

## Written evidence submitted by Duchenne UK

21 July 2020

### **SUMMARY**

- The relaxation of the legal duty to meet the provisions agreed in Education, Health and Care Plans (EHCPs) has had a severely detrimental effect on the education, support and quality of life of young people with Duchenne Muscular Dystrophy (DMD). These hard-won statutory rights, including EHCP time limits, must be restored in full as soon as possible, and the Government should amend EHCPs to ensure they don't need to be suspended in the future.
- The DMD community feel as though they have been an afterthought, with the serious nature of their disease ignored or lost in wider messaging. There has been little guidance other than shielding advice for families of children who are classified as 'clinically extremely vulnerable' - both during lockdown and returning to school. Going forward, updates to guidance for the general public should be published in tandem with an update for vulnerable groups, and only after consultation with the vulnerable groups and special consideration for their needs. It is unacceptable to alter generalised guidance yet leave vulnerable groups waiting for additional information.
- Measures to support families who have been shielding at home should be brought in immediately, with a view to make such provisions permanent. This should include access to personal protective equipment, antibody testing, remote learning, access to the National Tutoring Programme and mental health support. Time and again support for families has been reactive, not proactive. Measures should be put in place so there is an automatic package of support for families forced to shield in the future - whether that is due to a new disease or a 'second wave' of COVID-19.

### **INTRODUCTION**

1. Duchenne UK (DUK) welcomes the opportunity to give evidence to the Education Select Committee's inquiry on 'The impact of COVID-19 on education and children's services'. We are a leading medical research charity which supports patients and families affected by Duchenne Muscular Dystrophy (DMD), a rare life-limiting progressive condition.
2. DMD is a genetic disease that causes muscle weakness and wasting. DMD almost exclusively affects males, with only about 1 in 50 million females affected<sup>1</sup>. Diagnosis tends to be before the age of 5 and people with the condition will usually only live into their 30s. As a result, many Duchenne patients are school-aged. There are an estimated 2,500 people with DMD in the UK.
3. Children with DMD may require specialist special educational needs and disabilities (SEND) attention at school depending on the progression of the disease. This may involve physical and postural aids, ventilation assistance, and special forms of exercise. Some children may also have learning and behavioural challenges. However, many of the experiences of DMD

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<sup>1</sup> Nozoe, K.T., Akamine, R.T., Mazzotti, D.R., Polesel, D.N., Grossklauss, L.F., Tufik, S., Andersen, M.L., Moreira, G.A., 2016, 'Phenotypic contrasts of Duchenne Muscular Dystrophy in women: Two case reports', *Sleep Science*, vol 9, issue 3, pp 129–133. <https://doi.org/10.1016/j.slsci.2016.07.004>

families during the COVID-19 pandemic will be common to families with children living with other paediatric conditions.

4. It is worth noting that most people with DMD are classified as “clinically extremely vulnerable” (CEV) under shielding guidance, and as “vulnerable people” under the Coronavirus statutory instruments<sup>2</sup>.

### **EDUCATION, HEALTH AND CARE PLANS (EHCPs)**

5. People between 0 and 25 years old with DMD are entitled to an Education, Health and Care Plan (EHCP). A person is only granted an EHCP through a negotiation with their local authority in consultation with clinicians and educational professionals, and by completing a rigorous assessment. Once finalised the EHCP is a statutory document and its provisions must be met by law. While EHCPs contain provisions for many aspects of the individual’s life, here we will restrict ourselves to the education element of the plans.
6. For most DMD families, agreeing an EHCP is the only way to trigger access to specialist support services such as teaching assistants, and reflects not only the needs of their child but also the child’s dreams and aspirations.
7. In response to COVID-19 the Government has altered EHCPs in two ways:
  - 7.1. on 28 April 2020 the Secretary of State for Education issued a notice modifying section 42 of the Children and Families Act 2014 replacing the legal duty to provide for an EHCP with “reasonable endeavours”;
  - 7.2. on the same date the Secretary of State for Education made The Special Educational Needs and Disability (Coronavirus) (Amendment) Regulations 2020 (S.I 2020/471) which relaxes time limits for various EHCP processes.
  - 7.3. The notice has been renewed by the Education Secretary every month since, though the Department for Education has indicated it will not be reissued past the end of July, and S.I 2020/471 will remain in force until 25 September 2020<sup>3</sup>
8. This revocation of the rights of disabled and vulnerable children was done without consultation, notice, or an impact assessment. That is unacceptable and insulting to families who rely upon the statutory provisions outlined in their EHCP. It has led to serious negative impacts on the education of children with DMD, who are at a high risk of learning difficulties, and are often already behind their peers. Furthermore, as many DMD children experience mental health problems, anxiety is an established risk which may have been exacerbated by the removal of provisions.

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<sup>2</sup> For example in S.I 2020/350 and S.I 2020/684.

