

Report of parental feedback for Bromley Short Breaks consultation 2013/4.

In order to inform this consultation report, Bromley Parent Voice hosted two meetings for parents. Across the two meetings we engaged with 49 parents, two of these were new members of BPV. Text shown in italics are direct quotes from parents, notes from the author are shown in blue.

Information has been separated into the following headings:

- 1. Eligibility**
 - 2. Direct Payments**
 - 3. Personal Budgets**
 - 4. Market place**
 - 5. Riverside & Hollybank**
Sub headings: **Non Attendance**
 Riverside
 Hollybank
 - 6. Targeted Provision**
 - 7. Universal Services**
 - 8. Extending beyond age 18**
 - 9. Flexibility**
 - 10. Wish list**
 - 11. Family/social breakdown ~ long term risks for LA to consider**
 - 12. Communication & Information**
 - 13. Concerns**
 - 14. Ideas, comments and possible solutions**
 - 15. Legislation & Government commitment to providing Short Breaks**
 - 16. Action points for BPV**
- Appended letters from parents.**

1. Eligibility

Concerns were raised by parents that there is no panel that makes decisions. The processes are unclear and appear unfair. Parents do compare and whilst it is understood that awards may vary due to individual circumstances, there is a perception that those who shout loudest, obtain more.

Parents wish to see a clear, fair and transparent process.

Parents do not believe the points system assessment framework should have been withdrawn, they are also concerned that this happened without consultation. Parents feel there is a need for a transparent Resource Allocation System in order to implement personal budgets.

There needs to be a quicker response for when circumstances change. There is also a need for support whilst a child is in hospital.

When deciding on awarding Short Breaks there needs to be a holistic approach, taking into account the needs of the child, the whole family and wider circumstances.

There is much concern that Short Breaks will only be given to those who have an EHC plan. There is a lack of clarity on how the reforms (Children's & Families bill) will impact upon those who either do not have an educational need or the educational need is not deemed high enough for a plan.

Parents have requested a clear appeal process.

During Short Break meetings held last June a parent asked what right of appeal exists following unsuccessful assessment. No answer was provided however, Mark did admit that lack of formal diagnosis for a child would lead to an unsuccessful claim for Direct Payments. This is at best confusing, after all a child can enter specialist education provision and access Disability Living Allowance without formal diagnosis.

Some parents resent having to undertake assessment. One said it made her feel like she was begging. There are parents, who for a variety of reasons, do not trust social workers and therefore shy away from accessing much need Short Breaks.

“ Assessments are costly and families have to go through so many, Why can't they (SB team) accept diagnosis, DLA and/or specialist school placement as meeting eligibility?.”

A number of parents suggested there could be a baseline eligibility set without the need for assessment. If families need more than the baseline provision, they would then have to be assessed. The baseline idea could help cut down on the costly assessment process.

One parent suggested the following:

“You need to be qualifying for middle to high rate disability living allowance and therefore, able to claim carers allowance.”(sic) Note: Believe this is to be eligible for Short Breaks, also not all parents are able to claim carers allowance even if in receipt of DLA for child.

1. Eligibility cont.

“If you want Holly bank, you need to be on high rate to show a need for night time respite.”

“Once you qualify in principle then there needs to be an assessment of some sort. This will be very personal. Things to include should be: -Family set up, for example singles parent, siblings, locality of family members as well as the child’s needs and disability.”

There is a perception that if parents appear to be well off, own a nice house, work etc., then they do not need Short Breaks. [The Carers and Disabled Children’s Act 2000 on assessments & services states: The local authority’s decision under subsection \(4\) is to be made without regard to the means of the carer or of the person cared for.](#)

“The assessment is interpretation based Q&A’s with social worker. In my experience the social worker made assumptions.”

2. Direct Payments

“Without a grant or contract to provide a service, providers may worry that enough individuals will come forward with either Direct Payments or their own money.” This is a concern felt by all parents consulted.

