

APPENDIX A

# **Support for Parents and Carers of Disabled Children and Young People**

Report of the Education and Children's  
Services Scrutiny Sub-Committee

May 2012



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	<a href="http://moderngov.southwark.gov.uk/ieListDocuments.aspx?CId=302&amp;MId=4244&amp;Ver=4">http://moderngov.southwark.gov.uk/ieListDocuments.aspx?CId=302&amp;MId=4244&amp;Ver=4</a>	

# **1 Introduction and background**

- 1.1 The review's focus was a result of the sub-committee's interest in evidence which indicated that supporting parents had a major positive impact on their children's wellbeing and educational attainment. In the administrative year 2009/10 the previous sub-committee had produced a report on the importance of parental involvement in children's education. This concluded that there should be an emphasis on enabling parents to have the skills, knowledge and confidence to help their children as evidence indicated that this would lead to a big impact on their children's ability to perform well educationally.
- 1.2 The sub-committee produced a report in 2010/11 focusing on support for parents during school admissions. Alongside this review the sub-committee is also looking at a volunteer programme developed by CSV which has demonstrated success in supporting parents in challenging situations, including addressing child protection issues, by using mentors to support parents. This will be the subject of a separate report.
- 1.3 This report is focused on the best way the council can support parents and carers, so that they in turn can have a better quality of life and be in the best position possible to parent their disabled children, look after their wider family and participate to community life. Given the focus of the review the sub-committee prioritised evidence from parents and carers, organisations supporting families and evidence from council officers.

# **2 Methodology**

## **Call for Evidence**

- 2.1 The sub-committee put a call out for evidence from parents and carers and voluntary organisations that work with parents and carers of disabled children asking for comment on the following issues in particular:
  - Experiences as a service user
  - Practical and financial resources available
  - How skilled and informed they felt
  - Parenting
  - Caring
  - Maintaining family life
  - Employment and childcare
  - Physical and emotional well-being

## **Organisations that support families of disabled children and young people**

- 2.2 The sub-committee received evidence from two organisations that work in Southwark to support families; Contact a Family and Southwark Parent Carers Council (SPPC).

Contact a Family

- 2.3 Contact a Family is a national charity with a branch in Southwark that exists to support the families of disabled children whatever their condition or disability. They work with families; often at a time of crisis.

Southwark Parent Carers Council (SPCC)

- 2.4 The Parent Carer Council is peer led and their objectives are to positively change and enhance the lives of disabled children, young people and their families by working collaboratively with partners in Health, Education and Social Care, and to ensure parent carers' participation.

## **Parents and carers**

- 2.5 The review received evidence from six families through a combination of written submissions and verbal evidence taken at meetings.

## **Council officers**

- 2.6 The sub-committee received several reports from Southwark Council children's services officers including:
- Comprehensive consultation reports on Short Breaks which took detailed evidence from a range of partners;
  - Officer response to evidence received from family support organisations and parents

## **3 Context**

### **Numbers of disabled children and young people in Southwark**

- 3.1 The sub-committee received evidence of work done previously by Contact a Family and the SPCC to identify the number of children and young people with a disability and/or additional need and their parent carers.

3.2 Borough wide they estimate that there are approximately 2500 children and young people with a disability and/or additional need in the borough. 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

### **Families in touch with Contact a Family or Southwark Parent Carer Council and demographic information**

3.3 Contact a Family and Southwark Parent Carer Council also submitted data on the numbers of families they are engaged with:

- There are approximately 590 families registered with Contact a Family in the borough
- There are approximately 240 families registered with SPCC

3.3 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

### **Recession, austerity and budget reductions**

3.4 Local Government funding from central government has been reduced, and this has led to budget reductions across all sectors. The draft budget report to the overview and scrutiny committee of 13 December 2011 set out that “during 2011/12 £5.763m of savings have been achieved. When the significant reductions in government grants for children’s services are taken into account around £12m has been taken out of the budget. For 2012/13 the Children’s Services budget is proposed to be £86.4m. The total savings and commitments for the department remain unchanged from those agreed at council assembly in February 2011.”

3.5 Contact a Family reported that they have experienced financial cuts of 25%, and that they are waiting to hear what will happen after April 2012. SPCC recently lost their worker because of budget reductions. The evidence received from these organisations considered both the effects of organisational budget reductions and how they were seeking to adapt, alongside recommendations on the best way to deliver council services and support families given shrinking funds.

## **The impact of the recession and austerity on families**

- 3.6 National Contact a Family have produced a report called Counting the Costs 2010.
- 3.7 Key findings from a survey of over 1,100 families with disabled children found:
- 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.
  - Almost 90 % said that financial worries had a detrimental impact on their family life.