<sup>3</sup> <https://www.gov.uk/government/publications/guidance-for-full-opening-special-schools-and-other-specialist-settings/guidance-for-full-opening-special-schools-and-other-specialist-settings#temporary-changes-to-send-legislation>

9. While we recognise that in these extraordinary circumstances not all the provisions of every child's EHCP may be achievable, a blanket suspension of all EHCPs is a blunt tool. In practice this has resulted in the abandonment of many vulnerable children by unnecessarily removing their care and support, and their exclusion from education settings.
10. In many cases the responsibility for meeting the needs of an EHCP has been pushed on to family members who may already be struggling with the burdens of COVID-19 on their personal and professional lives, and may lack the necessary skills or abilities required. The burden on families is explored in more detail below in the 'Homeschooling and shielding' section.
11. There is no clear method by which families who feel that there was a failure to make "reasonable endeavours" to meet the provision of an EHCP can challenge the decision to withdraw or not provide support, or how local authorities and health commissioning bodies are meant to make and record a "reasonable endeavours" assessment. In practice, some local authorities and health commission bodies have been better than others at providing for EHCPs.

### **Recommendations**

12. The statutory requirements of EHCPs, including time limits, should be restored in full as soon as possible. EHCPs are a hard-won right, and these rights should not need to be put on hold for foreseeable, albeit extraordinary, events such as pandemics.
13. The Government should commit to put in place measures to ensure future national crises don't require the suspension of EHCPs. DMD families do not want special treatment, just the provisions they are entitled to in EHCPs. As access to their EHCP provisions are a right, EHCPs should be embedded with resilience. EHCPs could be adapted to provide a package of support which can be delivered during times social distancing is required. This package of support could include:
  - 13.1. remote learning or access to specialist tutoring or advice;
  - 13.2. the appointment of a dedicated social worker to act as a point of contact through the crisis;
  - 13.3. the provision of infrastructure - such as equipment like laptops and secure video conferencing facilities in schools - so vulnerable children can continue to learn and their specific needs are met.
14. Further recommendations on how families with vulnerable children can be supported at home can be found below in the 'Homeschooling and shielding' section.
15. A method of recourse and complaint should be made available to families who feel "reasonable endeavours" were not made to meet the needs of an EHCP.
16. Local authorities and health commissioning bodies must make plans now to ensure they are able to meet the full provisions within EHCPs as soon as EHCPs are restored in full.

**HOMESCHOOLING, SHIELDING AND RETURNING TO SCHOOL**

17. Parents across the country have had to juggle the pressures of working from home and childcare. This burden has been particularly felt by families with DMD children, who have found themselves without health or educational support and forced to assume the role of full time carers and teachers.
- 17.1. A survey by the Disabled Children's Partnership found 45% of families with disabled children felt their child's physical health had deteriorated during lockdown, and just over 70% said their child's emotional health had declined.<sup>4</sup>
18. Many families don't have the luxury of being able to care for their child's specialist needs at home. Yet due to the need to shield most families with DMD children have kept their CEV child at home and away from school and SEND support.
19. Despite this caution, many vulnerable children have returned to school.
- 19.1. From 1 June schools were asked to welcome back pupils in nursery, reception and years 1 and 6, and from 15 June, secondary schools, sixth form and further education colleges were asked to extend this to students in year 10 and 12.
- 19.2. Yet by 25 June children with an EHCP were returning to education settings at a rate much higher than the overall rate (23% v 15.6%<sup>5</sup>).
- 19.3. While we want vulnerable children to resume their education and socialise with their peers as soon as possible, this decision should be made based on the child's needs. It should not be because support at home is non-existent. Unlike other conditions, DMD affects all of the body's muscles, including respiratory muscles, so for families with DMD children the decision to send their children back to school during the outbreak of a respiratory illness could be a question of life or death.
20. There is no method to monitor the quality of homeschooling or remote learning. Parents report wildly varying standards between schools on the methods of remote teaching, the level of expectation from students, and the volume of school work. This is very worrying for children with DMD who are at very high risk of learning difficulties such as problems with learning to read and consolidate learning.
21. For many families, COVID-19 has resulted in the removal of their entire support network. Many young people with DMD, particularly those in their mid and late teens, rely on social care to meet their personal care and social interaction needs. Many families have had to take on these responsibilities themselves, in addition to their own full time jobs, which has caused excessive stress.