“As regards the matter of direct payments, our feeling is that in certain circumstances this can be a good idea but we worry greatly that it will inevitably lead to the diminution of services provided to parents via the Council and wonder whether it has been thought through. The more people who arrange their own care, the smaller the remaining group will be and the less efficient/cost effective providing services directly to them will be. Going down this route creates a self fulfilling prophecy.”

“On a personal level, the prospect of 'employing' and being responsible for people who care for our son is not a pleasant one. Not only are benefits of scale lost when trying to purchase services on a personal level, but there is the problem of all the administration and regulations involved with it. It seems to me that people who choose this option will need to be made fully aware of what their responsibilities and potential legal liabilities are. Things such as data protection, insurance, health and safety, tax etc. come to mind but there will be others I'm sure. If the council is going to push direct payments as an option it ought to be making people fully aware of all the legal implications and risks associated with so doing.”

Some parents feel that direct payments are a way of passing the responsibilities to source services back onto parents.

3. Personal Budgets

Consensus was that parents do not want the stress and hassle. Concerns regarding the market place not being established and what will happen if providers are not there. Vibrance advised about the PA register which was welcomed.

3. Personal Budgets cont.

Concerns regarding how personal budgets are calculated if Bromley does not have a resource allocation system (RAS). Again this needs to be fair and transparent.

Concern that only those with EHC plans will be eligible for Personal Budgets.

4. Market place

Contracting services can be time consuming and inflexible. The grant for ASD holiday provision during Oct half term, Christmas & Feb half term, illustrates how this process is flawed, with the LA hindered by the legal obligations of the tender process.

Until there is a developed market we would like to see long term contracts awarded to current providers. The reality is that SEND is a niche market with few providers. This is very unlikely to change as providing for SEND has high overheads and low profits.

5. Riverside & Hollybank

Non attendance

“There should be contract/agreement between LA, short break provider and family setting out responsibilities of all parties. This includes parents notifying provider if their child is not able to attend, with reason why i.e. illness, refusing to attend etc. Parents who fail to notify short break provider more than 3 times should have a penalty. Where parents notify provider and this is a regular occurrence then this should be followed up by Mark's team in case provision is not the right one.”

“The knowledge that much needed respite services like Hollybank and Riverside Play Schemes are being wasted is frustrating in the extreme and surely a plan B needs to be adopted so that available spaces can be offered to other families who may be able to take them at short notice. It makes no sense for facilities and staff to be wasted but of course, few people are likely to want to take up such places if doing so will simply mean them losing out on an equivalent service they'd already secured at a time to suit them. Clearly more effort needs to be made to ascertain the reasons for unexplained absences and to make parents aware that they have a responsibility to inform the relevant organisations if their child is going to be unable to access the provision. Some sort of sanction may also have to be considered for those parents who repeatedly 'abuse' the service.”

These comments were echoed by many of the parents, with many suggesting allocation should be reduced if there is regular failure to attend. It was also stressed that the Short Breaks team should investigate reason behind persistent non attendees as there may be an issue affecting family where they need support or a modified allocation of support.

A few parents suggested that if they shared transport it may encourage families to 'make the effort' to attend. The transport would be a private arrangement but parents asked if the LA and/or provider could help match families. This is because families do not necessarily know each other. This can be done in a discreet way e.g. service provider advertising family in Penge who can offer car share.

Non Attendance cont.

Allocation currently is made at convenience of the LA and/or provider rather than family. Dates are allocated three months in advance with no reminders. Many felt a text message to prompt families could easily be organised. [Note: BPV believe they may now be giving reminders and if approached can be flexible. This perception probably illustrates a communication breakdown rather than an issue.](#)

Hollybank try to 'match' peer groups and it was felt that Riverside could also do this. It was felt this may help encourage child to attend.

A number of parents asked if non attendance was still an issue and if so, what are the actual numbers? Concern was raised over Children's Disability and Short Breaks team efficiency if places are not being used.

