



HILLINGDON
LONDON

Education & Children's Services Policy Overview Committee

Developing a Short Breaks Provision 2008/9

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28th January 2009)
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INVESTOR IN PEOPLE

Developing a Short Breaks Provision

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CHAIRMAN'S FOREWORD



I am delighted to present this report on a highly importance subject, which has rightly been recognised by both central and local government.

All parents are aware of the difficulties of raising children but few of us are aware of the considerable additional stress and difficulty of coping on a daily basis with a child with disabilities. The burden of this is largely hidden within the family who, on the evidence presented, may often be headed by a lone parent.

The evidence and personal experience was compelling. The committee and I were grateful to them for taking the time to come and give evidence. This insight informed much of the later questioning of the “professionals” in the field.

Services need to build on the good work already being undertaken, including that of Moorcroft School, but also by widening the partnership with the voluntary sector.

Clearly some of the improvements involve additional cost and it is recognised that this may be difficult to achieve in the current economic circumstances. However, some changes relate to process, communication and provision of information with little if any additional cost. To quote the parents we spoke to, “it’s alright once you are in the

system”. There is a need for both the Council and its partners to ensure that clear, timely and consistent information is available to all parents who have children with disabilities.

On behalf of the Committee, I would like to thank the external witnesses and officers for participating in the review. We hope this can be used to make practical changes to the service in the borough.

Cllr Eddie Lavery

INTRODUCTION

Background

1. The government has recently recognized the need to improve services across the country for children with disabilities and their families, through the Aiming High for Disabled Children agenda. This requires each Council through its Trust arrangements to produce a strategy by 31 March 2009, in partnership with young people and their families to improve services for children with disabilities over the next 3 years.

2. National Agenda

The guidance published in May 2008 defines a Core Service Offer, which has the following service standards:

The short breaks strategy should:

- be based on a needs assessment of the local disabled child population, taking into account the voice of children with disabilities, young people and their families;
- offer a significantly greater volume of short break provision set against a 2007/08 baseline;
- use fair, understandable and transparent eligibility criteria that enable short breaks to be used as a preventative service and which do not restrict provision to those threatened by family breakdown or other points of crisis;
- offer a wide range of local short break provision, tailored to families needs and including:

- a) support for children with disabilities in accessing activities in universal settings, delivered through the following:
- the support of a befriending, sitting or sessional service;
 - measures that build the skills of universal service providers;
 - measures specific to severely disabled children that are undertaken to meet their physical access requirements in universal settings. These would build on and exceed DDA compliance and ensure that the most disabled are not disadvantaged.
- b) overnight breaks, with care available in both the child's own home and elsewhere.
- c) significant breaks during the day, with care available in the child's own home and elsewhere:
- provide positive experiences for children by promoting friendships and by encouraging social activities, new experiences and supportive relationships with carers;
 - provide culturally appropriate provision that meets the racial, cultural, linguistic and religious needs of children with disabilities and their families;
 - ensure that provision is available on a planned and regular basis and at the times when families and young people, need breaks - this should include evenings, weekends and holiday provision, and have the capacity to respond to urgent care requirements;

- provide age appropriate provision which ensures the following groups are not disadvantaged in accessing short breaks:

d) children and young people with Autistic Spectrum Disorder (ASD). These are likely to have other impairments, such as severe learning disabilities or have behaviour, which is challenging. Not all children on the Autistic Spectrum will require specialist additional short break services, but may require universal services to be adapted for their needs.

e) children and young people with complex health needs which includes those with disability and life limiting conditions who have reached the palliative care stage of their life cycle as well as other children and young people with complex health needs as well as other impairments – physical, cognitive or sensory impairments.

f) children and young people aged 11+ with moving and handling needs that will require equipment and adaptations. These children are likely to have physical impairments, and many of them will also have cognitive impairments and / or sensory impairments;

g) children and young people where challenging behaviour is associated with other impairments (e.g. severe learning disability). Children in this group will display behaviour that challenges services or behaviour that causes injury to themselves or others

h) young people 14+. The young people who fall into this group are people who are severely disabled and require services that are appropriate to their age.

