

Further report to Scrutiny Committee on support to families with a child with a disability

Summary and clarification of previous evidence

Contact a Family gave evidence at the Scrutiny Committee meeting on 19 October 2011. In addition to the written evidence previously submitted, Contact a Family informed the Committee that changes were proposed to their service which would have a significant impact support to families. A draft service specification from council commissioners included a move towards supporting those with a child under 5 only, allowing referrals into the service from social care only and refusing support to those who did not want to share their details with statutory services.

Contact a Family gave evidence to the Committee that these changes would not be welcome to families and that they were not in keeping with the council's stated aims and objectives, most notably in the Children and Young People's Plan.

Attention had been drawn to work done previously by Contact a Family and the Parent Carer Council to identify children and young people with a disability and/or additional need and their parent carers.

To summarise here:

We estimate that there are closer to 2500 children and young people with a disability and/or additional need in the borough (not 5000 as often quoted). Of these,

- Approximately 1500 children have a statement of special educational need
- Approximately 450 children are on the disability register
- Approximately 180 children receive a service through social care
- There are approximately 590 families registered with Contact a Family in the borough
- There are approximately 240 families registered with the PCC

Of the families registered with Contact a Family:

- About half have a child on the autistic spectrum
- About half consider their ethnicity to be Black British, Black African, Black Other
- About one third have a child under 5, another third have a child aged 6 – 11 and the remainder have a child aged 12 – 19

The Committee heard, in response to a question from a member, that families often self-refer. This would be most sensible for those who are not in receipt of a statutory service. The Committee was also informed that those who are not in receipt of a statutory service are often reluctant to become known to the state for a number of reasons. It is also well documented that the 'need to reach' groups in our community are much more comfortable making a connection with a community or voluntary group and

can then be signposted appropriately and with support if appropriate. The Children's Services Assessment unit has been keen to reduce the number of unnecessary referrals it receives and so it seems odd to require families to have to go down this route when it is clear that they will not be eligible for a statutory service, in order to access a service from agencies such as Contact a Family.

Referral by the Committee

A family of Mum, Dad and child also gave evidence to the Committee meeting on 19 October. This was a Vietnamese family with an eight year old daughter with multiple health issues and learning disabilities. Dad described his efforts to get a diagnosis and appropriate support for his daughter. He spoke about the fact that he felt she would not be able to achieve in secondary school as she is unable to speak or read. Having heard the evidence which was actually a request for help, the Chair of the Committee informally referred the family to Contact a Family.

Update

Contact a Family accepted the referral of this family who can be seen to be in need of support. Through an interpreter, we met with the family to find out what they would like support with. At the family's own pace, we will support them to manage multiple appointments with seven different statutory services, to apply for Disability Living Allowance and Carer's Allowance to maximise their income and in reapplying for a statement of educational need which had previously been refused. Despite their connection with seven statutory services and with the Special Educational Needs Co-ordinator in the school, no one had referred this family for this 'softer' support. Nor, as far as we can ascertain, has anyone completed a Common Assessment (CAF) allowing services to share information and the family to only need to tell their story once. This would obviously be of particular benefit to this family as Dad has limited English and Mum apparently none. Contact a Family will ensure that the CAF is initiated. We will also support Dad to ask for a six month exemption from signing on whilst he attends multiple appointments with his daughter as he is her main carer because of the language difficulties.

Contact a Family has identified this family as in need of support. There is no other family in this country and no connection with the Vietnamese community locally. We will offer to facilitate links with another family and we will offer opportunities to make a connection with the local community generally. From what we have been told, it is likely that the child will be assessed as having significant educational need and be eligible for a place in a special secondary school. If the child is unable to live independently as an adult, her future must be planned for by the state and her family, with obvious cost implications.

Lessons learned

This family was not known to Contact a Family despite many opportunities for statutory agencies to have given information about us. We believe there are many more families like this in the borough as evidenced by the numbers quoted above.

This is a family which should not be forgotten. They are in need. Support can be offered as the family requires and when they are ready for it. In this way, the child's needs can be met within a stable family unit which is not only best for the child and her family but will also be the cheaper option.

Please note that:

- The child is over 5 years old
- The family can be said to have self referred through the Committee

In conclusion

It is Contact a Family's practice to update referees with information about the families referred to us. We would like to submit this update as a response to your referral and also to further inform the Committee about the needs of parents of children with a disability for timely, relevant and accurate information and support. We believe this should not be limited to those with a child under 5, or those who are eligible for a statutory service, or that referrals should only be possible from a statutory service.

This family is an excellent example of how hard it is to manage caring for a child with additional needs and it is striking that the family would present itself to the Scrutiny Committee for help.

Contact a Family is pleased that it has been able to support this family and will continue to do so. We would like to ask the Scrutiny Committee to consider the immediate and long term impact of withdrawing support to families such as this. We recognize the need to make savings and that this will affect even the most needy, however, we believe that supporting families to cope and to develop the skills and knowledge which will enable them to become self-reliant and build resilience including in the child or young person, will be cost effective. Abandoning families will result in some failing and the cost of then caring for those children outweighs the cost of a service such as ours.

Appendix

The Social Policy Research Unit at York University published a report which is an easy introduction to the range of outcomes that carers would like to achieve from social care services.

These include:

- A life/identity of their own, over and above their role as parents/carers
- Having control over their life
- Spending 'quality' time with the person receiving support, over and above care-giving activities
- Maintaining physical and emotional well-being
- Having adequate resources
- Feeling skilled and informed
- Maintaining family life
- Service process outcomes relating to positive relationships with professionals and working in partnership with services

The full report can be found at: <http://www.york.ac.uk/inst/spru/pubs/pdf/Outcomes.pdf>

Outcomes for parents with disabled children and carers of disabled or older adults: Similarities, differences and the implications for assessment practice, Arksey, H. et al, SPRU, 2007