The full report can be found here:  
[www.cafamily.org.uk/pdfs/CountingtheCosts2010.pdf](http://www.cafamily.org.uk/pdfs/CountingtheCosts2010.pdf)

## **National research on the needs of families and the outcomes carers would like from social care provision**

- 3.8 Contact a Family have produced a national report titled “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.

The full report can be found here: [www.cafamily.org.uk/pdfs/wmmfs.pdf](http://www.cafamily.org.uk/pdfs/wmmfs.pdf)

- 3.9 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>

## **4 Findings and recommendations**

### **Fairer access to universal services**

- 4.1 In their evidence to the sub-committee SPCC reported that families understand that specialised services are under pressure so their recommendation was to improve universal services. They pointed out that only a small proportion, around 180 out of 2500 children with disabilities, receive a specialised service from the council so accessible universal services are therefore crucial to enable the majority of families to be included in community life. They reported that too often families are met with an attitude that is not helpful. Social isolation is a big issue for many families. They reported that families want to be included, and for their child to be included.
- 4.2 Contact a Family also highlighted this issue and they included evidence on their inclusion programme which offers a range of family inclusive activities to introduce families to new experiences. Many of these are within the borough and most are universal. Contact a Family's aim is to support families to enjoy activities which can be repeated independently. Examples gave included using local parks and libraries, taster sessions and courses at local swimming pools, and exploring local museums. Contact a Family also offers information and training to other settings and agencies to support staff to be inclusive in their practice.
- 4.3 Council officers acknowledged that families want fairer access to universal services and detailed work they are doing to meet some of that need through the Short Breaks programme. Evidence taken from the Short Break consultation indicated that universal settings in particular need to be more inclusive with the up skilling of frontline staff to better support

disabled children and young people. The evidence identified there was a particular need to ensure hearing and visually impaired children and young people are included in service provision and access to activities, as these groups are often isolated. More sports clubs have been requested by families and children, but it was noted that the disability sports programme is no longer available. There was a particular interest in swimming including disability swim sessions. Parents have also requested activities for girls supervised by female staff. Different kinds of activities to meet different needs (i.e. swimming classes delivered at different levels of ability) were also proposed.

### **Recommendation 1**

Improve the accessibility of universal services by developing and promoting disability awareness training for staff in Southwark's sports and leisure facilities; such as libraries, museums, swimming pools and parks. Ensure this includes training on meeting the needs of hearing and visually impaired children and children with autism.

### **Recommendation 2**

Encourage sports and leisure facilities to increase the accessibility of mainstream services and provide special sessions suitable for disabled children and young people.

### **Short Breaks**

- 4.4 Evidence received from family support organisations and parents indicated that 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. The council has done an extensive consultation on this and Appendix 1 is attached: Shaping Future Service Delivery – stakeholder proposals. The recent Short Breaks services statement highlights the wide range of universal support already available, and is helping to promote the local offer to families and to identify gaps which services are working to fill.

### **Recommendation 3**

Take forward the Short Break work plan.



## **The type of cuts being made, with a focus on under 5's rather than teenagers**

- 4.5 Contact a Family reported that they work with families; often at a time of crisis. They reported that this is often before a diagnosis has been received as this is frequently a time of particular uncertainty and stress for parents. However, the service reported that families often also need particular support around times of transition, for example moving into school or college. Contact a Family reported that because of budget reductions officers were emphasising service provision for families of the under 5's, however their organisational experience is that there are just as many problems when a child enters puberty and becomes physically and sexually mature. Concern was raised that services often drop off during this challenging time. In Contact a Family's organisational view limiting services to under 5's is not a good idea.

### **Recommendation 4**

Evaluate the services in place to support parents and carers of disabled children over the age of 5; particularly recognising the evidence received of the additional stresses that families experience when young people reach adolescence and in times of transition .

### **Autistic children and young people**

- 4.6 The evidence from SPCC highlighted what they termed as the "massive prevalence of autism". Many of the parents giving evidence had a child or children on the autistic spectrum. The Short Breaks scheme indicated that there is a need for increased service provision for children and young people on the Autistic Spectrum. This report noted that children on the Autistic Spectrum often slip through the net as they may not qualify for mainstream and/or specialist services.
- 4.7 Children and young people with dual diagnosis of ADHD and Autistic Spectrum Disorder are particularly vulnerable as they require one to one support to access services which required funding. Children and young people on the Autistic Spectrum with challenging behaviour are often hard to place, especially for overnight stays and respite care. The report recommended more suitable provision for these children, including enhanced training for carers. The evidence indicated that more provision is needed for children under 8 diagnosed with Autism, in particular.