- utilise the service provider that offers the best possible combination of skills and experience to deliver services of the highest possible quality to meet individual needs at the most efficient cost;

- promote information about available provision to the public, including details of eligibility - including threshold criteria - and routes to accessing the service.

3. National Indicator

The disabled children national indicator (NI 54) will look at parental experiences of services for children and young people with disabilities aged 0 to 19. The new indicator will be a core part of performance management arrangements aimed at improving the quality of services for children with disabilities. This is a key priority of the Child Health and Well-Being Public Service Agreement (PSA 12). This indicator is included in the National Indicator Set (NIS) and the NHS Operating Framework Vital Signs indicator set. A decision on the form of the indicator will be taken in Autumn 2008 and the indicator will be measured for the first time at local level in 2008/10. It will assess parents' general experience of disabled children's services delivering to the Core Offer standards.

4. Connections With Other Strategies

The strategy is also expected to ensure that related programmes also address the needs of children with disabilities and support to their families, including:

- Building Schools for the 21st Century;
- The Extended Schools programme;
- Sports and Play Strategies;
- The development of young people centres and the Integrated Youth Support Service agenda; and
- The Children Centres programme.

5. The key performance targets are:

- Support and enhance development in early childhood .
- Help young children develop well
- Help young children grow up healthy
- Ensure services reach all young children and their families, particularly those from more disadvantaged groups
- Listen to young children and their families and make services respond to their needs

Reason for the Review

6. To support the work of officers from the Council's Education & Children's Services Department who are looking at ways to develop the Short Breaks Provision, bringing together all the key aspects necessary information to advance the service.

Aim of the Review

7. To make recommendations that will guide Council policy on a strategy for the development of the Short Breaks Provision.

METHODOLOGY

8. In the current year we used five meetings to examine this issue. We began by using our July 2007 meeting to consider the Short Breaks Provision in Hillingdon, including what was being done and what the current developments were.
9. Meetings held in September, October and January involved taking evidence from a range of witnesses:
 - September – Parents' views on Short Breaks services
 - October – witnesses from the following service providers:
 - i. Children with Disabilities
 - ii. Extended Schools
 - iii. Merrifields Residential Respite Care Unit
 - iv. Moorcroft School
 - v. Youth and Connexions Service.
 - January – witnesses from the voluntary sector:
 - i. HomeStart, Hillingdon
 - ii. Log Cabin, Ealing
 - iii. Scope, UK.

We sought to gain information on the following issues:

- How far does the existing provision meet the needs of this group of children?
- Are there any particular pressures / issues affecting Hillingdon?
- What are the strengths and weaknesses of current approaches?
- What changes can be made in Hillingdon?
- How should agencies work more effectively together to address the needs of this group of children?

10. The findings from this review are presented in the following section of this report.

EVIDENCE & FINDINGS

The following evidence was gathered at the witness sessions, which took place at the Committee meetings in September, October and January 2008/09:

i. Types of current provisions – evidence was taken from a number of provisions currently used in the borough:

Moorcroft School:

- Runs various clubs – breakfast club, youth club, lunch time clubs including gardening & ‘glitter girls’ club, and after school clubs including sports activities, sensory club, ICT sessions & cookery club.
- Family learning sessions – families with children with disabilities visit Moorcroft School to use their equipment with help from the staff there.
- The staff make home visits to the families and hospital visits to children with disabilities, as part of the Reaching Out project.
- There is support for families with behaviour management issues
- The Summer Camp Scheme ran during the summer holidays this year, with very positive feedback from parents. The day ran from 09:30 till 15:00 for two weeks, with 23 out of 25 places filled by 11-19 year olds, costing £20 per child per day. A mini-bus was used to transport the severely disabled children to and from the school. The teacher/pupil ratio was good, but could be better if there was funding for more staff
- Staff are trained at the on-site resource centre. Staff understand which children need more attention and create a bond with the children.