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<sup>4</sup> <https://disabledchildrenspartnership.org.uk/wp-content/uploads/2020/06/LeftInLockdown-Parent-carers%E2%80%99-experiences-of-lockdown-June-2020.pdf>

<sup>5</sup> <https://explore-education-statistics.service.gov.uk/find-statistics/attendance-in-education-and-early-years-settings-during-the-coronavirus-covid-19-outbreak/2020-week-26>

- 21.1. While nursing and residential care homes for older people have attracted media attention, it is worth noting that these settings account for less than one third of people over the age of 18 receiving long-term social care.<sup>6</sup>
  - 21.2. When taking into consideration children under the age of 18 receiving social care too, it is clear that a far larger proportion of social care takes place in the home.
  - 21.3. While a “protective ring” was thrown around care homes, people looking after loved ones in the home were abandoned, and left without support.
22. For some, access to medical appointments, carers, education, friends, and family members is impossible due to the need to protect their CEV children by shielding.
- 22.1. Aware of their social responsibilities and of the Government’s guidelines, CEV households take the need to shield seriously.
  - 22.2. The ONS found that 63% of the 2.2m people shielding report following shielding guidance in full. 46% of CEV people have not left home since they were advised to shield.<sup>7</sup>
23. For others, the problem is not caused by lack of access. Points of contact and support such as social workers have been redeployed or removed entirely. In some cases families have found their support has been replaced with a recorded voice message.
24. Social isolation was already a problem for some before shielding became necessary, and COVID-19 restrictions have further compounded the issue.
25. Homeschooling not only disproportionately affects vulnerable children and their parents, it also has a profound effect on their siblings.
- 25.1. In order to meet the needs of children with Duchenne, parents may not have the capacity to additionally homeschool siblings. This should be recognised and extra support provided to families homeschooling CEV children and their siblings.
  - 25.2. There is the possibility that, in consultation with their clinicians, it is decided that some DMD children will temporarily not be able to return to school due to the need to voluntarily shield beyond July. This could result in siblings being kept out of school too.
  - 25.3. The very real danger is that medically-necessary shielding will lead to children missing out on school, and in the absence of alternative methods of learning

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<sup>6</sup> <https://chrishatton.blogspot.com/2020/04/recording-and-analysing-covid-19.html>

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<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/coronavirusandshieldingofclinicallyextremelyvulnerablepeopleinengland/9juneto18june2020>

they will fall behind in their education. This educational deficit for CEV children and their siblings must be addressed by the Government.

26. Many DMD families have concerns over returning to school, and the ability of schools to protect their children from COVID-19 and provide consistent SEND support - especially for children who require 1-on-1 support.
27. While the Government has provided guidance to education settings for staff who are vulnerable, they have not outlined how vulnerable children should return to school. School leadership teams want to do the best for their students, but lack the specialist knowledge or experience to make informed decisions, and lack the resources to implement alternatives.

### **Recommendations**

28. DMD families have felt abandoned during this pandemic. The Government must, as an urgent priority, ensure local authorities have the resources to offer immediate educational support to shielding families and children with SEND requirements. This could include:
  - 28.1. guaranteed 1-on-1 time with a specialist teacher more than once a week, for the affected child and any siblings who have missed school, to, for example, provide tutoring in core subject areas or help plan and organise the child's work for the week;
  - 28.2. guidance to education settings on curriculum expectations tailored for SEND children who have been homeschooling;
  - 28.3. information for schools on how best to welcome CEV children back to school with their peers safely.
29. Vulnerable groups were neglected during the redeployment of resources and staff due to COVID-19 related activities. In the future local authorities should prioritise establishing networks to provide mental health and education support for families shielding with vulnerable children.
30. Government guidance states that school absences will not be penalised if parents are following clinical or public health advice. This should be updated to explicitly include siblings of children in vulnerable groups.
31. Arrangements should be made so students with CEV siblings can attend school even if the CEV child has to shield. This could be through social distancing at school and 'bubble' classes.
32. Access to tutors and coaches as part of the National Tutoring Programme should be prioritised for children with rare diseases such as DMD, and this provision should be made explicit in written guidance. This access should be made available both for CEV children who return to school, but especially for those who cannot return and must voluntarily shield at home and their siblings.

**ACCESS TO PERSONAL PROTECTIVE EQUIPMENT (PPE) AND THE IMPACT ON EDUCATION**

33. Throughout this pandemic families and carers have reported that they have struggled to source adequate personal protective equipment (PPE) supplies of the correct quality.
34. Without PPE many shielding households have felt unable to allow education assistants into the home. This has been one of the reasons access to carers, clinicians and teachers has been restricted during this pandemic.

**Recommendations**

35. Shielding families should have access to supplies of PPE for themselves, their carers and other specialist services such as teachers made available to them as soon as possible.
36. This provision should stay in place even after wider shielding rules have been relaxed if families, in consultation with their clinicians, judge that they should continue voluntarily shielding.
37. Measures should be put in place so in the future families with CEV children have access to PPE if they are advised to shield.

**ANTIBODY TESTING AND RETURNING TO SCHOOL**

38. In a welcome move, the Government made antibody tests available to hospital and care home staff, as well as patients in hospital and social care settings. This was done in the recognition of the value of identifying those who have previously had the virus.
39. This information would be invaluable for shielding families to help them and their clinicians make the decision on whether adults can return to work or children can return to school.
40. However, despite care in the home representing a large proportion of social care settings (see 21.1), antibody testing is not currently available for shielding families.

**Recommendations**

41. Shielding families should have priority access to antibody testing in order to allow them to make informed choices on whether or not to continue shielding. This will be invaluable in giving CEV children the confidence to return to education settings.

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