Riverside

Children love going to Riverside - For those with who attend Riverside school, it is not a 'new' environment so less hassle for parents to get them there

Need further clarity on why Riverside might not be interested in retendering

"Provisions that need to be in place in Bromley must include a suitable environment equal to Riverside which has all the equipment needed for children with physical disabilities. There appears to be so much disparity with regard to this provision. Is it over subscribed or not, are there places or not, are people not turning up or is this a myth. This, in my opinion shows just how inefficient the social care team is and they really need to start to provide hard evidence to show what is actually going on. I know there is strong evidence that Riverside may be closing but it is very important that something should be in place to continue giving a similar service. Clear guidelines need to be drawn up so families are aware of the rules with regard to accessing this service and there should be more flexibility so that families are given times and dates suitable to their families needs. This isn't rocket science and is extremely easy to implement."

As can be seen by the above statement, parents are very concerned and anxious about the possible loss of Riverside. Parents are worried that there is nowhere else similar to Riverside. Parents are unable to identify similar provision to 'buy' service from. This is especially the case for those families that need specialist equipment such as hoists.

Riverside is seen as a youth club and not just respite.

Parents welcome the spread of location across borough that Riverside can provide. Parents do not want to travel long distances for Short Breaks. It is viewed as a safe environment.

"Any facility that is not Riverside would be a downgrade."

Parents would like greater flexibility to chose and/or change dates. They would also like the opportunity to buy some placements.

Hollybank

Most parents unhappy with idea of child staying with a 'host' family instead of central scheme.

"We are concerned at the lack of choice available to our families. There are few providers for children with high level of need and we are worried that without block contract from the borough the few that exist may disappear."

The LA has a determination to provide for children within borough rather than give out of borough placements. Many out of borough placements are residential so if children are to be kept within borough there will be an increased number requiring Short Breaks. This will result in a greater demand upon the specialist provision as these children have high level needs.

Some parents stated that Hollybank does not always meet the needs of child because:

- a. They do not offer age ('ability' is probably a better term here) appropriate leisure activities.
- b. There are bizarre collection time arrangements
- c. They are not taking children outside
- d. Some concern regarding training of staff.

BPV are aware there is to be an event run by Bromley Carers in March to talk about quality of care homes. This event is in association with Healthwatch Bromley and Bromley Council. We understand this is for adult provisions however, will similar information be made available to parents with regards to Hollybank?.

These were issues highlighted by a couple of parents however, the majority that have used Hollybank did not fault the service.

6. Targeted Provision

"The other thing I would like to see is more coach trips for families in the holidays. I think these would be a great success and be a good source of support as well a good day out. Mencap do these but I think there should be more. The autistic cinema days are also very good."

At a Short Break meeting held last summer, it was obvious that CASPA is a much valued provision. The families using this service are the ones where social skill (or lack of) prevent their children going to mainstream setting even with one to one support. CASPA is not a cheap after school provision, with or without direct payments.

It was clear that a number of families present at the meeting are single parents struggling financially. Good as CASPA is parents would not choose it over much cheaper and more convenient after school activities if their children could enter mainstream activities successfully.

CASPA does provide great understanding and support for those with ASD. There are possible long term savings to be made if this cohort is given appropriate support. [Note: See Edward Timpson MP comment at 8. Extending beyond age 18.](#)

7. Universal Services

"I also think local universal providers should be encouraged to include children with disabilities if they are deemed suitable with extra support. I think what would be useful would be for someone who was very passionate and knowledgeable were to go and visit some of these places and give a hard sell reassuring them that it could work. The type of provisions I am talking about are places like drama academies, sports clubs or holiday clubs. I do think that if this were to happen there would have to be realistic costs and families would need to be aware that they would have to pay for these provisions as they would for any typical child but they could use direct payments to pay for any additional support that they needed which could come from either the provider or someone known to the family."

Under fives have very little provision as it appears they are considered able to access universal services. We acknowledge that support provided for under five's on the autistic spectrum has improved. This is through the service offered by CASPA. Other providers are struggling to continue or have stopped their holiday provision. This is mainly because in the past they were grant funded but are no longer. Parents indicated they would like to use Direct Payments for such providers but there appears confusion over whether they are allowed to. Providers mentioned included Maypole and Kids & Crew.