Merrifields Residential Respite Care Unit:

- Due to some families with disabled children being single parents, the demand for overnight provision is very high.
- Children aged 0 -18 can attend the tea-sessions at Merrifields, with 7-18 year olds being offered overnight provision based on the severity of their condition – can range from one night per week to one night per month.
- The unit consists of four bedrooms, and emergency provision is available. 24 families attend Merrifields. There is another respite care unit in Ruislip, but it is not purpose built and does not have individual bedrooms.
- The first floor of Merrifields respite care unit is unused; after refurbishment the first floor could also be used as part of the respite unit.
- There is no waiting list to attend the care unit.
- Contract staff are employed at the respite care unit.

Children with Disabilities Team:

- Child focused work with 29 families (92 families have used this service in the last 3 years)
- A monthly resources panel identifies the needs of the children with disabilities and their family and will refer them to the Children with Disabilities Team
- Parents are able to buy services, including respite, through direct payment.
- An Outreach Service provides families with a social or health worker for up to 10 hours per week.
- Staff are trained within the team, and many are part-time staff. Many workers do not stay with the team very long, which is disruptive for the children. Therefore, extra funding would be used to employ more full-time staff.

- Extra funding would also be used to provide a larger range of services and increase Outreach services.

Extended Schools:

- This provision is a universal service that will need to make adjustments to cater for less able children.
- The provision within this service for the severely disabled may need to be located at a small number of schools for example Moorcroft School.
- Transport is an issue for this provision, as it is difficult for severely disabled children to travel. If the children are late for their activity, they do not feel included which is an adverse effect of the service. Parents of disabled children are very protective over their child, and would appreciate safe and comfortable purpose-built transport to and from the provision.
- A wide range of activities are provided and are advertised in schools included in the programme.
- There is a need for better training for staff, so they have the confidence and ability to work with children who have additional needs but may still attend a mainstream school.
- However, the Extended Schools provision does not know the number of children with disabilities or additional needs who might require access to its services.

Youth and Connexions Service:

- Provides a focused service to young people with learning difficulties. Each programme has a pre-identified learning outcome.
- The Summer Sparks programme was developed for children with learning disabilities. It is hosted in an informal environment in a youth-club style to encourage the children to engage in the activities.

- The mainstream summer Fiesta programme do not specifically cater for children with disabilities but they are not excluded from joining. Further programme adaptation may be required to achieve full inclusion.
- A brochure detailing the Fiesta service was sent to every school in the borough. Applications were taken via the website, however this does require a certain level of computer literacy and the service may benefit from a simpler application process.
- There are 2,700 summer places on offer at the Youth and Connexions service, with 2,100 places filled.

HomeStart, Hillingdon:

- HomeStart's mission statement is to select and train volunteers, who must be parents themselves, to support parents who are experiencing some form of difficulty, by weekly home-visits.
- Volunteers are selected for their positive and non-judgemental attitude and their ability to lend a sensitive listening ear.
- All volunteers are required to complete 40 hours of preparation training.
- Volunteer vacancies are advertised in the local paper and in the Hillingdon People magazine. 10 to 14 people are trained at once in the three courses run per annum.
- Volunteers engage with the family on a parent-to-parent basis. This contributes to parents experiencing HomeStart as support for the whole family and not just the disabled child.
- CRB checks and references are taken before volunteers are matched with a family.
- Referrals – families with disabled children are referred to HomeStart for a number of varied reasons.

- Respite – respite is offered to families in the forms of enabling parents to have a rest while the disabled child is taken care of in the house, or by taking the child out and allowing the parent to spend time with other siblings.
- Last year, HomeStart Hillingdon worked with nine families with disabled children including Autistic Spectrum Disorder, Global Development Delay and Down’s syndrome.
- Members were told about three case studies of families using the HomeStart Hillingdon service. Very positive feedback was received from these families, with one father of a disabled child saying, *“This is an extremely worthwhile service and HomeStart’s staff and volunteers are second to none.”*
- The Primary Care Trust, the Local Authority, City Bridge, Hillingdon Community Trust and BBC Children in Need make funding available for HomeStart.

