Support for Parents and Carers of Disabled Children and Young People

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

May 2012

Southwark Council

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

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

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 it 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

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

Recommendation 3

Take forward the Short Break work plan.

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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

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

Recommendation 6

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

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

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.

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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.

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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.

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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.

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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)

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

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Appendix 1

Short Breaks report

Shaping Future Service Delivery – stakeholder proposals

The following work plan has been collated based on consultation feedback and are suggestions and recommendations made by service users and providers including families.

WORK AREAS	DISCUSSION POINTS
Access to Services	
Eligibility Criteria	• Clearer explanations of eligibility criteria and referral pathways into services (pre and post assessment). • Review of joint working agreement/protocol between Children with Disabilities Team and Referral and Assessment Team to ensure families are signposted and referred to appropriate services.
Emergency support services for parents/carers.	• In the event that a parent carer has an emergency (i.e. hospital appointment, surgery, child in the hospital) where can they go to get help? • Many parents felt that in the first instance they would rely on their network of family and friends. As many CYP are not known to Social Care parents wouldn't feel comfortable contacting them in an emergency. In the event that a parent/carer was without support, where would they receive help in an emergency situation?

More inclusive/integrated activities	• Universal settings in particular need to be more inclusive with up skilled frontline staff to better support disabled children and young people. • Ensure Hearing and visually impaired CYP are included in service provision and access to activities, as these groups are often isolated. • More sports clubs requested (provision of disability sports program is no longer available); there is 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) • Consider short breaks to provide different activities for different ability levels; CYP should have a choice of activities during short breaks programs wherever possible – mix of ages and CYP will support socialization skills and break down disability barriers. • More activities needed that offer support to all CYP within Southwark with an additional need – as the majority are not known to Social Services, they should still be able to access services. • Review of referral routes to ensure that CYP not known to Social Services can be referred by other professionals or self-referred by parents. • For families who don't receive services and/or funding from Social Services, how can they be supported to access activities for their children? It is viewed that better access to services in the long run will help prevent CYP and families from escalating up the crisis ladder and are therefore more cost effective.

Publicity	• Southwark Council website including online regularly updated directory of services, but enhanced promotion of available services is needed included access criteria and cost to parent carers. • Family Information Service needs more regularly updated information from service providers. Consider a way to demarcate services in the online directory that families with disabled children have used and reviewed. • Leaflets, Brochures for distribution – accessible at Sunshine House, Libraries, etc. • Parent Conference for agencies to have information booths to provide information about services. • Offer parent carers including foster carers a series of workshops to explain more about: Short Break provision and what is available, Direct Payments/Personalized Budgets, Taxi Card and other issues of interest (i.e. funding for holidays).
Transportation Strategy	• Accessing short breaks is often difficult due to travel and transport arrangements. Some CYP will miss out on services, as it is too difficult for parent carers to bring them to/from activities. Ensure equal distribution of activities in the north and the south of the borough wherever possible. • How can CYP travel between school and local clubs/community activities? • Mobility allowance and Disability Living allowance can be used for transport to/from activities – may need to refresh this information with parents. • Some services have their own transport as Southwark has contributed to the purchasing of vehicles; review of contractual agreements to ensure that drop off and pick up for CYP is included.

	• Use of transport for out of borough provision needs to be included in the strategy, as currently there appears to be some difficulty with this (i.e. crossing into Lambeth). Commissioning of services and placements should align with/be supported by transportation provision. • School transport is only used during term time, and before and after school – consider using these buses during the day, on weekends and during the school holidays to maximize transport provision. • Transport for vulnerable young people post 16 who cannot travel independently would be useful, especially for working parent carers and/or those with other children to transport to school. • Review of the assessment process for school transport to include parent carer work/shift commitments, other children in the household and logistics of travel for drop off/pick up. • School transport currently is operating without designated/routine pick up times which can distress the children; parents are often having to take children to school so they arrive on time which adds extra pressure and stress (A new system is in place, still working through the logistics but is causing stress to some families). • There are less buses being used for school transport so timing is less flexible – this creates difficulty for parents with other children (i.e. bus scheduled for pick up at 8:30, parent needs to leave by 8:20 to bring other children to school). • Transportation is especially important, as parent carers feel very protective of their children being out on the streets of Southwark; they need to feel that their children are in safe environments and arriving/departing a provision safely will

	help to foster this trust. - Consider use of taxi card for group transport to share costs? - Consider Dial-A-Ride minibus for group transport to improve access to services.
Commissioning	
Cost Savings and good value for money	- Incorporate short breaks programs into universal services/core offer where possible. - Robust evaluation of services being provided and whether they are meeting the needs of service users. Service users may need tailor made/specialized care packages and some services could be more flexible with their care offer. - Utilizing in-house staff, partner agencies and parent carers to provide staff training and workshops around disability and safeguarding. - Sessional staff are only paid for hours worked; if a CYP does not attend an activity is Social Services still required to pay? Are parent carers still required to contribute? - Review of sites for short breaks in terms of value for money and facilities – are they meeting the needs of CYP and families? (I.e. Bacon’s College offer competitive rates, however they don’t have sufficient equipment for the Special Care Group during Playscheme; it is also not centrally located which adds transportation challenges). Can parallel activities be offered for other children at the same site?
Early Years Provision	- Commission additional Early Years placements, especially for children under 3. Currently there is a limited portage service however this group of children needs more activities with opportunities for social interaction. - Some work to be undertaken with private nurseries, which often refuse to accept children with additional needs or who

	shortly after starting claim that they cannot manage their needs. At least one private nursery has claimed that only toilet-trained children are able to attend their setting.
Increased service provision for CYP on the Autistic Spectrum	• CYP on the Autistic Spectrum often slip through the net as they may not qualify for mainstream and/or specialist services; CYP with dual diagnosis of ADHD and Autistic Spectrum Disorder are particularly vulnerable as they require 1 to 1 support to access services which required funding; CYP on the Autistic Spectrum with challenging behaviour are often hard to place especially for overnight stays and respite care. Investigate more suitable provision for these CYP including enhanced training for carers. • More provision needed for children under 8 diagnosed with Autism. • Further investigation around services provided by Resources for Autism and IBA.
Consultation	
Regular on going consultation with CYP, parents/carers/providers (i.e. 2-3 times per year)	I. Ensure that results of consultations are shared; wherever possible explain why some requests cannot be honoured. II. Offer various methods to collect feedback (i.e. face to face consultation, questionnaire, electronic survey, telephone survey) III. Parents to participate in the strategic planning of services wherever possible. IV. Robust methods to engage CYP and include their views and provide opportunities to introduce them to new and different activities (i.e. canoeing, sailing)

Resources	
Care package allocation	• Review of current ‘panel’ process; consider a wider multi-agency approach to include input from various service areas across the sectors including an Independent Person to offer a wider range of services to families. Consider keyworker/lead professional to attend the panel meeting to advocate on behalf of the family and further explain specific requests for services. • Transparency in how care packages are allocated and the eligibility criteria for services. • Inform parents of other services they may wish to access in addition to what is provided by Social Services and/or by using Direct Payments.
Extended use of available facilities	• Review of site provision to ensure maximum use and provide value for money. For example: Orient Street has capacity on the children’s side during school hours to provide a safe space for additional activities – i.e. under 5’s stay and play or a drop-in service to give parent-carers a break (staff requirements would need to be reviewed); Work experience placements from Spa School could use the building during the school day; Occupational Therapy assessments. Consider using Orient Street as an activity hub and/or resource centre including as a provider of Independence Training. This would maximize the building, improve the profile of the provision and encourage professional relationships between agencies. A pricing structure would need to be agreed.

