Ireland have epilepsy, or in terms of prevalence, 1 in every 90 people. Furthermore, up to a third of people with learning disability also have epilepsy. This often leads to complex care and support needs in education, employment and training.

As a charity we are keen to help support your engagement with people with learning difficulties and epilepsy, their families and support professionals.

Our response to the terms of reference

Term of reference 1. To examine the current range of choice and opportunities available for those with Learning Disabilities[1] on leaving full time schooling.

1. Epilepsy Action Northern Ireland support this term of reference. We seek clarification that this will include full-time and short-term residential educational placements, supported work placements and education in hospital settings (for people with learning disabilities who are in hospital for long-term treatment).

Term of reference 2. To seek the views of young people, family carers and groups representing children and young people with learning disabilities on what services they would like to see in place and how the current situation meets their needs.

2. Epilepsy Action Northern Ireland welcomes the Committee's expressed wish to work with as many relevant charities and organisations as possible on this engagement exercise. This should widen the level of feedback and engagement from individuals with learning disabilities and their families.

3. We ask for this term of reference to be expanded to clarify and include the mechanisms through which the Committee wishes to capture this evidence. For example the Committee could ask organisations to submit:

- Written evidence
- Individual case-studies
- Survey data (will the Committee issue a survey that organisations can promote?)

Term of reference 3. To research best practice in post school provision for those with learning disabilities.

4. We believe that all people with learning disability and epilepsy should receive coordinated health, care and social support to enable them to achieve their potential in education, training and employment. We firmly believe that enabling coordinated support should be one of the measures of best practice.

5. In addition to best practice the Committee must also examine examples of poor practice where people with learning difficulties and their families are let down. We urge this Committee to then examine how poor practice will be challenged or sanctioned. Unfortunately we firmly believe that in a market of competing priorities and dwindling funds, best practice will be more widely adopted only after enforcing action to eradicate existing poor practice.

6. What will best practice look like? We would judge best practice to include identifying SEN early in a setting, well planned out transition services and support between school, post 16 education, training and employment, integrated support to help with care and support needs, all or the majority of service users achieving their potential.

Term of reference 4. To examine if the quantum and quality of post school provision for those with Learning Disabilities is meeting the demand and develop recommendations to address barriers to participation and delivery of high quality provision.

7. We fully support this point. Again collecting experiences and examples of poor and inadequate practices and the consequences, will help the committee to identify barriers (including medical, financial and geographic) and develop plans to address them.

8. How will the Committee gather evidence of financial and funding barriers to participation in relevant services?

9. Meeting demand is more readily measured but how will personal achievement be quantified and qualified? One of the most important outcomes of a high quality provision is to enable the individual to achieve their potential. What framework will the Committee use to establish that current provisions and high quality provisions are enabling service users to meet their individual potential? [Please note, we fully appreciate that there is not one set of benchmarks to measure personal achievement within the population of people with learning difficulties. For some people the measure is obtaining employment, at the other end of the scale achievement is broadening a person's ability and willingness to increase their communication with a trusted person].

Term of reference 5. Given the complex and interrelated needs of individuals in this group to identify the barriers to co-ordination across departments – regionally and locally – and make recommendations for improvement.

10. We are extremely pleased to see this embedded in the Committees terms of reference. Organisations and individuals can (unfortunately) provide examples of where a service has been poor when a person has transitioned between different service types and geographical areas.

11. It is vital that staff working in Further Education Colleges and supported employment services receive adequate training in epilepsy. This should include awareness and first aid training for epilepsy. Although this consultation is about learning disabilities, a significant proportion of people with learning difficulties also have epilepsy. It is impossible to support this population effectively in their education, training or employment without making provisions for their medical needs and safety. Unfortunately we are contacted many times by families who have found that services providers lack understanding of the condition, its medical needs and impact on learning, memory, communication and behaviour.

12. Epilepsy Action Northern Ireland believe that all people with learning difficulties and epilepsy should receive coordinated health and care support to enable them to achieve their own potential in education, training or employment. More emphasis needs to be placed on professionals from all domains working as a team, and any decisions being centred on the individual. We believe all parties working earlier will lead to better understanding and appreciation for the support needed for the individual. Statutory assessment of each individuals needs after compulsory education (which would include psychological, medical, educational and employment advice) is the way to achieve this.

6. To report the Committee's findings and recommendations to the Assembly.

In reaching its recommendations the Committee will:

- a. Request that the Department details the range of provision it provides across all FE provision, vocational provision and employment support. What is the duration of courses and the number of hours per week (and what happens when it ends)?
- b. Assess the quality of current provision by looking at evaluations carried out.
- c. Assess whether DEL is living up to its commitments under the Bamford Report.
- d. Examine what approaches are working and what the barriers are.
- e. Examine the provision by FE colleges for those that are below level 2 and who have safety, supervision and holistic care needs and the options available to such individuals from Health and Social Care Trusts or new District Councils.
- f. Assess whether the definition of further education for this student population needs to be broadened: for example: to include physical activity, social and communication skills.

13. We fully support this aim. We largely agree with the approach, but urge the Committee to widen its framework for measuring success / best practice to ensure that the outcome and achievements of individuals with learning disabilities is measured and evaluated.

Omissions

14. We believe that the terms of reference should require the Committee to examine its definitions of learning disability. The current definitions are quite old now, and what we mean and understand about learning disabilities has moved on.

15. Cost of providing effective and adequate support should not be a barrier to achievement.

16. How will training of staff involved in these provisions be assessed and included in the inquiry remit. Increasing achievement for individuals requires that staff have received adequate training in assessing potential and planning achievement in individuals with learning disability.

Other Comments.

17. Epilepsy Action would welcome any opportunity to contribute to service templates for delivering best practice support to people with learning difficulty and a medical condition such as epilepsy, in education, training and employment.