



Committee Inquiry into Post Special Educational Need Provision in Education, Employment and Training for those with Learning Disabilities

This submission has been formulated by Action Duchenne, a UK charity founded in 2001 to fund cutting edge research into curing Duchenne Muscular Dystrophy. We also campaign for the best standards of education and care for all those living with the condition. Duchenne is the most common fatal genetic disorder diagnosed in children, affecting approximately 1 in every 3500 live male births (around 2500 people have DMD in the UK) and leads to progressive muscle weakness caused by a mutation in the gene that encodes for dystrophin. This gives rise to serious medical problems, with heart and lung related issues reducing the typical life expectancy for those with Duchenne to their late twenties.

Short life expectancies have historically influenced teachers, patients and parents to subtly lower their expectations that someone with the condition would live a fulfilling adult life. However, recent progress in standards of care and our knowledge about Duchenne has improved life expectancy drastically, with many men now living into their 30s and 40s. As a consequence of these improvements, it is now integral that all those with Duchenne are equipped with the means necessary to live fulfilled (as well as longer) adult lives, with education assuming a vital role.

Patient experiences in Denmark illustrate this need perfectly, with men now often living into their 50s (Rahbek 2005). However, because of low-expectations of achieving jobs, independent living and relationships, these men have a vastly reduced quality of life, a fact that is largely attributable to their education not being taken seriously. To avoid this 'Denmark effect' in Northern Ireland, it is essential to consider what systems could be established to support real outcomes in adulthood for young people with rare diseases like Duchenne.

In undertaking this task, relevant parties must further understand the learning difficulties associated with the condition. Numerous studies have proven that Duchenne can engender problems with both reading and phonological awareness in addition to increasing the risk of neuropsychiatric disorders. (Ricotti et al 2013: 30% exhibited symptoms for ADHD, 29% had internalising problems, 22% met criteria for ASD. Comorbidity also disproportionately prevalent; 75% of ASD also had ADHD with the usual rate 1/3).



1. Raising Aspirations

1.1 We feel strongly that efforts to take education seriously must include raised aspirations towards good educational outcomes and opportunities for work. Older men with Duchenne, who were not expected to be alive, have become a 'forgotten generation' and wish they had the level of independence, choice and control in their lives that good educational outcomes could've help provide. We campaign to ensure the same mistakes will not be replicated in the current younger generation of people with Duchenne.

1.2 All of us have hopes and dreams for our lives and young people with Duchenne are no different. They have the same right as anyone to look forward to a future of fulfilling relationships, meaningful employment and control over how they live. (PFA Better Life Outcomes 2013).

1.3 It is important that all professionals working with families and young people understand the condition and the barriers it presents. However, it is equally important that education, health and care professionals listen to what young people and families tell them about their aspirations in adult life and establish an integrated approach that will support them to achieve these aspirations.

1.4 Indeed, much of the existing focus is on training health and care professionals to be better able to recognise and support the alleviation of symptoms associated with the condition. However, whilst this is important, it does not integrate the training of education professionals to help them understand the condition, the barriers it presents and the educational difficulties it can engender.

1.5 What is required is integrated planning from health, education and care, starting from as early as 14 years and focussing on the hopes of the patient, rather than their diagnosed condition. This needs to include specialist careers advice delivered by qualified staff who have experience of working with disabled young people. This experience should also offer examples of disabled people who have achieved the goal of a full adult life who may thereby act as role models.

1.6 Post school education should include opportunities to develop the skills, qualifications and confidence to find paid work. It would be useful to look at a range of supported employment options including [trainee ships](#) and [supported internships](#) which can feature as part of a study programme for a young person post 16/19 education. The role of supported



employment agencies in providing advice and guidance as well as job coaches to support in employment is crucial.

1.7 Part of our work includes direct support for young people with Duchenne aged 14 – 25 in Transition. This preparing-for-adulthood programme is called Takin' Charge and focuses on raising aspirations amongst young people and families affected by Duchenne. This includes encouraging participants to think about being adults who can have jobs, independence, strong community support as well as good health outcomes. We are pleased to contribute to discussions about what might better support this to happen in Northern Ireland.

2. Ways Forward

2.1 We would recommend that during the period of gathering evidence, the committee investigate the Preparing for Adulthood programme (PFA) which is funded by the Department for Education UK as part of the delivery of support for SEN and disability reform under the Children and Families Act, 2014.

2.2 It is a programme delivered by a partnership between the National Development Team for inclusion (NDTi), the Council for Disabled Children (CDC) and Helen Sanderson Associates. (HSA).

2.3 The partnership brings together a wide range of expertise and experience of working with young people and families at a local and national level, and aims to support young people into adulthood with paid employment, independent living and community inclusion.

[Preparing for Adulthood](#)

3. Other groups to seek advice from apart from [Action Duchenne](#) -

3.1 [DMD Pathfinders](#) is a user-led charity which promotes choice and control and quality of life for teenagers and adults with Duchenne Muscular Dystrophy in the UK. It campaigns for improved standards of health and social care and provides advice, guidance and support to teenagers and adults with Duchenne Muscular Dystrophy on issues such as independent living, housing, employment and welfare rights.

3.2 In addition, [Decipha CIC](#) have experience of working successfully to support young adults to achieve life outcomes that were hitherto unconsidered.

3.3 We would welcome the opportunity to give oral evidence.

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