Log Cabin, Ealing:

- The Log Cabin, founded in 1977, is an inclusive playground for children and young people who have special needs or a disability.
- The aim of the Log Cabin is to make a positive difference to children’s lives by providing exciting and stimulating play opportunities in a safe, caring and fun environment.
- Over 400 disabled and mainstream children use the facility with their families.
- The Log Cabin was Runner Up for the Children’s Adventure Playground of the Year award (London Play) twice in the last three years.
- The Log Cabin consists of a large indoor hall, arts & crafts room, indoor kitchen, quiet areas, an interactive multisensory

room, soft play room, an outdoor play area, sports area and a wildlife area.

- During the holiday time, a 'Play Scheme' is run from 08.30 till 17.45. On average, 55 children attend this every day, with 20 of these children requiring one to one support from one of the 30 members of staff.
- During term time the Log Cabin is open from 09.30 till 15.30. The cost of attending a full day is £92.53.
- After School sessions are run from 15.30 till 18.30. The cost of this session is £52.87 for severely disabled children and £12 for mainstream children. A two course hot meal is provided at the after school session, which is attended by 20 children, 10 of whom require one to one support. Sessions are also run on Saturday afternoons.
- Three mini buses are used to transport some of the children to and from the Log Cabin.
- Staff encourage children to be more confident. Physically disabled children are encouraged not to let their disability hold them back. Children are also given emotional support.
- Staff arrive before the children every day and share any issues regarding the children. The children also have a Committee where they can give feedback regarding the services.
- Managers are required to have NVQ4 qualification, and all other staff must have NVQ 2 or 3. As well as paid staff, volunteers are also recruited but require more training due to the nature of the problems of the children.
- Local schools and businesses are encouraged to send volunteers to the Log Cabin and organise fundraising.
- The facility receives a grant from the Local Authority. The LA pays for children who are referred to the Log Cabin by them.

The parents of the other children pay for their use of the Log Cabin. (40% of the children at the Log Cabin are referred).

- The Log Cabin has a turnover of £500,000.

Scope, UK:

- The not-for-profit organisation was founded in 1952, specialising in taking care of children with cerebral palsy.
- Scope works to ensure the inclusion of disabled children within their local communities through leisure activities, providing children with a sense of independence.
- A range of services are provided: personal care in the home, support to disabled children with complex health needs, community and leisure support, short term and emergency support to families, including overnight supervision if required.
- Disabled children are referred from the Care Management Teams. Each child is provided with a support plan developed for each individual. The outcome focused plans ensure benefits for the child as well as providing parents with breaks.
- There is a flexibility of delivery, giving choice and control to the child and their family.
- Scope Inclusion teams currently exist in Devon & Cornwall, Suffolk, Lancashire, Cumbria, Nottingham and West London (Hounslow).
- The Scope Inclusion team in Hounslow operate a block contract delivering 11,600 hours of short breaks per annum to over 50 families from diverse backgrounds. Children between the ages of 0-18 years with physical disabilities, learning difficulties, ASD, challenging behaviours, epilepsy, complex health needs, sensory and communication impairments are cared for.

- A nursing team is on hand to care for children with health needs.

ii. To improve services, the Authority had commissioned the Children's Society's CNL Consultancy to undertake a consultation with parents of children with additional needs aged 11-19 years.

The views of 38 parents / carers were obtained through a combination of focus groups and one to one interviews and the following suggestions were made in relation to the Short Breaks provision:

- It is vital to have regular short breaks from providing high levels of care 24 hours a day.
- Short breaks should be easy to access. The eligibility criteria should be broadened. The current criteria is perceived to be too high.
- There should be choice. This includes the provision of a range of short breaks, such as someone to take the disabled child and their siblings out, overnights, weekend breaks and holidays that a young person can go on without their parents.
- The use of direct payments for receiving short breaks should be less bureaucratic.
- More local respite care families should be recruited to provide short breaks.
- To have trained, reliable and trustworthy staff.
- To provide emergency placements in case a parent gets ill.

