

Evidence for Southwark Council's Education and Children's
Services Scrutiny Committee
Support for parents and carers of disabled children and
children with special educational needs
Contact a Family, October 2011

Contact a Family is the only UK-wide charity providing advice, information and support to the parents of all disabled children (aged 0 – 19). We have been working in Southwark for 15 years and have strong connections with local families, statutory services, other local organizations and agencies supporting families with a disabled child, and the wider community.

Over these 15 years, we have provided a service to thousands of individual families. This wealth of local experience, together with the information we gather from the hundreds of thousands of families who engage with Contact a Family across the UK, gives us a unique insight into the life experience of families caring for a child with a disability.

Details of how to find out more about what we offer and what families tell us about the ways caring for a child with a disability impacts on their lives are at the end of this paper.

On behalf of all families caring for a child with a disability we would like to submit this evidence to the committee.

1. Knowing who we mean

Contact a Family was commissioned by the Southwark Aiming High for Disabled Children Project Board to attempt to identify all families caring for a child with a disability or additional need. Historically, there has been estimation that there are 5000 children with a disability or additional need in the borough. The work that we did suggests that a more realistic figure would be 2500 – that is: children who are known to a service, and/or have a statement of educational need.

Contact a Family found that, although it is possible to know how many children have a statement, and how many are on the Disability Register, these two listings are not compatible. There is also no way of gathering information about children who have specific health needs, nor of merging this data with education or social care needs records.

At the time of our analysis, approximately 1500 children were in receipt of a statement of educational need, about 450 were noted on the Disability Register and an even smaller number (around 180) received a service from the Children with Disabilities and Complex Needs team.

In order to plan services effectively, there is a need to identify who they are for and to join up the intelligence that already exists.

2. What is support?

The support that Contact a Family offers is tailored to the needs identified by each family. It will vary from family to family and from time to time. We aim to build a relationship with families and to develop their skills, knowledge and resilience over time. We are a dip-in-and-out service with families using our support at different levels. We are also an holistic service, so that we offer a full service to everyone if they want it. And we are an inclusive service – for any family living in Southwark with a child with any disability or additional need up to the age of 19 (Note: this may be extended to 25 as a result of recommendations from the Green Paper: *Support and aspiration: A new approach to special educational needs and disability*).

The support we offer is intended to enable families to live the lives they choose to live.

We know that, as a result of caring for a child with a disability, many families experience:

- financial issues
- relationship issues
- isolation
- lack of confidence and self esteem
- health issues

We know that positive outcomes for the child are more likely in a well-functioning family. We also know that families who are supported to seek their own solutions and to become resilient are less likely to need support in the future. We can assume that children in these families are also more likely to be resilient and reach their full potential as adults, thus requiring less support in the future.

Preventative services which enable families to have a quality of life must be preserved in order to avoid more expensive support becoming necessary.

3. Who do families engage with?

Many families prefer to engage with non statutory services. We know that if a family has a bad experience with one service they will not engage easily with any other. By being independent, Contact a Family can often build a relationship with a family to gain their trust so that other agencies can be introduced.

We also know that families benefit from and value peer support. Much of what we do has an added element of linking families for mutual support. This works well as, although we continually meet families new to us, we also continue to have contact with families we have known over time because of our dip-in-and-out service and because we will support a family until the child is at least 19.

It is best practice to use non statutory services to support 'need to reach' families. Families should have the opportunity to offer each other support.

4. What do families tell us they want?

Families want to be included, and for their child to be included.

Our Inclusion Programme offers a range of family inclusive activities to introduce families to new experiences. Many of these are within the borough and most are universal. Our aim is to support families to enjoy activities which can be repeated independently.

Examples are using local parks and libraries, taster sessions and courses at local swimming pools, and exploring local museums. We also offer some opportunities which are more expensive and/or further away which families would find very difficult to access. Examples are trips to theme parks, the Pantomime, and the seaside.

Families may choose not to use services if they do not feel welcome. Contact a Family offers information and training to other settings and agencies to support staff to be inclusive in their practice.