## **Recommendation 5**

Where resources allow provide additional services and support for children and young people with autism; particularly those with challenging behaviour or ADHD and for children under 8

### **Data registration**

- 4.8 Parents and family support organisations said that they thought it was really important that the disability register was kept updated, even if families do not receive formal services. Parents and family support organisations emphasised that early help is much better and data registers could help with this. Better data recording would also give more accurate information as disabled children and young people could be on various data records because of a medical condition, having a statement of special educational need, being on Southwark's disability register, being in receipt of social care through a eligibility assessment etc. The evidence indicated that these data sets do not always relate to each other in clear and functional ways.

## **Recommendation 6**

Keep Southwark's Council Disability Register updated and set up a dialogue with partners on protocols to share data in ways that are transparent, lawful and that will assist families and partner organisations supporting families.

### **How well medical and social care is integrated and communication with families**

- 4.9 Parents complained that they have to tell services the same thing again and again, which is frustrating and dehumanising. They requested that the sub-committee think about how the council can do data sharing better and more sensitively. A parent spoke about her experience; explaining that her child was referred to social workers by a medical professional, but the social workers were not particularly interested in the medical diagnosis and this meant that, despite the referral, she did not receive the assessment she needed. Parents spoke about the tension between the medical and social work teams, and the respective conceptual models that they used. Parents said that professionals from Health and Social Care teams do not have access to their respective records, even if they are co-located in places such as Sunshine House.

## **Recommendation 7**

Explore how the council can do data sharing better and more sensitively. Particularly look at the request that social workers take into account information available from health practitioners when making assessments of children and families.

### **Assessment for services**

- 4.9 Parents spoke of the delays they had experienced in getting an assessment from the disabilities/complex needs team (social care) and the Special Educational Needs (SEN) section. Parents found this difficult to understand, particularly if an assessment had been recommended by the health service. A parent complained about delays from the SEN team when it comes to issuing a statement of special need. Her child had eventually received a statement; however she was dissatisfied that the process had taken too long and commented that her son has since been permanently excluded from secondary school. She said she felt sure that if the correct support mechanisms had been in place this would not have been the case. A number of parents expressed frustration that social care assessments are issued without full reference to the medical diagnosis. Parents thought this showed a lack of consistency and highlighted the disjuncture between social and health services.
- 4.10 Parents said that their perception was that the policy seems to be to say no the first time, then parents have to go back and make the case, then eventually you get what you need. Parents commented that this advantaged more articulate and pushy parents. They said that services should be given to those who most need them, not those who shout the loudest. A parent contrasted their perception of how Health and Social Care respectively assess need in this way: the NHS admits you have a need and puts you on a waiting list; the council denies that you have a need at all. The waiting list approach was considered better in helping a family coming to terms with a child's diagnosis and likely prognosis.
- 4.11 Parents reported that the delays in receiving a service added to stress, and that a small amount of service, or early intervention, would be more cost effective as it prevented families escalating up the ladder of crisis. Parents stated that often a relatively small amount of support can enable families to support themselves and continue to function. Evidence received emphasised that assessments of children's needs for both care and education should be carried out early, when requested by another professional or by a parent, to enable the council to fulfil its commissioning responsibilities and plan ahead for future need.

- 4.12 A number of parents cited the work of Contact a Family in supporting them in accessing services and helping to negotiate the system. Parents from Contact a Family and SPCC explained that many parents do not understand what services are available or the laws surrounding access. They therefore need support in accessing them. SPCC stated that parents and carers need clear accessible information and that this cannot just be on the website. SPCC went on to explain that there needs to be more transparency, particularly on how decisions are made so that parents can be clear on the process.
- 4.13 Parents also said that once a 'statement of special educational need' has been received it is vital that this is adhered to. A parent commented that a child's statement is a vital tool for parents and teachers, as it is a legal document stating who our child is, what she needs and how those needs will be met.

#### **Recommendation 8**

Guarantee that all children will receive an assessment by social and educational services if referred by a professional. Undertake these as early as possible in recognition of the importance of timely support.

#### **Recommendation 9**

Provide clear advice and support to parents and carers on their rights, through publications and support organisations

#### **Recommendation 10**

Ensure that statements of special educational need are adhered to

#### **Common Assessment Framework (CAF) and 'single point of access'**

- 4.14 The Contact a Family manager commented on the importance of finding families before they go into crisis to prevent further difficulties. The manager reported that officers are saying that unless there is a Common Assessment Framework in place Contact a Family are being asked not to provide services. They reported that this creates difficulties as some people have had a bad experience of statutory services. Contact a Family emphasised that it is very important that families can self refer so the organisation can meet the needs of these families.
- 4.15 Officers stated that they believe families should be able to access services in the way that best suits them. They reported that the council is working with partners and voluntary sector partners, to develop a 'single point of

access', which will make it easier and quicker for families to receive the support they need. Officers reported that the Common Assessment Framework (CAF) is an assessment tool designed to support the early identification of children with additional needs and reduce the number of times that parents have to tell their story. Officers envisage that as the tool is increasingly used by agencies it will ensure that detailed assessments are completed more quickly. Officers are developing systems to promote the identification of families so they can be supported and which bring systems together (this is 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).