	Tuke School (and others) have comprehensive facilities available during half-term and holidays that could be utilized; hoists, multi-sensory rooms and hydrotherapy activities would be well received by program participants; school staff may even be interested in working in the scheme (contractual agreements permitting), providing consistency, understanding of local communities and need, with health and safety checks and training already in place. • Consider multi-use sites for after school and club activities where siblings can attend and/or activities for parents; parallel activities reduces travel time and cost, allows a break for the whole family and then parents/siblings can provide support for CYP with additional needs if required.
Staff Resources	• Wider pool of carers needed to provide short periods of respite care, especially within the family home. Consider increased utilization of pool of sessional contact supervisors to provide cover when required; these are staff who would be employed by Southwark Council and would have undergone all required safety checks and training. • More foster carers needed – strict criteria and lengthy assessment processes means many carers don't qualify or move on before they are accepted. Improved process for vetting carers who can supervise CYP in their own home, working up towards an overnight/weekend break for the parent(s). • Agency staff are expensive and can be inconsistent; service providers and parents feel that agency staff often don't offer good value for money; it is also felt that in order to attract good quality carers, staff pay rates need to be re-evaluated.

	• Better paid/skilled/trained staff may mean less 1 to 1 support needed and can offer 1 to 2 support, which is more cost effective. This also helps to balance staff and client numbers in the event of an absence during scheduled activities. • Recruitment of more male carers, especially for boys. • More mentors, 'befrienders' and volunteers to work with CYP. This kind of service is well received by families and provides good value for money. • Consider designated Short Breaks Coordinator to ensure Southwark offers a comprehensive short breaks service integrating all CYP with special needs; would facilitate managing, arranging and monitoring service provision. • Consider Brokerage Worker role to support CYP and families to be provided appropriate services. • Further discussions around maximizing staff working with CYP in Southwark in lieu of using agency staff; i.e. the creation of a staff pool for staff who would like to work extra hours and work with CYP in different settings (possibly with different contractual arrangements to avoid overtime pay). This also supports staff continuity and stability for families.
Safeguarding Responsibilities and Integrated Service Delivery	
In-school support	• Develop stronger links between mainstream and special schools for better support of CYP with additional needs. • Work undertaken with schools about disability awareness, building empathy and understanding how to meet the needs of individual CYP and developing in-school support programs for CYP without specialist or 1 to 1 support.

	• Review of incidents of bullying and exclusion of CYP with additional needs from mainstream schools; with the expansion of Academies there are a limited number of mainstream school places for this group of vulnerable CYP so in-school support is essential to prevent exclusion. • Work to be undertaken with schools to support cultural shift around supporting CYP with additional needs including refreshed strategies for in-school support. • Consider program to support CYP to travel independently to school – i.e. walking school bus, escort to school from home or pick up point (volunteers, 6th form or college students, older siblings) and organized ‘carpools’ between parents (i.e. taking a group of children to school on foot, by bus or car). This also supports working parents and those with several children to transport to and from school. • School governors to include parent(s) of CYP with additional needs to advocate and provide link to services and information.
Integrated Working and Information Sharing Process	• Increased use of CAF for information sharing and a more holistic assessment and referral process. • Further development of Key worker and Lead Professional roles • More structured approach to Team around the Child/Young Person/Family to ensure professional networks are working together to safeguard vulnerable CYP and their families.
Multi-agency working	• More robust systems to encourage multi-agency working care planning and information sharing including shared IT system (i.e. eCAF/SharePoint). Integration between services and professional networks will have a significant and positive impact on service delivery and family experience.

	- For services where referrals are received by parent carers and/or social workers, information from other professionals is not shared or provided which may be critical for the CYP and the agency providing a service. - Best practice to be shared across the children’s workforce.
Transition	- Well planned and managed transitions from Early Years provision to Reception, Primary to Secondary and from Children’s to Adult Services for CYP who are 18+ including a Team Around the Child/Young Person meeting for professionals to share information and knowledge about each client. - Staged and managed transitions to new sites are also important, especially for CYP on the Autistic Spectrum for whom routines and consistency are essential to their safety and well-being.

Appendix 2

Help getting back to work for parents and carers of children with disabilities

Findings from DCATCH project, April 2011

Introduction

The aim of this project was to help parents and carers of children and young people with disabilities or special needs living in Wandsworth to get back into work.

In phase one of the project, a package of support was developed and promoted widely to Wandsworth parents and carers. The package included group training Back to Work 'taster' sessions, one-to-one coaching sessions, plus generic information on childcare options etc. In addition, financial support was made available via DCATCH, to help parents and carers with deposits if they needed childcare.

In phase two – the implementation stage of the project during February and March 2011 - a pilot training programme consisting of three x 1.5 hour sessions was run at the Early Years Centre in Wandsworth. This was attended by five parents. In addition, pilot coaching sessions were provided for six parents. To be flexible to carers' needs, coaching was offered either face to face or by telephone. (See Appendix for details of participants). Both training and coaching ended with participants drawing up an action plan to either get back to work or, as a route to work, to take up volunteering.

Summary

Overall, participants were very positive about the support offered via the pilot activities. To date, two people have enrolled in volunteering projects as a next step. The present economic climate does not make this the best time to be job seeking and the offer of

financial help for childcare deposits was not taken up as by the end of the two month pilot period, parents were either not yet ready to return to work immediately or had not yet found suitable opportunities. We hope to re-visit the participants in six months time to see how they have progressed.
Like all parents, our pilot participants face practical difficulties in returning to work such as finding work hours to suit or affordable, trustworthy childcare. However, these challenges were all the greater as a consequence of having a child with special needs or a disability. We found that participants tended to fall into one of the following groups when it came to readiness for work:

- Confident and competent – ready to work if there are job opportunities with sufficient flexibility to fit alongside children's needs

- Competent but not confident – need greater confidence in self, benefits system and childcare provision to get over the fear that working will only add to their current stress levels

- Complex needs – these might be caused by additional external factors such as having several children to look after or several carer roles or the impact of frequent illness of child or parent. As well as impacting on confidence, competence could be impaired by general low self esteem, depression or other factors affecting their ability to stay focused and productive

The impact of health issues on participant's ability to attend activities needs to be considered in developing services and materials. The illness of a child or the parents' own health issues mean time must be allowed for set-backs and information should be offered a variety of flexible ways – face to face, via the internet, email, phone etc.

With this in mind, we have developed a range of on-going support including:
1. A body of work to be passed on to other agencies such as Contact a Family who may be able to offer follow up services in future.
2. A dedicated section in the FIS information hub available in paper or electronic format on help parents and carers of disabled children
3. Enhanced appointments service for parents and carers as a result of lessons from the project
4. Better signposting to other services as a result of the connections made with them during the project
5. Aiming High FAQ sheet on myths and realities of returning to work
6. Help Getting Into Work toolkit
7. Dedicated section for parents and carers of disabled children in the updated FIS Financial Help for Families guide
8. Participants in the pilots have cascaded information down to other parents (for example, we were invited to present to other parents at the Battersea Imani Project at the suggestion of one parent participant)

9. Potential to run further workshops for parents and professionals, using materials developed from the project (3 ‘lunch and learn’ sessions are scheduled for June as part of the ongoing FIS service to parents)
10. Case study examples of people who have managed to combine work and caring locally to inspire other parents and carers

1. Background

The aim of this project was to produce a package of support to families who would like to return to work following the birth of a child with a disability via:

- Generic information - publicity
- Bespoke advice
- Provision of deposits for childcare where necessary

The project got the go-ahead in October 2010. The development stage lasted from mid October to mid-December. The implementation stage ran from mid-December to end of March 2011. This report summarises the development and implementation stages and outcomes arising from the project.