8. Extending beyond age 18

Following extract is from a message to the Association of Colleges (AoC) about preparations for reforms to special educational needs. These comments were made by Edward Timpson MP on 8th December 2013.

"For instance, we know that just under a third of young people with special educational needs (SEN) statements at 16 are not in education, employment or training at 18, compared to 13% of their peers. Employment rates for those with learning difficulties are much lower still, at less than 10%.

The consequences of this can be seen in the £5 billion local authorities spend every year on social care for adults with learning difficulties - costs that are second only to the costs of supporting the elderly. Yet I believe, and I'm sure you believe, that we can do so much better than this, both on outcomes and budgets.

A 2011 National Audit Office report into special education found that supporting a person with a learning disability into work could - as well as increasing their income by between 55 to 95% - cut lifetime costs by around £170,000.

And if they can also be supported to live semi-independently rather than in residential care, their lifetime support costs could shrink by around £1 million.

So there's as much of an economic as a moral case for reform, with every incentive for local authorities to work with you to get this right."

Parents have a real concern that there is a lack of services/provisions for over 18. [Note: we welcome Debbie Christie involvement of BPV and hope this can lead to better provision for this cohort.](#)

8. Extending beyond age 18 cont.

“We are very worried about the lack of appropriate provision for those aged 18 and above. Hollybank is clearly an underutilised resource and we can see no good reason why they, and other providers, could not continue to accept children aged up to 19. Doing this in the short term would at least allow more time for the Council to complete its review and ensure that suitable services are available once children can no longer access those they’ve previously come to rely upon. We are parents of a teenage boy and are painfully aware of how limited our options for entertaining our son now. He loves playing in the local park etc. but we’ve become increasingly aware that other parents are conscious and even suspicious of his presence amongst the younger children. This isn’t only an issue in local parks, it affects all public places we take him to and greatly inhibits our options without turning ourselves into complete social outcasts.”

9. Flexibility

Parents would like to see greater flexibility on how direct payments can be used. There is some confusion over use of family members or friends not registered as childminders. Within Adult Services family members can be paid by direct payments as long as they do not live in the same home as the young adult. Parents would like greater flexibility on Short Break provision e.g. be offered a mix of Mencap childminding and Direct Payments. Parents would like to be able to ‘buy’ place on Mencap coach trips, either through Direct Payments or private funds.

10. Wish list

Contract needs to be LONG - Our children need Continuity
Journey times are an issue - Sites needs to be within easy reach of vast majority of population
Quality of provision needs to be age (ability) appropriate
Provision should encourage child to be more independent
Possibility of paying but not direct payments as majority of parents find these confusing and lots of hassle
A day with variety
Reliability of staff
Medical facilities
Good facilities - Soft play, sensory room, physical equipment, sunken trampoline
Flexibility on dates
After school/weekends/holidays
Safe
Parents would like sitting service, either come to your home or somewhere for child to stay.
Parents would like access to Tree Tops (Parkwood Hall provision).

10. Wish list cont.

More choice and flexibility regarding overnights and sitting service

Emergency contact list

Borough to publish a list of Hollybank and Special School staff who would be available for PA work.

Develop Short Breaks for 18-25 year

Some parents expressed that they would willingly pay privately for provisions however, found provisions are few and far between.

11. Family/social breakdown ~ long term risks for LA to consider

“We know many parents like us are determined to do their best to look after their children for as long as possible. However, the sad reality is that if adequate respite provision isn't provided the likely result will be family breakdown, much loved 'special' children being taken into care and quite possibly suffering mental health issues due to lack of contact with 'normal' people and a non-existent social life. Since the cost of this in both financial and health terms would be enormous, it would make sense for the Council to try to better support parents in that situation, not take away the services they rely on or impose, indirectly, the additional burden of being responsible for employing and managing their own carers.”

Early Support is currently targeted towards children with a high level of need but we should also provide for those with moderate or lower needs. There have been many studies undertaken, across the political parties, that have recommended early intervention and warn of the long term impact of inadequate support. If not supported early our families can face bleak outcomes. Such outcomes may result in many of our families requiring support from Health, Social and Adult services further down the line. This would see costs escalating and an increase in family breakdown.

