



Edward Timpson MP

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Den Margaret,

I wanted to thank you for giving me the opportunity to hear the concerns of the Forward-ME group. Children and young people with ME and chronic fatigue syndrome have the same right to a good education and secure family life as anyone else. I sympathise with the distress that individuals and their families must feel when the professionals supporting them do not appear to understand the issues they face. The members of Forward-ME play a vital role, not only in raising awareness about ME and CFS, but in helping to ensure that professionals understand children and young people's individual circumstances.

The issues raised by the group demonstrate that there is still a way to go until every child and young person receives the support they need. I am, however, optimistic that the reforms we are making, most recently through the Children and Families Bill, will change things for the better. It will take time for the impact of these reforms to be fully realised, but they are underpinned by a system that is focussed on the needs of individuals and their families, rather than process or narrowly defined organisational responsibilities.

It will come as no surprise that similar issues were raised across the group. Rather than answering each question individually, I thought it would be helpful to provide a combined response to all members of the group. I would be grateful if you could forward this letter to them on my behalf.

Raising awareness of ME and CFS

Several questions asked about the action being taken to raise awareness of ME and CFS amongst professionals.

Where relevant guidelines have been issued then professionals have a responsibility to ensure that they are aware of them and take them into account when making decisions. As I mentioned in the meeting, I will raise the particular concern about health professionals' awareness in my discussions with the Department of Health.

The Government has a broader role to support good decisions that are based on accurate information. One of the most important ways in which we can do this is to encourage professionals to work together and give proper account to the views of those concerned. This aim is at the heart of the reforms we have introduced, as illustrated by the revised SEN Code of Conduct, statutory guidance on safeguarding and statutory guidance on the education of children unable to attend school because of health needs. It is also underpins the statutory guidance that will accompany governing bodies' new duty to make arrangements to support pupils with medical conditions. This particular guidance is out for consultation until 14 March and the group may wish to comment upon it.

Child protection processes for children with ME and CFS

A significant number of questions related to use of child protection proceedings in relation to children with ME and CFS.

Each decision about whether a child requires extra support or protection will be unique and there will always be a need for professionals to exercise their judgement in relation to an individual case. That is why our revised safeguarding guidance strengthens the focus away from processes and onto the needs of the child.

It is important to highlight that the involvement of social services does not, in itself, imply that a child requires protection. Social services have an equally important role in providing support to families who need additional help. It is understandable that parents may feel anxious about the involvement of social services and that this anxiety could be heightened by previous experience of professionals' lack of understanding about ME and CFS. We are working to improve the overall quality of social work practice, in line with Professor Munro's review of child protection. We are also looking at the quality of social worker training. Last year we asked Sir Martin Narey to look at the initial education of children's social workers and consider how far current training arrangements meet the requirements of today's children services. We recently published Sir Martin's report, which presents a compelling case for reform.

As I mentioned in our meeting, Isabelle Trowler has been appointed as the Chief Social Worker for Children and Families. Isabelle will lead reforms to social work education and will be setting out what a newly qualified children's social worker needs to know and be able to do. She is also giving some thought to how we might develop a more thorough test of a new social worker's practice at the end of a first year of employment. This will ensure that emphasis on raising quality runs through initial education and into practice. I understand that Isabelle has accepted your invitation to meet the group. I have, therefore, copied this letter to

her so she is aware of the discussion we have had on these issues.

I appreciate that there will, unfortunately, be times where practice falls short of the high expectations we have set. Government cannot intervene in individual child protection cases but there are local authority complaints procedures that allow parents to challenge decisions relating to child protection. In addition, the Local Government Ombudsman provides an independent route to pursue a complaint where local processes fail to resolve the issue. The support provided by the members of the group in these difficult circumstances is, of course, extremely valuable.

Government does have an important role in ensuring that the accountability processes for public services place an emphasis on the views of those people the service is intended to support. Since November 2013, Ofsted have inspected local authority child protection services and services for looked after children (including local authority fostering and adoption functions) under a single, combined framework. This framework examines the help, protection and care provided from the time it is first needed by a vulnerable person until they have been successfully helped; whether that is remaining with their families, becoming a looked after child or starting their lives as a young adult. As part of the inspection process, inspectors will review a number of cases and identify individuals they would like to meet. This is likely to include children, young people, parents and carers across the child protection spectrum, from early help to care proceedings. In addition, whilst it is not Ofsted's role to consider individual complaints, they do operate a whistle blower hotline so that people can report concerns about practices and procedures for the safeguarding of children and young people.