2. Development of the Help Getting Back to Work package

2.1 A pilot package was developed which included the following:

a) Group back to work training sessions covering a range of back to work topics

b) Individual coaching sessions to help with goal setting and action planning

c) Generic information provided 9-5 Monday – Friday via the Wandsworth Family Information Service (who were briefed to forward enquiries on to the project co-ordinator)

d) Offer of help with financial costs
Assistance with financial help towards the cost of childcare for people starting a new job

Eligibility for take up of the above included:

- ✓ Parents in receipt of DLA
- ✓ Children attending a special school or accessing special early years provision
- ✓ Medical evidence of significant medical disability
- ✓ Receipt of tax credits at a higher rate

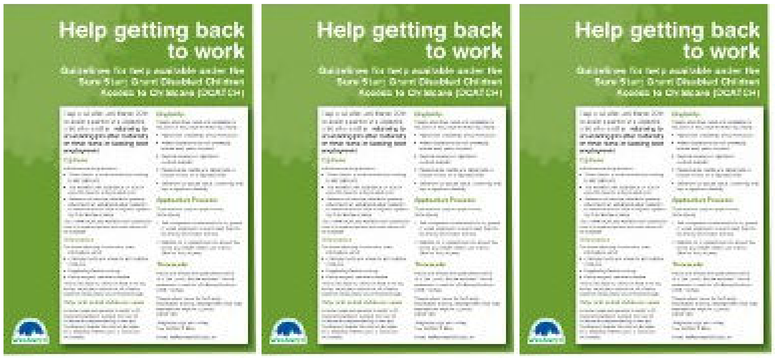
- ✓ Statement of special needs confirming child has a significant disability

2.2 **Promotion and timescale of the project**

Alongside building relations with potential stakeholders, materials were developed between October and November 2010 and PDFs and hard copies were produced December 2010.

A leaflet to promote the initiative for circulation to parents and professionals working with parents of children with disabilities was created.

In addition, guidance notes outlining the offer, eligibility criteria, timescale and application process was also developed.



An initial postal and email publicity drive was done prior to Christmas, with follow up emails and communications in the new year. This went to:

- Council website and borough-wide activities as part of the general FIS offer.

- Dedicated 'Getting back to work' information via the Council website and leaflets circulated by email and in hard copy to local job centres, Children's Centres, the local PCT, the Early Years Centre, Contact a Family, SENCOs and other services.
- The project was also advertised in Brightside.

3. Implementation stage of Help Getting Back to Work

3.1 Pilot training sessions

Taster training sessions were offered on the following topics:

- Identifying transferrable skills gained as a carer and jobs to suit
- Finding or negotiating flexible working
- Finding and paying for childcare and planning emergency cover
- Managing work/life and making it work

A pilot series was run at the Early Years Centre, Siward Road during February 2011. Having consulted with Madeleine Levy at EYC, we agreed to hold sessions in the middle of the day, making it easy for parents to attend between school hours. A crèche was provisionally booked for any parent needing it.

Five people registered for the three taster sessions and everyone managed to attend at least two of them.

Nobody booked a crèche place so this was not provided. However, one parent arrived with her baby, not having booked the crèche. We were able to accommodate the child in the room where the workshop was taking place.

The aim of each taster session was to build awareness of the opportunities open to parents of children with special needs, to consider some of the barriers and to build confidence and competence in assessing skills, job seeking, choosing childcare and understanding employers' needs around flexible working. Sessions were a mix of interactive group work, working in pairs, brainstorming and self completion questionnaires designed to grow awareness.

Sessions were not only an opportunity for participants to enhance their chances of returning to work. They were also an opportunity to test out the draft materials created at the development stage. To avoid re-inventing the wheel, content for the sessions was evolved following consultation with the national charity, Working Families. A series of complimentary worksheets were developed and participants were given copies of WF's return to work guide: Help Getting Into Work for parents of children with disabilities or special needs: .

3.2 Issues arising for participants in the training sessions

The 5 participants all had at least one child with a disability or special need. In total, they had ten children between them. Three were single parents.

Because of their circumstances, all participants wanted to find part time, flexible work. Apart from money, they identified the benefits as being:

- Using current skills
- Feeling good
- Being a role model to my children
- Learning other new skills
- Social aspect of going out to work
- Stimulus of a different setting
- Children develop skills and confidence away from parent
- Quality time with children when home

The biggest concerns participants had were:

- Impact on benefits and stress of insecurity if jobs fell through owing to child's needs impacting on availability for work
- Lack of jobs
- Lack of confidence
- No employer wanting to employ someone with caring responsibilities
- Lack of suitable childcare
- Lack of flexible working opportunities
- Explaining re child's needs at interviews
- Lack of skills
- Being 'only me' on the home front
- No time to fit work in around health appointments etc

On the plus side, participants agreed:

- There is a lot of help and information available to access
- Perseverance can pay off
- Confidence can be built up with practice or using 'transferrable confidence' from other aspects of life
- The perfect employee with 'no strings' doesn't exist and employers know this
- Some employers recognise the maturity and skills parents have gained at home or as carers
- Some employers are carers themselves and may therefore be sympathetic
- There is evidence to suggest that there is a wider acceptance of flexible working than previously
- Large employers, such as B&Q, Sainsbury and Waitrose have carer policies
- Research suggests that smaller local SME's can be more 'family friendly' than larger employers

Participants were given homework after each session and drew up an action plan at the end of the sessions. Goals included,

- Getting into voluntary work to help build confidence and skills
- Researching courses to gain further qualifications
- Contacting local large employers about their carer policies

Example employer opportunity
Nandos has its head office in Putney. The manager of the accounts department has a child with special needs. When his bookkeeper had a baby with disabilities, he encouraged her to come back to work one day a week, rather than give up, as she suggested. This way he retained her skills and she found the one day break away from home a lifesaver.

Example employer barrier
One participant approached Asda regarding a part time role and received a positive response. However she was told she would need to begin by working weekend shifts – a problem as she was a single parent with three children.

3.4 Coaching sessions

As an alternative or additional support to the group taster sessions, parents were offered the opportunity to have up to 3 one to one coaching sessions, held at the town hall or by phone (see appendix A for a break down of participants). Coaching sessions were designed to offer participants a confidential space in which to agree practical short term goals and plan next steps with the help of their coach.

Six people took up the opportunity of coaching, three of which used all three sessions, two used two sessions and one person used one. Typical issues identified were:

- Low self esteem
- Discounting the amount of ‘work’ already undertaken as a volunteer etc
- Lack of confidence when it comes to job interviews
- Immediate and unpredictable needs of children
- Tendency to procrastinate rather than focus
- Need to set boundaries around family demands
- Self limiting beliefs around personal potential and employer opportunities
- Lack of awareness of flexible working options / childcare solutions

- Lack of communication with partner around sharing care of children and partner's own potential for flexibility

3.6 Generic information

Members of the FIS helpline team were briefed at staff meetings about progress with the project and information available to hand out to parents in addition to their existing knowledge through Aiming High. A new section was also created in the 'information hub' to house Aiming High and other materials relating to special needs children.

The project co-ordinator made several visits to promote the initiative. These included:

- A talk to the team of advisors at Job Centre Plus, Clapham
- A talk to the child social work team at St George's hospital
- A lunchtime workshop for women at the Imani Project in Battersea
- An evening talk to parents of children with diabetes in Wandsworth

3.5 Money for childcare

Although money was offered to help pay for childcare as part of this initiative and was publicised directly to all relevant contacts, including job centre managers, no applications were made to access these funds. This may in part be attributable to the fact that all the parents, apart from one child of 4, had children of primary school plus and were looking for part time work to fit with their child or children's school day.