We urge the LA to consider potential long term savings if families are supported with their caring roles.

12. Communication & Information

We had a show of hands across the 49 attendees:

There were 9 parents aware of the LA Short break consultation meetings, of these 6 managed to attend.

Only 4 parents had heard of Mylife portal.

Only 6 knew of the Local Offer

12. Communication & Information cont.

Parents did not attend Bromley's meetings because:

1. They were unaware of them. Information was on My Life portal which parents had not heard of.
2. Dates and timings
3. Parents feel LB Bromley do not listen to parents. *Note: Some parents decided not to attend the BPV meetings as they felt there was little point, expressing comments such as "we spoke to council last summer and nothing changed". This illustrates a need for improved feedback.*

"If services do exist then very hard to find - Currently all information seems to come through word of mouth not the council"

"Council meetings last minute and at difficult times for parents (6pm!)"

For retendering, parents want to be involved on all tender process Parents to be involved in the commissioning of Short Breaks both in terms of rights specifications and decision making panel.

"Local Offer doesn't exist!"

" Local offer is not easy to understand. Why is it on Mylife and not on Bromley.gov?Put it on now!!!"

Concerns that not all social workers/assistants have given or give correct information to parents.

"Parents get their information from other parents because they are open, honest and have our best interests at heart".

Some parents get information from Pel.

"LB Bromley are not great at listening to parents. "

Some parents suggested that they should be able to access Short Breaks through their GP. *Note: This is a good idea. At recent Carer's forum, CCG reps said that GP's would keep a carers register. The CCG are also looking at ways to support carers so that they do not escalate into a costly health situation. Alongside this NICE have just issued guidelines around autism with recommendation that all diagnosed autistic people should have a care plan and that all those with a care plan should have a key worker. Believe there is room here for the LA to work in unison with the CCG to develop Short Breaks for carers.*

13. Concerns

"If provision contract is not fulfilled/not up to standard then does money get lost and facility doesn't happen?"

"With the point system removed how can short breaks be quantified - Very concerned!"

"Out of borough resources - Hassle and lack of communication"

Parents would like any contracts for provisions to be long term. Do not want upheaval of regularly changing providers. Continuity is vital for many children.

Sibling support is very scarce and families would like to see an increase in support around siblings (both with and without disabled child). Again parents are happy to pay for this support but cannot currently source it.

"Personal Budgets will only work if the facilities exist!"

Fear that market may not develop as there is little profit catering for special needs. Parents experience is that when universal services open their doors for special needs groups, it is always at the 'graveyard' times i.e. when they would not lose money.

This is exacerbated if specialist equipment and/or staff are required.

14. Ideas, comments and possible solutions

"During the summer holidays particularly there must be many school or other buildings which are either closed or underused which could be suitable. There are people out there who'd be willing to help but who don't have suitable facilities and can't afford to hire them on the open market."

Could the facilities at Darrick Wood, Marjorie McClure etc. Be made available to families outside school hours/usage?

Central Booking system where facilities can be booked on line (BPV Website?)

"Bromley has in the past provided support (equipment, facilities, insurance cover etc.) to volunteers engaged in such activities as renovating local parks etc. Could they not build upon this concept and make available facilities for parents and other volunteers to use for the provision of activities for our children?"

"I have also thought about some of the local leisure centres opening up their facilities to children with additional needs and this again needs a good hard seller to speak to the manager at somewhere like the Pavilion to see if a few times over the holiday period the facilities could be used exclusively for these children for a few hours. "

14. Ideas, comments and possible solutions cont.

“Hawes Down is not a viable solution - It does not have the capacity or the facilities” This comment stems from discussion on where children could attend if Riverside stopped providing. Other parents would like to have greater use of Hawes Down. Would like to have opportunity to hire facility for birthday parties etc.

Some parents would be willing to pool direct payments for a service. Whilst this seems sensible parents were quick to point out that there are problems with this idea. Issues mainly centre around who would organise pooling of payments, Who would organise service and how this could be opened up to others. Many parents are isolated, they do not know other parents especially if child is taken to school on transport.

