

Written evidence submitted by Jane Raca

Who am I?

I am a solicitor who practised litigation for 11 years in major law firms, before giving up work to look after my severely disabled child. My son has cerebral palsy, is unable to walk or talk, is doubly incontinent, epileptic and severely autistic.

In 2007 I took Birmingham City Council to the Special Educational Needs and Disability Tribunal to get my son into a non-maintained specialist boarding school, where he now lives. I have written a book, *Standing up for James*, which contains detailed evidence of the workings (and failures) of the current system for disabled children who also have SEN. This was released on 3 September 2012. It has a foreword by Rosa Monckton in which she says '*Jane Raca has written a very important book which should be required reading for every MP...*' I am sending a copy of my book to the Chairman of the Education Select Committee, Mr Graham Stuart MP, and fervently hope that every Committee member will be able to find the time to read it.

My evidence

I have evidence to give that could be a submission under several of the questions that the Committee has asked. I answer the questions specifically at the end of this letter.

The evidence relates to the most severely disabled children, such as my son.

Where a family can no longer cope with the care of such a child, because he or she requires intensive care/therapy/interaction 24 hours a day, then this is initially defined as a social care issue. The parents must turn to social care to provide respite and support at home. Cash strapped councils are failing to do this. When the family begins to fall apart, as it inevitably will do, then at present the parents have four choices:

1. They can appeal to the Local Government Ombudsman
2. They can apply for a judicial review of the refusal to provide support
3. They can ask for the child to be 'accommodated' (taken into care)
4. They can appeal to the First Tier Tribunal.

The problem with the first option is that it takes months; even years even as the parent must exhaust a council's internal complaints procedure first before going to the Ombudsman.

The problem with the second option is that it is expensive, time consuming and the court cannot look at the underlying merits of the case, only the decision making process of the local authority.

The problem with the third option is that the council may not agree to accommodate the child. I was told twice that my son didn't 'qualify' to be accommodated even though my marriage was breaking down and I was suicidally depressed. Also, why should a parent have to suffer the ignominy of handing over their child to the state, in order to get that child the care it requires?

The problem with the fourth option, is that the parent will only succeed if they can show that the child's special educational needs requires a 'waking curriculum'. Proving this is a complex and technical matter. It is also a highly artificial way to look at the needs of a severely disabled child.

The introduction of EHC plans is fantastic. However, unless the health and social care elements of them can also be enforced through the First Tier Tribunal, (or another independent body) there is a very real possibility that they will not happen.

So, to answer the Committee's questions specifically.

General

1. Is there anything missing from the draft Bill?

A mechanism whereby a decision of a local authority or health service in relation to the health and social care elements of the EHC plans can be challenged in an independent forum.

Specific

1. Whether it would be appropriate to move away from "special educational needs" and use the term "learning difficulties and/or disabilities" instead in the new system?

Most definitely, but this will only be a token change if the education and social care elements of their EHC plans are not enforceable against local authorities and health services.

3. Should the scope of the integrated provision requirement be extended to all children and young people, including those with special educational needs?

Yes, as this would support disabled children without SEN, but again the non - educational parts of EHC plans must be challengeable and enforceable.

January 2013