4. Outcome of the project

4.1 Feedback from training sessions

"It's been an eye opener for me as a carer of my daughter. It's given me a way forward. Coming to the sessions has helped me to set goals for myself. I have also gained a lot of information I didn't know – in particular knowing that if you find a good employer, they are willing to take you on and are flexible".

Feedback at the end of the 3 sessions was that the hour and a quarter sessions were 'about right' in length and helped in:

"Focusing my mind on what I want to do and how to move forward"
"Thinking about different options for getting back into work"

People especially welcomed hearing other's experiences, finding out they were 'not alone' and getting practical tips from peers

"The information given and listening to what other group members had to say"

Fuller feedback from the taster sessions is attached in appendix B

4.2 Outcome from coaching sessions

The coaching sessions produced some big breakthroughs for individuals

"A huge burden has lifted for me from being able to talk to my son about my plans as a result of this coaching" (parent with HIV and a daughter with special needs, concerned about not being a good role model for her son)

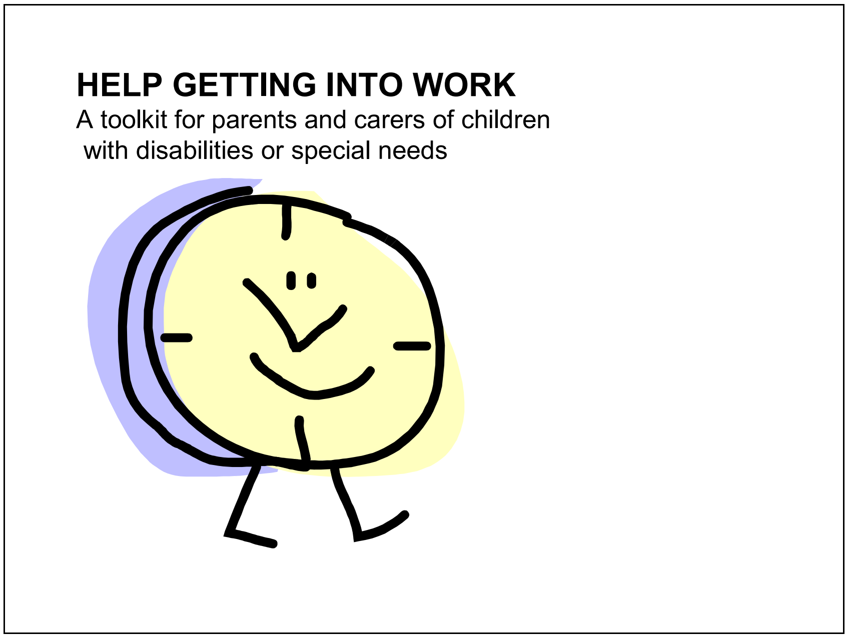
"This has been an enlightenment – one session was enough - you made me say out loud the reasons why l felt l would find it difficult to return to work and l realised that most of it was in my own mind and that it was about my confidence"

As well as an overarching goal around getting back to work, clients agreed goals to reach prior to each session and at the end of the third session, they had managed to clarify whether to continue with voluntary work, go into study or pursue part-time work.

"I definitely feel that I have been more productive over the past few days. I am currently research part time working opportunities, ideally 2 days a week. I have also been accepted as a Homestart volunteer but I will have to do 8 weeks training"

See appendix C for a sample feedback form

Another product developed for coaching clients, was a self completion 'toolkit' they could work on between sessions (see Appendix D)



HELP GETTING INTO WORK
A toolkit for parents and carers of children
with disabilities or special needs

4.3 Outcome in terms of general information provision

During the project's duration, there was a significant increase in overall enquiries regarding children with disabilities which rose from 92 in the last quarter of 2010 to 154 in the first quarter of 2011.

While this increase cannot be directly attributed to the DCATCH project, it is probable that the additional publicity and activity surrounding this initiative helped to raise overall awareness of Aiming High.

A new Fact Sheet on Frequently Asked Questions on Getting Back Into Work for parents of children with disabilities is being produced as a result of the project. This will draw from the comments and tips people shared in both the taster and coaching sessions.

Lessons from the project have also contributed to the updated generic guide: Financial Help for Families in Wandsworth. This now has a dedicated section for parents of children with disabilities or special needs.

5. Conclusions

This was the first project of its kind run by Wandsworth FIS and there was a window of just 6 months in which to research and develop our offer to parents, to produce promotional materials, undertake a marketing campaign and pilot our offer. In the event, 4 out of 5 people completed the three 'back to work' workshops and 6 people took up the offer of coaching sessions between February – April 2011. See Appendix E for further details.

So far, none have reported getting a job, but several report having taken the first steps towards positioning themselves to be ready for work when it becomes available.

5.1 Readyness to work

Parents of disabled children wishing to return to work are already at a disadvantage to other parents not in work because of their child/rens' condition. But there were further factors too and people tended to fall into one of the following categories:

A: Confident and competent – ready to work if there are job opportunities with sufficient pay and flexibility to fit alongside children's needs

B: Competent but not confident – need greater confidence in self, benefits system and childcare provision to get over the fear that working will only add to their current stress levels.

C: Complex needs – lacking in confidence, plus other preventive factors such as: large family size, impact of frequent illness of child or parent, having several carer roles or other factors that hinder the individual's ability to focus on job search as much as they intended.

5.2 Setting realistic goals

Bearing all this in mind, while the taster sessions were helpful in getting people thinking about the issues in general and reassured them that they were 'not alone' in struggling with the issue, the individual coaching sessions provided a more focused opportunity to tailor individual goals and set realistic targets suited to an individual's circumstances. Examples of these were:

- Researching job opportunities, using a broader range of search methods than before
- Taking up volunteering roles as a first step, using their experience as carers as a basis for helping other new parents or helping with adult dependant care.
- Practicing strategies to help set boundaries and keep focused on job searching
- Accepting that they were ‘good enough’ doing all they do now, rather than beating themselves up for not having a job
- Talking to a child about how to describe what ‘mum does’ at school

5.3 Looking ahead

At the end of March 2011, funding for the project came to an end and with it the opportunity to offer the breadth of services on offer through the pilot. Alongside the progress many of the pilot participants felt they had made, the legacy of the project is:

- A body of work to be passed on to other agencies such as Contact a Family who may be able to offer follow up services in future.
- A dedicated section in the FIS information hub available in paper or electronic format on help parents and carers of disabled children
- Enhanced appointments service for parents and carers as a result of learnings from the project
- Better signposting to other services as a result of the connections made with them during the project
- Aiming High FAQ sheet on returning to work issues
- Help Getting Into Work toolkit
- Dedicated section for parents and carers of disabled children in the updated FIS Financial Help for Families guide
- Potential to run further workshops for parents and professionals, using the materials developed during the course of the project (3 ‘lunch and learn’ sessions are scheduled for June as part of the ongoing FIS service to parents)
- We are starting to collect case study examples of people who have managed to combine work and caring locally. See Appendix G

Appendix A The participants and type of service used

Participant	Taster sessions	Coach sessions
Parent (female, black British, single) with 3 children (youngest severely disabled) and a life limiting illness herself	Yes	Yes
Parent (female, white British, married) with one severely disabled child	Yes	
Parent (female, black British, single) with one autistic child	Yes	
Parent (male, white British, married) with 4 children including one with statement of special needs	Yes	
Parent (female, black British, married) with one disabled child	Yes	Yes
Parent (female, white British, single) with three children, one of which has learning difficulties and personal health issues		Yes
Parent (female, black British, single) with three children, youngest of which developed a disability at age 8		Yes
Parent (female, white British, single) with child with complex disabilities about to transition to adulthood		Yes
Parent (female, black British, single) with four children, three of which have learning difficulties		Yes

Appendix B Feedback from taster sessions

Five people attended the first two taster sessions. The third session overlapped with the Transitions event and one of the participants missed the session because of attendance at the latter. One other participant was ill in hospital and therefore missed the final session.