On more positive note, some parents would still be willing to pool money for a service brokered by a voluntary sector organisation e.g. coach trip organised by Mencap

Parents could work with LA to develop market place. There was a number of parents who would like to have access to swimming with specialist staff, others that would like to access a programme such as wheels for wellbeing which is over subscribed. General comment was that whilst there is a scattering of provision across the borough, these also had long waiting lists.

A few parents recalled that both Riverside and Marjorie McClure used to be open on Sundays for swimming. Many felt this would be a great provision for their children.

Some parents felt they could offer sitting service to other parents and would like to be able to use Direct Payments for this.

Parents value peer to peer support.

15. Legislation & Government commitment to providing Short Breaks

Parents are aware that *central Government made provision of over £800 million in non ring –fenced grants to local authorities for the provision of Short Breaks between 2011-12 and 2014-15. In addition, £40 million of capital funding has been made available to local authorities in 2012-13, in a repeat of last year’s award ([information from Department for Education website 17/10/2012](#))* The Government recognise the importance of Short Break respite such that they have maintained the level of funding despite being in times of austerity. This money is not ring fenced and relies upon local authorities using it wisely.

There are two aims for Short Breaks:

1. To enable the child to participate in fun, interesting and safe activities
2. To provide a break from caring for the parents. [Extract from DfE Statutory guidance on how to safeguard and promote the welfare of disabled children using short breaks](#)

Right of carers to assessment. [Carers and Disabled Children's act 2000. Carers' assessment](#)

3.13 Under section 6 of the Carers and Disabled Children Act 2000 parents of, or persons with parental responsibility for, a disabled child have a right to an assessment of their needs as carers if the local authority is satisfied that the child and his/her family are persons for whom it may provide services under section 17 of the 1989 Act.

As outlined in the Assessment Framework: 'The needs of parent carers are an integral part of an assessment. Providing services which meet the needs of parents is often the most effective means of promoting the welfare of children, in particular disabled children.'

[Extract from The Breaks for Carers of Disabled Children Regulations 2011\).](#)

*Duty to make provision*³. *In performing their duty under paragraph 6(1)(c) of Schedule 2 to the 1989 Act(1), a local authority must—*

- (a) have regard to the needs of those carers who would be unable to continue to provide care unless breaks from caring were given to them; and*
- (b) have regard to the needs of those carers who would be able to provide care for their disabled child more effectively if breaks from caring were given to them to allow them to—*
 - (i) undertake education, training or any regular leisure activity,*
 - (ii) meet the needs of other children in the family more effectively, or*
 - (iii) carry out day to day tasks which they must perform in order to run their household.*

*Types of services which must be provided*⁴.—*(1) In performing their duty under paragraph 6(1)(c) of Schedule 2 to the 1989 Act, a local authority must provide, so far as is reasonably practicable, a range of services which is sufficient to assist carers to continue to provide care or to do so more effectively.*

(2) In particular, the local authority must provide, as appropriate, a range of—

- (a) day-time care in the homes of disabled children or elsewhere,*
- (b) overnight care in the homes of disabled children or elsewhere,*
- (c) educational or leisure activities for disabled children outside their homes, and*
- (d) services available to assist carers in the evenings, at weekends and during the school holidays.*

Short breaks services statement

[The Breaks for Carers of Disabled Children Regulations 2011](#)

5. (1) A local authority must, by 1st October 2011, prepare a statement for carers in their area (a "short breaks services statement") setting out details of—

- (a) the range of services provided in accordance with regulation 4,
- (b) any criteria by which eligibility for those services will be assessed, and
- (c) how the range of services is designed to meet the needs of carers in their area.

The Breaks for Carers of Disabled Children Regulations 2011 cont.

(2) The local authority must publish their short breaks services statement, including by placing a copy of the statement on their website.

(3) The local authority must keep their short breaks services statement under review and, where appropriate, revise the statement.

(4) In preparing and revising their statement, the local authority must have regard to the views of carers in their area.