- There should be flexibility, where parents can book breaks at short notice.
- To have short breaks which are affordable.
- To expand the current provision, both in the statutory and voluntary sectors.
- To have short breaks which provide fun activities for the children and which would also help to train young people to develop independent living skills.
- To provide short breaks when a child is first diagnosed so that parents have time together.

iii. Role of short breaks and how these help parents and carers:

- In its most basic form, a short break (formerly known as respite care) is a means of giving one person a break from another person.
- Short breaks are about giving the child a break from their parents and carers, as well as the reverse.
- Short breaks are important because they promote the independence and social development of the child, as well as, allowing the parent / carer time to 'recharge' and prepares them for their child becoming an adult.

iv. Extent to which current short breaks provision meets the current need:

- Types of current provision:
 1. Extended services after school
 2. Family based respite service
 3. Outreach services – provided in the child's home including outings and activities outside the home

4. A sitting service
5. Community services – Youth Services, leisure, play and Green Spaces
6. Residential short breaks

The parents of children with disabilities discussed the provisions. The following comments were made regarding various areas of the services that need to be reviewed:

- Cost of provision can be a problem and parents appreciate the flexibility offered by direct payment.
- Access to short breaks could be improved – witnesses agreed that Outreach Services were good when ‘you were in the system’ but were initially very difficult to access – and that ‘it is a fight to get the Services you need’.
- Eligibility criteria and access – Needs assessments are carried out to help find out how the Council might assist parents and to determine the individual levels of need (eligibility for short break services). This can be a stressful and unsettling time for parents/carers, anxious whether opting for home-based support, they might experience difficulty in re-accessing short break services. Both witnesses agreed that the current assessment period was too long and overly bureaucratic. Suggestions included: reducing the length of the assessment period and improving the transparency of the eligibility criteria guidance. The witnesses also said that the eligibility criteria for access to short breaks was too narrow and currently excluded many seeking help. Broadening the criteria would enable more parents to access short breaks provision.
- Assessment and managing expectation - One witness explained how after their needs were assessed, they were offered 4 hours per week in term time, and anticipated 15 hours per week during the summer holiday. However, the actual summer holiday support was 10 hours per week (2 separate blocks of 5 hours). Consequently, it is essential that

each parent is assisted and guided through the formal process so that there is no misunderstanding the level of care allocated.

- One witness had used the Acorns club. £30 per day was deemed too expensive for the level of care offered. The same witness had also used the Star Club. This provided care between 10 am and 3 pm, Monday to Friday for the first 2 weeks of the holiday period, costing £30 per week. Short breaks must be affordable.
- Timing and flexibility of short breaks could be improved - At present, short breaks are made available to carers in 'blocks of time' that are dictated by the availability of qualified staff. The witnesses explained that the current provision did not meet their needs, as the time offered did not coincide with when they needed to access services. One witness explained that they had not been able to access the services they needed in either the 3 weeks before the start of the summer holidays or the last 3 weeks of the 5-week summer holiday period. Limitations on when services are available meant that short breaks provision is perceived as being too prescriptive and could be made more user friendly.
- Mobility and Access to transport facilities – A witness explained that there had been an occasion when a short break had been requested, only to find that the allocated carer was not mobile. The child had anticipated activity time away from family home, only to be disappointed to find the care provided (at home) had not met their (or their parents /carers) expectations.

v. Views of parents regarding the current approach to short breaks:

- Witnesses agreed that short breaks are a positive experience. They give the child and parent a break from one another and allow the parent / carer to recharge their batteries. They also give the child an opportunity to develop social skills and interact with other children.
- Clear information and guidance – A witness explained that they disagreed with the level of need and number of hours per week that

had been allocated to their child by the Needs Panel. However, information on a right of appeal or the complaints procedure had not been included in correspondence from the Council. Officers explained that a complaint against the decision of the Panel could have been made in writing to the Head of Service but this was not made explicit. Clearly aspects of the appeals and complaints process could be improved.