Three people attended the last session. Although none of them are yet about to start new jobs, all of them had a specific action plan with next steps towards getting one.

Feedback on the sessions was positive:

2 out of three thought the session length was ‘about right’.
One thought it was too short

2 thought the handouts were ‘very relevant to me’.
One thought they were ‘of relevance’

Asked what was the most useful thing about the sessions, responses were:

- The information given to us and listening to what other group members had to say
- Focusing my mind on what I want to do and how to move forward
- Thinking about different options for getting back into work

Asked what the least useful was, 2 put N/A and one put ‘nothing’

Suggestions about what else to include in future sessions were:

- More information about potential local employers and training schemes
- Positive suggestions of work that can fit with caring responsibilities

Two participants have booked follow up coaching sessions to work on their action plan.

Unexpected outcome:

One participant had approached ASDA about flexible working and been told that there are flexible working options. However, the days when newcomers are offered jobs are weekend working days as regular long term staff get the pick of the more social working week hours. This is a barrier for lone parents and it would be interesting to research what general retailer policy is about this.

Appendix C Example of a coaching feedback form

1. What worked well for you?
   - I enjoyed the workshops sessions, particularly the first one which was very helpful in terms of getting the group to look at how we divide up our time every day and how we could be more productive.
   - It was really encouraging to meet parents that are in a similar situation to me.
   - I liked the fact that the workshop was only for an hour and fifteen minutes and the start time was great as I was able to collect my son from school without any problem.
   - The location was good.
   - The telephone coaching has been very useful. It has enabled me to clarify what I want to do and examine whether my goals are realistic given my circumstances.
   - The resource materials have been very helpful e.g. ‘goals for next 90 days’ and ‘beat the clock’.

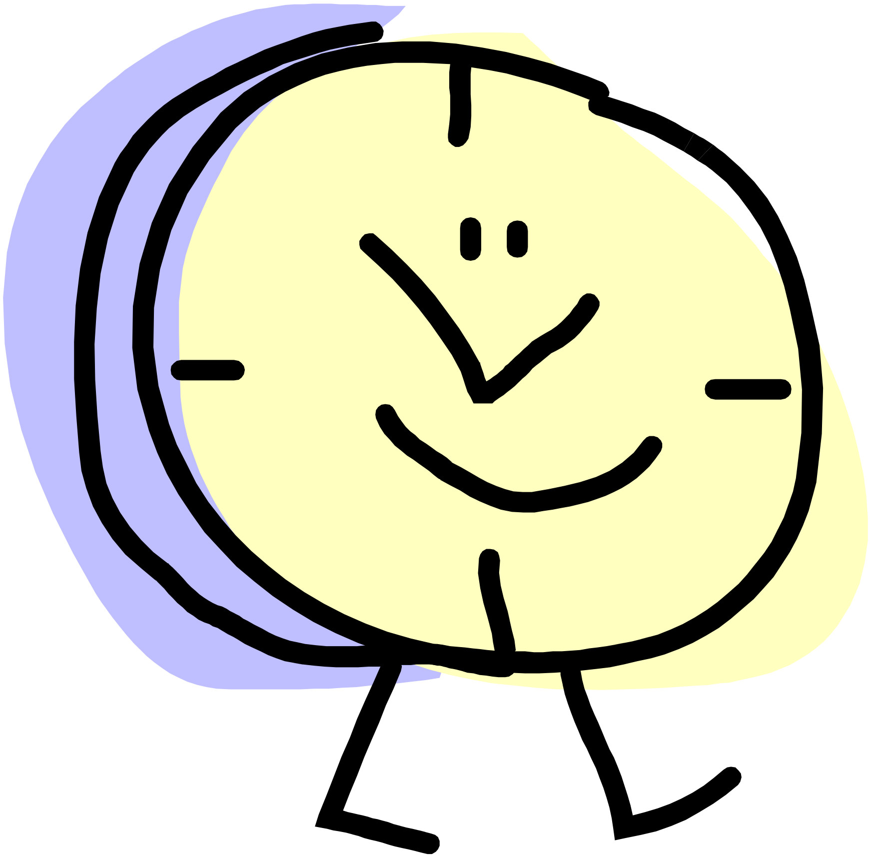
2. Is there anything we might have been done differently?
   - Change the room to one which was quieter
   - Maybe have 2 sessions rather than 3

3. What other information or support would help you most right now?
   - Help with filling out job application forms
   - Producing a good CV
   - Tips on preparing for interviews
   - Information about groups and organisations that help parents of disabled children get back into work or provide training schemes.

4. What are your next steps in terms of researching getting back to work?
   - Looking at training options
   - Researching local charities and businesses for part time working opportunities
   - Registering with agencies that specialise in part time work placements.

5. What tips would you give other parents starting to think about it?
   - Be realistic! If you have been out of work for a long time looking after children it might be difficult going straight back into full time work.
   - Make sure that you have a good family support network that are able to look after your child if you go back to work, or sort out other appropriate childcare.

HELP GETTING INTO WORK



A toolkit for parents and carers of children with disabilities or special needs

Wandsworth Family Information Service 2011

This toolkit is a starting point for anyone with caring responsibilities considering a return to work.

It is designed so you can complete it in your own time, either step by step or selecting only the sections that are relevant to you.

There are references to further sources of help you can turn to when you are ready to apply for jobs or want further guidance.

Part 1: What sort of work would I like?

- My interests
- My transferable skills
- Practical considerations about returning to work
- What or who can help me?

Part 2: Finding work and help for parents/carers

- What work and where to look
- Flexible working options
- Legislation to support working parents

Part 3: Starting back and making it work

- Why employ me?
- Making it work - childcare, planning back-up and self care

Part 4: Action Planning

- My next step
- Action checklist
- Further help

Part 1: What sort of work would I like?

Who am I now and what sort of work would I like to do?

My interests

1a. Make a list of your experience and interests – especially those that could be used in the workplace or that you have to offer an employer. Include:

- any formal qualifications you already have or are working towards.
- experience gained from paid and voluntary work
- skills gained through your hobbies and from family life.
- languages you speak apart from English

………………………………………………………………………………………

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(continue listing your experience on a separate sheet if necessary)

1b. Thinking back over your experiences at work, at home, pursuing hobbies or doing voluntary work – list up to three things that you especially enjoyed or feel proud of

1.

2.

3.

Transferable skills

The skills we develop in managing a home and caring for a child/ren are often taken for granted. But many of them may be transferable to the workplace.
A typical list compiled by a parent of a disabled child or one with special needs might include some of the skills in the table below.

Place a tick by all the skills you can identify with or have developed some expertise or mastery in. Some skills you will enjoy more than others – place a tick by your top 3.

Typical skills parents of children with disabilities or special needs say they have developed	**I have (or am developing) mastery in this skill (tick as many as apply)**	**I enjoy mastery of this (tick at least 3)**
Time management		
Telephone skills		
Organisation and planning		
Driving		
Negotiating skills		
Conflict resolution		
Record keeping		
Catering		
Guiding or instructing others		
Budgeting		
Knowledge of the benefits system		
Knowledge of the education system		
Disability awareness		
Letter or email writing		
Word processing		
Researching information on the internet etc		
Team leadership		
Attending to detail		
Keeping calm under pressure		

Other skills		

Practical considerations

As well as thinking about what will help you get into work, what practical considerations or constraints do you need to flag up at this stage?