Finance is often restricted for our families and this can be a barrier to accessing or providing what other families take for granted, such as replacing worn out appliances, new school uniforms, holidays and treats. Contact a Family supports families to maximize their income through accessing benefits, small grants and special offers.

Families would like to have regular breaks from their normal routine. They want good quality and meaningful experiences for their child and they want a chance to recharge their own batteries. And they want choice.

Families tell us it is hard to get good quality information. We offer one to one information and advice and we offer a quarterly newsletter plus a monthly email update. We also use texts to send reminders or small items of news or offers.

Contact a Family also has a website, Helpline, publications and a presence on Twitter, Facebook etc which all families can access.

Families want what they are entitled to. They want good quality services, to be considered as partners, and to be respected as an expert on their child and his/her needs.

What the future should look like

Contact a Family, on behalf of all families with a child with a disability in Southwark, asks that the committee consider these recommendations:

- develop systems to promote the identification of families so they can be supported and which bring systems together (related to Aiming High for Disabled Children, the Green Paper *Support and aspiration: A new approach to special educational needs and disability*, the Child Poverty Strategy and more)
- recognize the value of interventions which enable families to use their own resources, develop resilience and have a quality of life
- understand the benefit and power of peer support
- treat parents and carers with respect and truly seek and value their contributions (and those of their children) to planning and evaluating services
- support community and voluntary sector agencies and groups in offering a wide range of opportunities to families. Collaborate with and value the sector. When commissioning, offer contracts which are long enough to allow security and development.

Contact a Family wants to be able to continue to offer a quality service to all families with a disabled child in the borough. We want to see a holistic response to the needs of families across all parts of Children's Services, which will mean working together effectively and efficiently, and actively seeking the views of parents and carers and children and young people in a meaningful way.

I would like the opportunity to present this paper in person on 19 October and to answer any questions the committee might have. Thank you.

More information

For general information about Contact a Family and the families who use our services, see our website: www.cafamily.org.uk

Findings from some recent Contact a Family reports:

Counting the Costs 2010

Key findings from a survey of over 1,100 parents include:

- Almost a quarter are going without heating (23%). Up from 16% in 2008.
- One in seven (14%) are going without food. Down from 16% in 2008.
- More than half have borrowed money from family or friends (51%) to keep financially afloat or pay for essentials, such as food and heating. (42% in 2008)
- More than 40% have applied for a charity grant. Up from 25% in 2008.
- Almost three quarters (73%) are going without days out and leisure time with the family. Up from 55% in 2008.

Our family, our future

Features the stories of 30 families from across the UK whose children are affected by a range of disabilities and conditions and gives parent carers a voice to talk about their achievements, acknowledge the challenges, reflect on their aspirations and fears for the future and above all to celebrate their family life

What makes my family stronger

Key findings of the report are:

- Almost 70% of families with disabled children said that understanding and acceptance of disability from their community or society is poor or unsatisfactory.
- Over 60% of families said they don't feel listened to by professionals.
- Vital support services such as short breaks, a key worker and childcare are unavailable to almost half of families.
- Over 60% of families said they don't feel valued by society in their role as carers.
- Half of families with disabled children said the opportunity to enjoy play and leisure together is poor or unsatisfactory.

Information about Contact a Family Southwark

Our current newsletter and Annual Review are attached. These can also be accessed on our website: www.cafamily.org.uk/inyourarea/london/southwark/index.html

A full analysis of the local survey conducted in autumn 2010 can be found in our Winter 2010 newsletter (see the website). You may also find the parents' peer support contributions gathered at our Annual Conference in May 2011 interesting. These are reported in the Summer 2011 edition of the newsletter, also available on the website.

In the Annual Review, you will find an analysis of the families who are actively engaged with us, and reports on our activities over the last year. Our newsletter gives a flavour of the information we share with families and the professionals and agencies who also support them.

To contact me for any further information, please email: Naomi.gilbert@cafamily.org.uk