



working with parents of children with special needs

Mike Weatherley
By Email

18th September 2013

Dear Mike,

Re. Care Bill Provisions to Extend to Parent Carers

As you know Amaze works locally supporting families with disabled children in particular their parent carers. We know they need access to good quality information, advice and support in order to get the best outcomes for their child(ren).

We recently surveyed all parent carers in touch with Amaze and I am including the analysis report and vital messages (below) that their feedback showed.

It is clear that parent carers need more support early on, and throughout, their caring journey in order to avoid more costly interventions if families fall into crisis later. A significant proportion of parent carers feel incredible (financially and socially) isolated and face mental health problems.

As such I am writing to you about the **Care Bill** which is progressing through the Lords at the moment. This Bill offers enhanced rights to assessment and support to carers of adults:

- Access to assessments will no longer be restricted to carers providing 'regular and substantial care'
- Carers will no longer have to request an assessment of their need for support but will be offered an assessment by their local authority.
- Adult carers (and young carers) of adults or children and young people will have a right to services as a result of that assessment

I am writing to ask that these enhanced rights and support MUST be extended to parents and carers of children or young people.

Vital statistics from our parent carer survey

- 7,000 children and young people in the City with special needs, 3,400 have a significant disability. Amaze has up to date records of over 1,500 of these CYP on the Compass register
- Over 50% of disabled children are living in (or on the margins of) poverty – locally 23% live in Moulsecoomb & Bevendean and East Brighton
- It costs three times more to bring up a disabled child than one who is not
- 341 parent carers completed our survey, from these:
 - 11% are caring for a disabled child who has been fostered/adopted
 - 18% have additional need/disability of their own
 - 16% are caring for <1 disabled child
 - 70% of respondents are completely or mainly alone in their caring role
 - 22% haven't had a day/evening off from caring in over 6 months

- 71% feel they don't look after themselves enough/neglecting themselves
- 20% feel socially isolated
- Only 33% usually get a good night's sleep
- 58% feel stressed/anxious/depressed some of the time, 18% feel this way all of the time
- 17% are currently on medication prescribed by their doctor
- 15% said they need, but don't receive, counseling
- 60% have had to stop/reduce work as result of caring responsibilities
- YET... Only 15% are receiving any respite/short breaks package
- Of those who do, 82% said any reduction to their package would have a devastating impact on their family
- 40% would be interested in managing a personal budget and direct payments in the next 1-2 years.

Please see the attached report for the fuller details/analysis.

Also, I have written previously this year about the Children and Families Bill but remain very anxious that the draft legislation continues to exclude disabled children if they don't have an identified SEN. There is a real risk that parent carers are going to fall through the gap between the Children and Families Bill and the Care Bill – combined with falling local authority budgets leading to cuts in local services for their children.

Alongside charities Contact a Family and IPSEA, Amaze is concerned that these Bills miss the opportunity to offer vital enhanced protections for children with disabilities and parent carers and I urge you to continue to press the government to address the shortcomings in these Bills.

As before I would be happy to welcome you or the Ministers responsible for these Bills to visit Amaze or the PaCC to hear first-hand why disabled children and their parent carers are some of the most vulnerable people in your constituency and so in need of your support.

Yours sincerely



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