Here are some examples:

- Need to work part-time only
- Need to work close to home
- Need flexibility to take time off work for appointments etc
- Need for career guidance
- Need to gain training or experience before applying for a job
- Need to build up confidence
- Need to feel there are others I can trust to delegate childcare to
- Need to assess the impact on household income/benefits if working

List the top three considerations or constraints that apply to your situation

1.

2.

3.

What or who might help you address these?

…………………………………………………………………………………..

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…………………………………………………………………………………..

Need more help?

1. It is a good idea to ask someone you know to help you work through the exercises and give you feedback
2. visit www.nextstep.direct.gov.uk or call them on 0800 100 900 for information on finding courses, writing your cv (work experience), help with

funding to learn and interviewing techniques. You can also browse job profiles and arrange to speak to a local advisor

Part 2: Finding work and help for parent/carers
Identifying sources, flexible working options and legislation to help carers

What work and where to look?

What kind of work are you looking for right now? For example, you could return to a previous area of work before you took a break to care for your child, or you might want to do something different, utilising the skills you have gained in the meanwhile.

The following table shows a variety of work options and considerations. Before taking any decisions, be sure to get advice and a 'better off' assessment to see what impact working will have on any benefits you may be receiving. You can do this at Job Centre Plus.

Work option	Considerations	Sources
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Working for a small local business	People like working for small firms because they can get more involved in the team than is sometimes the case in a big organisation. Small, firms can be family oriented and quite flexible if you find the right one. People who run them have often made this choice because of their own work/life balance needs. As an employee, you will probably be on PAYE (pay as you earn) for tax purposes.	Job Centre Plus Local Press Local agencies Via word of mouth Internet
Agency worker	Agency work can be fairly flexible about the amount of hours you do and you could flex your hours according to the time of year. For example taking time off during school holidays.	Local agencies Job Centre Plus Local press
Self-employment	Could you work independently? This way of working could offer you greater control over where and when you work. But you will get no sick pay, holiday leave, training or support. You will need to be self motivated and be willing to handle your own tax and NI as well as accounts.	www.businesslink.gov.uk www.spareroomstartup.com
Volunteering	This is a good route if you want to build up confidence, gain experience and find out if you enjoy the stimulus of working	Local charities National charities based in London

	outside the home. It is a good stepping stone into work but you are only likely to receive travel expenses and perhaps a contribution towards lunch	www.london.groundwork.org.uk

Tips

People looking for work to fit with bringing up a child with special needs say:

- It can take longer than average to find the right fit but persistence pays off
- Don't let rejection get you down – fear of failure stops lots of people reaching their full potential
- Take advantage of local training courses or volunteer work to build your confidence
- Don't restrict yourself to your previous work area. Think outside the box and explore anything that will broaden your pool of potential work options
- Focus on the positives – for example the skills you've gained whilst at home, rather than worry about what you may have forgotten. Take pride in your accomplishments
- Ask your friends for introductions or suggestions of good leads. Tell them the kind of job that would be your ideal fit – the chances are they may have friends or relatives in the field. Word of mouth and personal recommendations count for a lot
- Find a helpful professional – for example through Job Centre Plus, Ingeus, or a former employer who could point you in the direction of work opportunities

Flexible working options

Most people seeking to return to work when they have caring responsibilities need some sort of flexibility to cope with work/life issues. Flexibility can mean many things:

Flexible full time work:

Doing standard working hours but flexing start and finish times or having a shorter lunch break – often called flexitime. This could include working a compressed week, so that you fit full time hours into fewer days – a four day week or 9 day fortnight, for example. This could work well for someone needing a full time salary but with some flexibility about the working week. It could also be suggestsed where an employer says the job cannot be done part-time but may be prepared for a bit of flexibility in return for someone with the right skills. You will need to fit your flexi-time with others if the job requires cover at all times but this may not be essential for jobs which don't have rigid start/finish times.

Flexible workplace:

Working offsite – for example, visiting customers/clients and catching up on deskwork from home. This could be either full time or part time. This kind of working arrangement is suited to roles where you have a certain amount of autonomy about how you plan your day and where you do your work – sales, project work etc which involves you alone.

Part-time working:
This could be part-time weekly, annualised hours (working more during busy times of the year, less at other times), term time only working, job sharing etc. It may be a good option to fit with school times/holidays etc. It could work well in a job that requires you fitting in with fairly rigid team needs - front desk work, for example or where customers are coming in for fixed appointments.

Winning tip:
Employers may be willing to be flexible but say that it helps if people can be flexible back sometimes. Whatever option you go for, you may still need occasional flexibility if your child is ill, so try to offer flexibility about making up for lost time or helping your employer out in an emergency – it is all about give and take.

Employees with caring responsibilities recommend keeping an employer in the loop about your caring role and being proactive in showing that you have a strategy for dealing with emergencies.

My preferred work options:

Option 1

…………………………………………………………………………………………

………………………………………………………………………………………….

Option 2

…………………………………………………………………………………………..

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Legislation to support working parents:

Many people caring for a child or adult dependent are concerned about taking time off in the case of an emergency or for appointments etc.

Yet employers often say that some of their most loyal and reliable staff are those with caring responsibilities – precisely because of the coping skills they have developed. Even if a carer has to take time off for emergencies, employers say they are more likely to make up for time off and to go the extra mile and less likely to let the side down by taking ‘sickies’ without reason.

That said, if you are applying for a new job, it is a good idea to demonstrate that you have thought through a back-up plan in case of emergencies (this is covered in more detail in module 3). Employment legislation also gives you the right to time off in a variety of ways:

Annual leave:
All employees are entitled to paid annual leave as soon as they start work for an employer. The legal minimum amount is 24 days per year for a full time job.

Time off for emergencies:
You have the right to take unpaid time off work to deal with an emergency involving someone who depends on you. This legal right applies only to genuine emergencies and the time taken must be reasonable in the circumstances – typically 1-5 days.

Parental leave:
Parental leave gives parents the right to take a period of time off work to look after their child. However you must have worked for your employer for at least a year. Leave can be taken at any time up to your child’s 18th birthday if he or she is disabled. It is unpaid leave and could be used, for example, to take time off in the school holidays when it is difficult to arrange childcare.

The Right to Request Flexible Working
When you have been employed in a job for 26 weeks, you acquire the right to request flexible working if you are the parent of a disabled child under 18 receiving DLA. Your employer must consider the request seriously and can only turn you down on specified grounds.

Full details of current employment legislation can be found at: www.direct.gov.uk

Part 3: Starting back and making it work
Why employ me? childcare and planning back-up

Why employ me?

Two big hurdles to getting back to work are often a loss of confidence and concern over employer's response to caring responsibilities

Think about all the benefits you could bring such as greater maturity and self motivation or knowledge of the local area if you are seeking work near to where you live.

The best time to bring up the subject of your caring responsibilities is when an employer has already expressed interest in you as a potential employer. Think realistically about the needs of the job and with this in mind, try to negotiate what hours would be to enable you to work most effectively. Suggest a trial period.

Instead of apologising for having caring responsibilities, point out some of the skills you have developed and some of your strengths. Could any of the following benefits apply to employing you?