Appended to this report are three letters from parents. Such was the strength of feeling with some of our parents, they sent letters in addition to attending meetings. We have taken out personal data to ensure anonymity for these families.

Action points for BPV.

1. BPV to request local statistics on increase in numbers and complexity
2. BPV to follow up on Local Offer, how do we make parents aware of it?
3. BPV to request assessment framework is reinstated and looked at to ensure holistic approach. Separate assessment for ASD?
4. BPV to find out if it is national or local policy that Short Breaks are not given when a child is in hospital

Letter One

Dear Kay

Thanks to you and your colleagues once again for arranging a very interesting and important meeting during which some very important points arose.

As regards the matter of direct payments, our feeling is that in certain circumstances this can be a good idea but we worry greatly that it will inevitably lead to the diminution of services provided to parents via the Council and wonder whether it has been thought through. The more people who arrange their own care, the smaller the remaining group will be and the less efficient/cost effective providing services directly to them will be. Going down this route creates a self fulfilling prophecy. On a personal level, the prospect of 'employing' and being responsible for people who care for our child is not a pleasant one. Not only are benefits of scale lost when trying to purchase services on a personal level, but there is the problem of all the administration and regulations involved with it. It seems to me that people who choose this option will need to be made fully aware of what their responsibilities and potential legal liabilities are. Things such as data protection, insurance, health and safety, tax etc. come to mind but there will be others I'm sure. If the council is going to push direct payments as an option it ought to be making people fully aware of all the legal implications and risks associated with so doing.

The knowledge that much needed respite services like Hollybank and Riverside Play Schemes are being wasted is frustrating in the extreme and surely a plan B needs to be adopted so that available spaces can be offered to other families who may be able to take them at short notice. It makes no sense for facilities and staff to be wasted but of course, few people are likely to want to take up such places if doing so will simply mean them losing out on an equivalent service they'd already secured at a time to suit them. Clearly more effort needs to be made to ascertain the reasons for unexplained absences and to make parents aware that they have a responsibility to inform the relevant organisations if their child is going to be unable to access the provision. Some sort of sanction may also have to be considered for those parents who repeatedly 'abuse' the service.

We are very worried about the lack of appropriate provision for those aged 18 and above.

Hollybank is clearly an underutilised resource and we can see no good reason why they, and other providers, could not continue to accept children aged up to 19. Doing this in the short term would at least allow more time for the Council to complete its review and ensure that suitable services are available once children can no longer access those they've previously come to rely upon. As the parents of a teenager, we are painfully aware of how limited our options for entertaining our son now are. He loves playing in the local park etc. but we've become increasingly aware that other parents are conscious and even suspicious of his presence amongst the younger children. This isn't only an issue in local parks, it affects all public places we take him to and greatly inhibits our options without turning ourselves into complete social outcasts.

We know many parents like us are determined to do their best to look after their children for as long as possible. However, the sad reality is that if adequate respite provision isn't provided the likely result will be family breakdown, much loved 'special' children being taken

into care and quite possibly suffering mental health issues due to lack of contact with 'normal' people and a non-existent social life. Since the cost of this in both financial and health terms would be enormous, it would make sense for the Council to try to better support parents in that situation, not take away the services they rely on or impose, indirectly, the additional burden of being responsible for employing and managing their own carers.

Bromley has in the past provided support (equipment, facilities, insurance cover etc.) to volunteers engaged in such activities as renovating local parks etc. Could they not build upon this concept and make available facilities for parents and other volunteers to use for the provision of activities for our children? During the summer holidays particularly there must be many school or other buildings which are either closed or underused which could be suitable. There are people out there who'd be willing to help but who don't have suitable facilities and can't afford to hire them on the open market.

I trust you'll pass on our comments and concerns to the review and thanks again for all your hard work!

Letter Two

Copy of letter sent to local MP and councilor

Dear,

I am contacting you regarding the possible changes to respite and short break services for disabled children currently under review. I attended a meeting at Bromley parent voice last Friday where the subject was provisions available in the borough. There were some very worrying issues and I wish to raise them with you and hopefully get your views on the subject too.