### **Recommendation 11**

Ensure that the Common Assessment Framework (CAF) enables organisations to support families of disabled children, that there are no unnecessary barriers and that the CAF acts as a collaborative system for statutory and voluntary services to identify and support families in need.

### **Family life and employment**

- 4.16 In the evidence received families pointed out they do not exist in isolation from the rest of the world. Their evidence spoke of the difficulties in sustaining paid employment and the impact on siblings of having a disabled child with limited support in difficult circumstances. They requested that in assessments and consultations the council takes into account parents' responsibilities for other children or work commitments when taking decisions about the services and support these families should receive.

### **Recommendation 12**

Ensure assessments and consultations take into account parents' and carers' responsibilities for other children or work commitments, particularly when taking decisions about the services and support these families should receive.

### **Recommendation 13**

Promote provision for parents of disabled children to find meaningful employment, whilst also fulfilling their caring responsibilities. Parents recommended at pilot developed by the London Borough of Wandsworth (see appendix 2)

## **Information**

- 4.17 Contact a Family reported that families tell them it is hard to get good quality information. They reported that they offer one to one information and advice. They also produce a quarterly newsletter plus a monthly email update and use a variety of social media to keep people updated. SPCC also emphasised the need for good quality information. The Short Breaks consultation recommended regular updates of the Southwark Council website and Family Information Service with a peer review function, leaflets and brochures for distribution through community locations; workshops on issues of relevance (Direct Payments/ Personalised Budgets, Taxi Card, funding for holidays e.t.c) and an annual conference.

### **Recommendation 14**

Provide families with information on statutory, community and generic services available through events, publications and support organisations.

## **Schools**

- 4.18 As noted above parents want an early assessment for a Statement of Special Educational Needs. A parent raised concerns that families cannot highlight an Academy school for their children, if a statement is received. Parents expressed frustration with their relationships with schools; one parent indicated this had broken down. Other parents emphasised the importance of communication and the difficulties children have had at mainstream school. One parent reported that his child would be distressed because the support worker was not available, but the school had not informed him. The parent went on to say that he has even offered to train staff at the school but this has not been acted upon.

### **Recommendation 15**

Work with all schools to promote better relationships and communication between home and school for families of disabled children and young people

## **Consultation**

- 4.19 Evidence on consultations emphasised treating parents and carers with respect and truly seeking and valuing their contributions (and those of their children) when planning and evaluating services. A parent raised concerns

about consulting on services that the council is legally required to provide. The Short Breaks consultation was given as an example of good practice.

### **Recommendation 16**

Improve consultation and engagement by:

- Ensuring that results of consultations are shared; wherever possible explain why some requests cannot be honoured.
- Offering various methods to collect feedback (i.e. face to face consultation, questionnaire, electronic survey, telephone survey)
- Providing opportunities for parents to participate in the strategic planning of services wherever possible.
- Using robust methods to engage children and young people and include their views .

### **Parents and carers as resource**

- 4.20 SPPC explained that parents and carers want to work in partnership with professionals; they reported that parents are a resource and feel underused. SPPC called on the council to understand the benefit and power of peer support. They requested the council recognise the value of interventions which enable families to use their own resources, develop resilience and have a quality of life. This was seen as the best way of delivering services in a time of shrinking resources.

### **Recommendation 17**

Value parents as a resource and the power of peer support; particularly in times of scarce financial resources

### **Community and voluntary sector**

- 4.21 Evidence called on the council to support community and voluntary sector agencies and groups in offering a wide range of opportunities to families. They wanted the council to collaborate with and value the sector. When commissioning, community organisations requested the council offer contracts which are long enough to allow security and development. Family support organisations emphasised developing systems to promote the identification of families so they can be supported and which bring systems together.

### **Recommendation 18**

Commission contracts for as long as reasonably possible

## **5 Summary of recommendations**

### **Recommendation 1**

Improve the accessibility of universal services by developing and promoting disability awareness training for staff in Southwark's sports and leisure facilities; such as libraries, museums, swimming pools and parks. Ensure this includes training on meeting the needs of hearing and visually impaired children and children with autism.

### **Recommendation 2**

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### **Recommendation 3**

Take forward the Short Break work plan.

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### **Recommendation 6**

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**Recommendation 10**

Ensure that statements of special educational need are adhered to.

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