A benefit of employing me	Yes	?	No
I have established roots in this area and am unlikely to move in the near future			
I may need to take time out occasionally to look after a sick child, but I have always had a good sickness record myself and am considered a reliable employee by previous bosses			
I am resourceful and have a good network of people who can help with back-up if I need it in an emergency			
If I have to take time off for an emergency, I may be able to make the time up at a later date and/or cover for someone else when they are sick			
I am always very conscientious about my work, in the same way that I conscientious in caring for my family			
My experience and level of maturity means I can work under my own initiative and don't need much supervision			
Other benefits or values that I can offer are:			

Making it work

Childcare

The cost of care, finding someone you can trust and the emotional impact of separating from your child are all important considerations. Your child's condition will also affect the kind of care you can go for.

Don't let this discourage you. Providers are being helped with training and support to make access to services more universal to all. The Family Information Service can help you find all kinds of registered childcare in the Borough or signpost you to other private provision.

The cost of care may be offset by working tax credits. You may be able to find work with an employer who gives Childcare Vouchers. If your child is severely disabled, you may qualify for a nursery place, respite care or Direct Payments.

If you are in a position to work but are not sure if it is worthwhile, remember that the investment you make now, should be offset by the financial advantages of being in employment in the longer term (Job Centre Plus should be able to help you do a 'better off' calculation to see how your income would compare with receiving benefits).

There are other cost benefits too: you are a role model for your child/ren – an investment in their future. Meanwhile, time away from your child may foster greater independence and a better quality of relationship when you are together.

Planning back-up

Predictable events such as appointments, annual holidays etc

Once in work, plan ahead as much as possible and flag up dates when you may need to take time off well in advance. Try to help others on your team out when you can to compensate for times when they may need to cover for you.

Childcare emergencies

Parental and emergency leave provision means that you can take time out to care for a sick child or go to medical or school appointments. Some 'family friendly' employers have carer or compassionate leave to enable people to fulfil caring duties.

If you are living with a partner or relative, they may be able to take time out from work to assist with back-up care in emergencies. Get them to check what their employer's policies are about this in advance so that you have a back-up strategy in an emergency.

If you live alone, see if you can buddy up with someone else in a similar situation and agree to help each other out in emergencies.

Self care

Juggling lots of balls can be very stimulating. It can also be draining. When we are 'doing it all' for everyone else, it is essential we take care of ourselves in order to sustain our role.

Write here three ways you could take better care of yourself:

1.

2.

3.

What are the benefits of investing in your own wellbeing?

………………………………………………………………………………………

………………………………………………………………………………………

………………………………………………………………………………………

Part 4: Action Planning
My next step, action checklist, further help

My next steps towards finding a job

Action	By when	Who/what can help

What, if anything might stop you from doing any of the above?

Action Checklist

Below is a checklist of topics covered in the toolkit
How many of these can you tick off at this stage?

- I am clear about what skills, experience and interests I can offer
- I have gained the following transferable skills:
- I have identified the practical considerations or constraints of working

- I know who to turn to for help in overcoming the challenges identified
- I have researched what kind of employment I want
- I need to train up on:
- I know what flexible work options might work for me and the kind of job I am looking for
- I have some strong selling points for why an employer should consider me, despite my caring role
- I have spoken to friends and contacts to find out what work connections they have
- I have researched childcare options to suit my needs
- I have a back-up plan at the ready in case of emergencies
- What will help me keep on top of everything is:

What else would help right now?

……………………………………………………………………………………………..

Family Information Service (FIS)

If you need help with local childcare provision or to discuss flexible working options, contact the FIS: 020 8 871 7899 to talk to an adviser or to book an appointment.

Further help:

Development of this toolkit would not have been possible without reference to the national charity, Working Families' publication: **Getting Into Work.** This is a more detailed guide for parents of children with disabilities or special needs. This can be downloaded for free from their website at: www.workingfamilies.org.uk. Working Families also have a dedicated helpline for working parents with disabled children: 0800 013 0313

Appendix G Case study example

Work and caring for a child with a disability.

Nick was born with Pallister Killian Syndrome, a chromosomal disorder which means he has profound learning and mobility difficulties. He uses a wheelchair and lets us know what he wants by using a whole range of sounds, eye movements and gestures. It takes time and patience to get to know him and to be able to understand his unique way of communicating. Nick is now thirty and lives at home with me and the dog, his two brothers having flown the nest. He needs twenty four hour care and has a busy life.

I first returned to work when Nick was about two and a half and apart from a two year break when his younger brother was born, have continued to do so, slowly increasing my hours and developing my career. During this time I returned to study and qualified as a social worker in 1995 (when Nick was fifteen). I now work full time for Wandsworth Children's Specialist Services.

Balancing work and family is tough for all parents but I think that having a child with special needs makes it just that bit more complicated for several reasons:

there may be more of an assumption that you will stay at home to care for your child because they have special needs.

because of this assumption there is an added sense of guilt that you are not dedicating your whole life to your child. Society still expects women to take on the main caring role.

there are likely to be more appointments and meetings to attend which are all held during working hours.

there are not sufficient services after school or during the school holidays for children with special needs.

All this makes it harder to get the balance right.

My Experience

It never occurred to me not to work. I needed the money, the stimulation and the satisfaction of doing a good job. Just like any parent I also wanted to provide my three sons with the best possible care. Ben and Jack could tell me if people were unkind or if they were unhappy. With Nick, I had to take even greater care that he was being looked after well. In looking for extra care I got very clever at making things work. My top tips are:

- Be brave and don't let potential barriers put you off. You can make things work. If I had waited for the perfect care package I would be at home now, very fed up and resentful.

- Think about how people already involved in your child's life can help. One of the teaching assistants from Nick's school looked after him for two hours twice a week until I got home. This was arranged through Share a Family but Direct Payments should make this easier to arrange. Family members can help too; Nick went to his aunt's home every Friday night. (and still does) This meant I did not have to rush home one night a week. Having a few, familiar carers involved in Nick's care also helped to keep him safe.

- Be strong about saying what is right for your child and your family. You are the expert. If necessary talk to someone who can influence decisions. When my local councillor got directly involved, things happened.

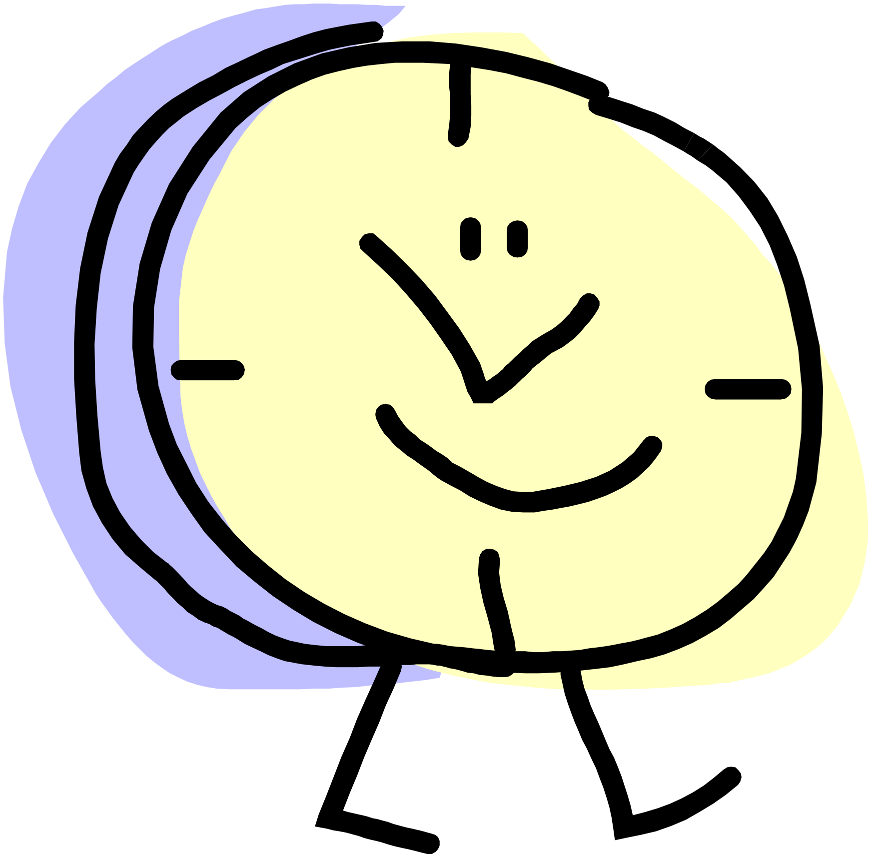
- Find other parents who are in a similar situation. I sometimes thought I was the only mother from Nick's school who went to work. I wasn't, I just didn't know who they were. There is strength in numbers.