- The witnesses explained that when they were first contacted by Social Services there was a thorough assessment. However, neither witness could recall whether any information or leaflets had been given to them, which explained the full range of services on offer for children with disabilities.
- Consistent information - Information about short breaks provision varies from institution to institution. One witness explained that her child attended a special school but no information on short breaks had been provided. The other witness had had a different experience. Her child's school had provided information and telephoned her to ensure the child received the level of support anticipated. Clear, universal guidance on short breaks must be made readily available from schools, Council offices and municipal buildings such as libraries.
- Protocols for contacting carers – One witness explained that on one occasion when their Outreach worker had been off sick, they were not guided or informed about how to make alternative arrangements and they forfeited the care that they had anticipated. Protocols can be strengthened and customer contact training could be provided to ensure a consistent service.

vi. Steps, which could be taken to improve short breaks provision in Hillingdon:

- Short breaks need to be easier to access and the eligibility criteria could be broadened. A well advertised single point of contact between

parents/carers and the Council is required. This will ensure parents and carers know how to access the information and care they need.

- The introduction of a wider summer holidays play scheme. This would provide an activity for children and also a short rest for the carer. The Youth and Connexions service and Moorcroft School did offer some summer schemes in 2008, but this service needs to be expanded to reach all special needs children.
- To provide greater flexibility in short break provision. The introduction of weekend breaks, which could be booked at short notice, would enable parents and carers to have a total break from providing care. This would enable adults to attend social and family or cultural events such as weddings or Christenings. The witnesses agreed that parents/carers need regular breaks from caring.
- Officers explained that work was ongoing to provide extra support for families which did not constitute a 'short break' such as support in accessing Early Years and child care, extended schools services and Council managed play schemes and Youth Services.
- To provide emergency placements in case a parent or carer becomes ill.
- More staff required – The witnesses agreed that additional trained, trustworthy and reliable staff are essential.

CONCLUSIONS

The Committee reviewed the duties, functions, performance of and potential for improvements in the Short Breaks provision in Hillingdon. A summary of the Committee's conclusions and recommendations are below.

- 1. There is a need for a flexible Short Breaks provision based on family needs.**
- 2. The view of parents needs to be considered to ensure the provision meets the needs of those using it.**
- 3. The extended schools providers need to know how many children with disabilities or special needs wish to attend. The provision will need to be expanded both in special and mainstream schools.**
- 4. There is a need to expand a specialist and inclusive service, such as Moorcroft School.**
- 5. The need to ensure staff are adequately trained to successfully meet their job criteria must be highlighted.**

Following this evidence we therefore recommend that the Council develop the Short Breaks provision in accordance with the following recommendations to be approved by Cabinet:

RECOMMENDATIONS:

Recommendation 1: That the Cabinet consider the following ways to improve the Short Breaks Provision in the borough.

Recommendation 2: Review signposting of services to ensure clear and consistent information is available via both our own information services including the contact centre, schools and via our partner agencies including the PCT

Recommendation 3: The demand of extra services within the Extended Schools programme to be assessed. Provision of inclusive services with mainstream setting to be reviewed together with the expansion of specialist provision via the special schools. This would build on the current excellent work undertaken by Moorcroft School.

Recommendation 4: To expand the current flexible payment arrangements ensuring that parents / carers can access the types of provision that best suits their needs.

Recommendation 5: Ensure that suitable transport is available to enable all children to access extended school services.

Recommendation 6: Provide clear information to all users on appeal process.

Recommendation 7: Review management of outreach service to ensure that cover is available when regular workers are absent. Methods of communication to parents to be reviewed.

Recommendation 8: The Fiesta booking process to be reviewed to ensure ease of access for all users.

Recommendation 9: The current residential provision needs to be reviewed to see if it is practical and cost effective to replace the current inadequate Howletts Lane provision with an expanded and purpose built provision at the Merrifields site.

Recommendation 10: Further work to be undertaken to ensure that there is a smooth transition between child and adult services in particular for the most needy users.

Recommendation 11: To improve the range of services improve and develop links with the voluntary sector. Investment in services such as HomeStart appears to provide good services at a cost effective price.

Recommendation 12: Use the existing expertise of voluntary sector providers to provide additional breaks for families.