



Amaze and PaCC
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25th February 2013

Dear Caroline

Re. Children & Families Bill and Every Disabled Child Matters Campaign

As you know, Amaze is a small local charity working to provide information, advice and support to families with children with special needs in Brighton and Hove. Our helpline takes over 4,000 calls per year and we have details of over 1,800 children with special needs on our Compass Database. We support the Parent Carers' Council (PaCC) which represents over 200 parent carers. The PaCC provides a 'voice' in how services in the City should be developed and delivered to their children.

Over the last 18 months we have been working closely with colleagues at Brighton and Hove City Council and other partners within the SE7 SEN Pathfinder to try to ensure the new legislation and developed policy and practice would be the best it could be, supporting parents to take part in pilots to test new approaches to personal budgets, outcomes planning and developing the local offer. Being part of the pathfinder locally has taken a considerable amount of time/effort – mostly unresourced on our part – but has also been very inspiring as parent carers and professionals have been working together to come up with improved ways of doing things.

We were therefore disappointed to read the draft legislation as outlined in the Children & Families (C & F) Bill, in particular that the protections would not be extended to all disabled children. Disabled children who do not have special educational needs will not be included in the new system. According to the Department for Education, a quarter of children identified as disabled under the Disability Discrimination Act do not also have an identified special educational need.

We are extremely worried that locally about 500 disabled children who don't have special educational needs will be excluded from the benefits of integrated health and social care services. We are also worried that this will create a 'perverse incentive' for local authorities to provide lower quality information to families with disabled children who don't have special educational needs, by keeping them outside the proposed 'local offer'.

I urge you to review the analysis from Contact a Family, the Every Disabled Child Matters Campaign and IPSEA on the C & F Bill as they provide a clear analysis of where it may fail some of the 24.5% of children and young people with a special educational need in Brighton and Hove.

We are asking you to take action to ensure:

1. That the Bill is amended to **ensure all existing essential protections and entitlements** for children with special educational needs **are maintained**. This is something that Edward Timpson committed to when questioned by the Education Select Committee during their pre-legislative scrutiny. As you will see from IPSEA's analysis, this commitment has not

been successfully reflected in the C & F Bill. Specifically the Government should address the points of concern contained in IPSEA's detailed analysis of the C & F Bill.

2. That the Bill is amended to introduce a single assessment process and a single plan across **education, health and social care with equal duties** to / enforceability by individuals across all three elements. Until this is done, the system only covers education. Without this amendment, only children or young people with special educational needs will be entitled to a new Education, Health and Care plan.

3. Those **children who are disabled but do not have special educational needs will not be covered**. We think the sections of the bill should cover ALL disabled children, not just those with educational needs (clauses 20-21). At this stage, the Government could address this within the Bill by simply adding 'and disabled children' when they say children with special educational needs. They have asked the Education Select Committee to undertake pre-legislative scrutiny before the Bill is put before Parliament.

4. We would like to see **parent carers' right to assessment and support** to be similar to those set out in the draft care and support bill for adult carers of disabled people. We think this is an important part of improving things for children and young people with disabilities and will clarify the current system (clauses 22-24).

5. We need clearer, and **more parent carer involvement in making decisions** at all levels, with professionals making more use of parent carer forums (clause 29). Our City Council actually does this well locally by involving the Parent Carers' Council (PaCC) in many strategic/operational groups.

6. The **local offer** should be more than just a published list of local services. Based on a study of local need, it should be developed with parents to **set out; how these needs will be met, who is responsible for delivering these services** and how the local offer will achieve a better result for children, their families and their rights (clause 30).

We would be grateful if you could ask Edward Timpson MP for his support in making these amendments and to make sure that EVERY disabled child matters. If they are ignored, could you please request an explanation is given on each as transparency is essential to gaining parental confidence in the system.

We would be happy to talk to you in more detail about this, or indeed welcome you again to Amaze or the PaCC to hear more about our services and to hear first-hand why disabled children are some of the most vulnerable people in your constituency so in need of your support.

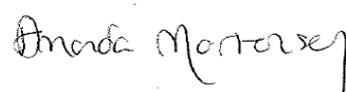
Yours sincerely,



Rachel Travers

Amaze CEO

and



Amanda Mortensen

PaCC Co-Chair