

Rt Hon David Cameron MP
10 Downing Street
London
SW1A 2AA

9 December 2013

Open Letter (by email and post)

Dear Prime Minister

I am the mother of a severely disabled child. He has cerebral palsy, epilepsy, learning disabilities, challenging behaviour, and is severely autistic. He uses a wheelchair, can't walk or talk, can't use his left hand and is doubly incontinent. I am writing to you to express my concern over the lack of social care provision for children like him.

Many local authorities are failing to provide respite and home carers, and this is causing great suffering. There are parents trying to survive for years, raising their children on little sleep, with no breaks and no help. They are experiencing depression, exhaustion and marital breakdown. They have no hope of affording the ongoing specialist care which is needed. If they can summon the strength to take on their local social care department, they face a lengthy, ineffectual complaints process. What they need is a fast, independent forum, with the power to award the necessary support for their child.

The children and families' bill misses a golden opportunity to achieve this. It introduces joint education, health and care (EHC) plans in place of statements of special educational needs. For the first time parents will have all their disabled child's needs recorded in one place. But they will still only be able to appeal the education content of the plans to an independent tribunal, as is the case now. That happened to my family; we won an appeal over my son's school, but it took us another five years to get the social care he needed. Why can't the bill provide a right of appeal to tribunal, over all the contents of EHC plans?

The government has said that it doesn't support a right of appeal against social care issues. It doesn't want local authorities to be under a statutory duty to provide the care part of individual EHC plans, since they may not have enough money to look after both disabled children and children at risk.

This is the finite resources argument, and goes to the heart of the matter. We define ourselves as a society by the priorities we choose. Surely these priorities include providing humane levels of support to people who from birth will never be able walk or talk, let alone work? This should not have to be at the expense of protecting children at risk of abuse. Pitching those two sets of critical needs against each other is unacceptable.

The National Autistic Society has presented the government with a petition of over 10,000 signatures on the importance of a single point of appeal from all parts of EHC plans. That is a lot of parents, but it is also just the tip of the iceberg. They are telling you that they are not prepared to carry on battling on all sides. They need the EHC plans to make a real difference to the most vulnerable people in our society.

Yours sincerely

JANE RACA
Author Standing up for James