There were a couple of specific questions about the number of families of children diagnosed with ME and CFS who are currently under investigation by social services. There is a balance to be struck when deciding on a proportionate amount of data for local authorities to report. The Department collects and publishes data on the overall proportion of children in need whose primary need was 'illness or disability'. A breakdown of this data by disability is provided, however, we do not collect data relating to individual health conditions. The latest publication, covering the year ending March 2013, can be accessed using the following web link: <http://tinyurl.com/ox2a87y>.

Education of children with ME and CFS

A number of the questions posed related to the education of children unable to attend school as a result of ME and CFS, in particular the point at which it would be appropriate for them to return to a mainstream school.

Where children are unable to attend school, or have long term absences because of health needs, it is likely that their local authority will have a duty to make other arrangements for them to continue their education. Our revised statutory guidance to local authorities on this issue, *Ensuring a good education for children unable to attend school because of health needs*, sets out that the

local authority should be prepared to take responsibility for the education of children who will miss 15 or more days across the school year. Decisions on the most appropriate provision for an individual, including the use of education within the home, are ultimately for the local authority to make. The guidance, however, reinforces the importance of taking account of the views of children, their parents and professionals. We are currently revising this guidance and the SEN Code of Practice, in line with your helpful comments, to support appropriate decisions on the use of online learning for children unable to attend school.

Many children who are absent because of their medical condition see returning to school as an important step. For those who are well enough, there are clear benefits in being able to interact directly with their peers. I appreciate that, for children with long term and fluctuating conditions, decisions about reintegration can be particularly difficult. This is why they need to be made locally and involve the child, their parents and relevant professionals. Statutory guidance sets out that local authorities should work with schools to set up an individually tailored reintegration plan for each child.

Ultimately, the Department could consider a parent's claim that a local authority had failed to discharge its duty to arrange suitable education, or had done so in a way that no reasonable person would. There is, however, a high bar to Government intervention and it is unlikely that the Department would be in a position to make judgements about the appropriateness of the provision arranged for a particular individual. Wherever possible, disagreements about the education of an individual are best resolved at a local level. The local authority's own complaints process should be used where a parent is unable to resolve concerns that the authority is not providing the education it should. The Local Government Ombudsman can also consider complaints about a local authority where this process has been exhausted.

To address the point that was raised at the meeting, *Ensuring a good education for children unable to attend school because of health needs*, is statutory guidance that relates to a specific local authority duty. Whilst we reinforce that others, including schools, will have an interest in it, only local authorities are required to have regard to it by law.

In practice, it is vital that schools, local authorities, health professionals and other support services work together to ensure children with health needs get a good education. The majority of schools take these issues seriously and work to ensure that the health needs of their pupils are being met. We are aware, however, that some parents of children with medical conditions may have had poor experiences in getting the right support. This is why we are introducing a specific duty on governing bodies to make arrangements to support pupils at school with medical conditions.

Delivering the aims of the Children and Families Bill

As a number of questions highlighted, school nurses have an important role to play in delivering the aim of greater coordination between education and health

services, encapsulated by the Children and Families Bill. We are working with the Department of Health on ensuring that schools receive the help they need to support pupils with medical conditions effectively.

Each local authority will make a decision on the number of school nurses required through the Health and Wellbeing Board, according to the evidence presented in the Joint Strategic Needs Assessment. All schools will have access to school nursing services, but school nurses will not be the only healthcare professionals available to help support pupils with medical conditions. School nurses may take the lead in identifying and securing appropriate health services, but they will not always be involved in delivering support or training.

If a school felt that it was not receiving the support it needed from health and social care partners then it could discuss its concerns with the local authority (as the commissioner of school nurses) or the clinical commissioning group (for other healthcare specialists). Ultimately, if a school remained dissatisfied they could address these concerns to their local health and wellbeing board.

I hope that this information is useful to you and the members of Forward-ME. If you have any remaining questions please let me know and I will ensure that you receive a response.

Yours ever,

Edward

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