- Be realistic about what is good for you. Nick was twenty before I worked full time and it is still hard going.

- Be clear with your employer about any request for flexible working arrangements. You now have a right to have your request considered. When Nick was at school I made it clear that I could not be at work until 9:30 am. My manager was wise enough to recognise that equal opportunities are not just about treating everyone the same.

Looking back I feel quite proud that I have been able to work; study and provide a loving home for my three sons. Balancing work and home life is tough and with Nick, the juggling act will continue until I stop working. Over the years, what made it easier has been my family and friends who have been a constant support throughout Nick's life as well as some great work colleagues and managers who really understand flexible working. What would have made it much, much easier was an equally flexible after school service and provision during the school holidays. Parents of all children should be able to make the right choices for their family. Good Luck.

HELP GETTING INTO WORK



A toolkit for parents and carers

Wandsworth Family Information Service 2012

This toolkit is a starting point for anyone with caring responsibilities considering a return to work.

It is designed so you can complete it in your own time, either step by step or selecting only the sections that are relevant to you.

There are references to further sources of help you can turn to when you are ready to apply for jobs or want further guidance.

Part 1: What sort of work would I like?

- My interests
- My transferable skills
- Practical considerations about returning to work
- What or who can help me?

Part 2: Finding work and help for parents/carers

- What work and where to look
- Flexible working options
- Legislation to support working parents

Part 3: Starting back and making it work

- Why employ me?
- Making it work - childcare, planning back-up and self care

Part 4: Action Planning

- My next step
- Action checklist
- Further help

Part 1: What sort of work would I like?

Who am I now and what sort of work would I like to do?

My interests

1a. Make a list of your experience and interests – especially those that could be used in the workplace or that you have to offer an employer. Include:

- any formal qualifications you already have or are working towards.
- experience gained from paid and voluntary work
- skills gained through your hobbies and from family life.
- languages you speak apart from English

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(continue listing your experience on a separate sheet if necessary)

1b. Thinking back over your experiences at work, at home, pursuing hobbies or doing voluntary work – list up to three things that you especially enjoyed or feel proud of

1.

2.

3.

Transferable skills

The skills we develop in managing a home and caring for a child/ren are often taken for granted. But many of them may be transferable to the workplace.
A typical list compiled by a parent of a disabled child or one with special needs might include some of the skills in the table below.

Place a tick by all the skills you can identify with or have developed some expertise or mastery in. Some skills you will enjoy more than others – place a tick by your top 3.

Typical skills parents of children with disabilities or special needs say they have developed	**I have (or am developing) mastery in this skill (tick as many as apply)**	**I enjoy mastery of this (tick at least 3)**
Time management		
Telephone skills		
Organisation and planning		
Driving		
Negotiating skills		
Conflict resolution		
Record keeping		
Catering		
Guiding or instructing others		
Budgeting		
Knowledge of the benefits system		
Knowledge of the education system		
Disability awareness		
Letter or email writing		
Word processing		
Researching information on the internet etc		
Team leadership		
Attending to detail		
Keeping calm under pressure		

Other skills		

Practical considerations

As well as thinking about what will help you get into work, what practical considerations or constraints do you need to flag up at this stage?

Here are some examples:

- Need to work part-time only
- Need to work close to home
- Need flexibility to take time off work for appointments etc
- Need for career guidance
- Need to gain training or experience before applying for a job
- Need to build up confidence
- Need to feel there are others I can trust to delegate childcare to
- Need to assess the impact on household income/benefits if working

List the top three considerations or constraints that apply to your situation

1.

2.

3.

What or who might help you address these?

……………………………………………………………………………………..

……………………………………………………………………………………..

……………………………………………………………………………………..

Need more help?

3. It is a good idea to ask someone you know to help you work through the exercises and give you feedback
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Part 2: Finding work and help for parent/carers
Identifying sources, flexible working options and legislation to help carers

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- Take advantage of local training courses or volunteer work to build your confidence

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- Focus on the positives – for example the skills you've gained whilst at home, rather than worry about what you may have forgotten. Take pride in your accomplishments

- Ask your friends for introductions or suggestions of good leads. Tell them the kind of job that would be your ideal fit – the chances are they may have friends or relatives in the field. Word of mouth and personal recommendations count for a lot

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My preferred work options:

Option 1

……………………………………………………………………………………………

…………………………………………………………………………………………….

Option 2

………………………………………………………………………………………..

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Legislation to support working parents:

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Yet employers often say that some of their most loyal and reliable staff are those with caring responsibilities – precisely because of the coping skills they have developed. Even if a carer has to take time off for emergencies, employers say they are more likely to make up for time off and to go the extra mile and less likely to let the side down by taking 'sickies' without reason.

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Part 3: Starting back and making it work
Why employ me? childcare and planning back-up

Why employ me?

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If I have to take time off for an emergency, I may be able to make the time up at a later date and/or cover for someone else when they are sick			
I am always very conscientious about my work, in the same way that I conscientious in caring for my family			
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Predictable events such as appointments, annual holidays etc

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2.

3.

What are the benefits of investing in your own wellbeing?

………………………………………………………………………………………

………………………………………………………………………………………

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Part 4: Action Planning
My next step, action checklist, further help

My next steps towards finding a job

Action	By when	Who/what can help

What, if anything might stop you from doing any of the above?

Action Checklist

Below is a checklist of topics covered in the toolkit
How many of these can you tick off at this stage?

- I am clear about what skills, experience and interests I can offer
- I have gained the following transferable skills:
- I have identified the practical considerations or constraints of working

- I know who to turn to for help in overcoming the challenges identified
- I have researched what kind of employment I want
- I need to train up on:
- I know what flexible work options might work for me and the kind of job I am looking for
- I have some strong selling points for why an employer should consider me, despite my caring role
- I have spoken to friends and contacts to find out what work connections they have
- I have researched childcare options to suit my needs
- I have a back-up plan at the ready in case of emergencies
- What will help me keep on top of everything is:

What else would help right now?

……………………………………………………………………………………..

If you need any further information, please contact the Family Information Service and we will do our best to help or signpost you to other services.

Further help:

Family Information Service (FIS)

If you need help with local childcare provision or to discuss flexible working options, contact the FIS: 020 8 871 7899 to book an appointment.

Apprenticeship schemes

For information about apprenticeships, combining paid work experience and training, contact Lifelong Learning at Wandsworth Council: Tel: 020 8871 8627 or email: aredman@wandsworth.gov.uk

Getting Into Work is a more detailed guide for parents of children with disabilities or special needs. It is produced by the national charity Working Families. This can be downloaded for free from their website at: www.workingfamilies.org.uk. Working Families also have a dedicated helpline for working parents with disabled children: 0800 013 0313