

**Written evidence from Parental Submission 167**

1. I am the parent of a 15 year old son who is a bright lad. He was diagnosed in 2013 as having a lifelong medical condition : Inflammatory Bowel Disease, and since has developed associated anxiety. He unfortunately missed a whole year of school, Year 9, due to the disease making him too ill to attend school. The school were "less than supportive" and trivialised his condition, and the LA failed to take any action to support my son.
2. Pleased to say his health is now much improved and he's now back in a new school, in Year 10, studying for his GCSE's. He has an ambition to be an engineer, but he's struggling and still hasn't started to receive the support I believe he should be receiving and should have commenced two years ago.
3. Advocating for my son has literally monopolised my life and due to this, I have not been able to work (having been redundant in May 2017). This protracted experience, where neglect of statutory duties has been rife, has been adversarial at best, and on numerous occasions downright nasty, and sad to say it is affecting my health.
4. This cannot possibly be right that a parent, already dealing with an ill child, has to be put through hell to secure the support her child needs and where statutory duties apply.
5. I have had a tremendous struggle to secure an EHC assessment for him. After two years of struggle with his health and 20 months since requesting an EHC assessment, the decision "not to assess" was finally overturned following appeal to First Tier Tribunal and then to the Upper Tier Tribunal, giving the instruction that the assessment must commence in Nov 2018.
6. Whilst an EHC assessment has been done (but with lots of issues still remaining about that) and a draft EHC plan produced, I am again locked in battle with our local authority about the content of the plan. The LA have so far ignored my requests for a flexible and timely response to support my son's "fluctuating physical and mental health" needs and seem oblivious to wider legislation and my pleas for them to take a preventative approach in support my child "to keep him well".
7. The SEND legislation unfortunately gives scant guidance for such fluctuating need nor the need for preventative positive action /support, and I fear this "gap" in statutory guidance for such a situation as we find ourselves in means it is looking inevitable that we will have to go to appeal at the SEND tribunal yet again. Further, if the First Tier Tribunal cannot support my appeal then it may well be necessary to progress matters to the Upper Tier Tribunal on a point of law.

8. I believe higher legislation regarding Human Rights, Children's Rights, and Disability Rights at a European and United Nations level are not being taken into consideration here, and yet, for us to go to the SEND Tribunals to get a ruling on these matters, whilst this would be extremely useful for any other kids with fluctuating medical conditions in the future facing such "barriers to achieving to their best", it seems unfortunate, from experience, that any such action I take now to try to obtain an UTT ruling will be a lengthy process that very well may delay my son the support he needs at this very crucial point in his academic studies (and especially feeling disillusioned having already been put at such a disadvantage by being so badly let down by the education system in the past two years).
9. Having spoken with several disability charities I have not been able to identify any "best practice" advice for a child with any type of illness that causes fluctuating need. It is frustrating that no "example EHC plans for a child who has fluctuating need/ fluctuating illness" can be identified as these are unfortunately not published. Also it appears no legal precedence/ case law exists to help in this regard (I have had much contact with the legal advice charity IPSEA but they are not aware of any such previous EHC plans or Tribunal cases / precedence).

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