Firstly, my background is that I have a child who has severe autism and learning difficulties. My child is a pupil at Riverside school in Orpington and attends the Saturday and holiday club currently run there, we also receive 1 night a month at Hollybank for respite. Our child is enjoying school and loves attending the holiday club on occasions and is very happy to be there.

The issues I would like to raise are as follows:

1. Riverside Saturday and holiday club scheme -

The marvellous Riverside school currently runs a club on certain Saturdays and on allocated days in the school holidays from 10am to 4pm. It is very popular with parents as many children already attend the school and many of the staff help run the club so the kids are familiar with everything and settle nicely. There are also a wide range of activities centred around sensory needs, such as soft play, sensory room, great outdoor space, trampoline, swimming and safe play equipment. The facilities are all there to accommodate all needs including physical, such as changing equipment and hoists etc. It's a safe and secure environment where our children can have a fun and enjoyable day.

Many of us have another child or children so spend this time being able to do something with our other child that is not usually possible. When my child is at the club for a day I will take my other child shopping, bowling or skating, cycling, basically an activity which is not possible when we have our autistic child with us and it gives my other child a chance to have my full attention for a time. So it's a really vital service for us and without it our lives would be seriously affected.

* The scheme at Riverside may end at the end of this summer and as of yet no alternatives have been arranged. The problem will be is there are very few other places that can offer the equipment, safety and environment that Riverside can. The club cannot be held in a church hall or community centre as there would be no facilities to accommodate the children. They need to have sensory and physical equipment, they cannot be expected to stay in a room just with some toys. These are children whose attention span is often very short so a variety of activities need to be available. Also there has to be changing and toileting facilities which does not just mean a disabled lavatory, hoisting equipment etc and a room for medication to be kept safely.

The only other place we could think of that could be used for a club is the Marjorie McClure school in Chislehurst. It would have most of the facilities and still be fairly accessible for people who live in Bromley/Orpington/Petts Wood and Biggin Hill, the main areas served by Riverside.

If Riverside school do not want to run the scheme themselves we feel that it should be an option for a 3rd party to run the club and use the school's facilities. After all, Riverside is such a fantastic place with 1st class equipment and probably one of the best in all the boroughs, it seems crazy not to take advantage of that and get the absolute most out of it, as it's already there why not use it? There is no reason why equipment should get broken as far as I know I do not believe that happens at the moment so I think it would be unlikely to be a regular occurrence even if it were run by another party. And I assume there are insurances in place for certain equipment and eventualities.

At the meeting the general feeling was that Riverside was the absolute perfect environment to run a respite club and we would all be extremely sad to see that diminish.

2. Hollybank respite care -

My child spends 1 night a month at Hollybank presently. Our child's sleep can be quite erratic so for the 1night to know that all of us will be able to have a full nights undisturbed sleep is pretty vital.

The centre has great facilities including soft play, sensory room, art room, lovely garden and is totally safe and secure. When our child goes there I know that not only is he enjoying himself with a variety of activities but also he is kept safe by the trained staff, looked after and cared for and he cannot get out of the grounds. I don't know if you have ever been there but if not I would strongly advise it as it really is a fantastic place that Bromley should be very proud of.

The other option that many of us who use Hollybank are offered is something which I believe is referred to as a foster scheme. This is where your child is looked after by another family in their house for 1 or 2 nights or however long the respite is for. Now if you asked most people if they would be happy for their child to stay in a strangers home, 99% of them I am sure would say no. So I do not see why it is thought that it should be acceptable for parents of a disabled child be to happy to do that. There is no way and it would be totally out of the question that I would ever allow my child to stay in a strangers home, for even an hour let alone a whole night. He cannot speak so could not tell me anything about what was happening and they could accidently forget to lock a door and within minutes he could be outside in the road. Anything could happen and I would not know about it, it is a completely terrifying notion to be honest and we would never allow our child to participate in that sort of scheme.

I understand that the running of Hollybank is obviously an expense but it is an amazing facility that is already there. It is purpose built and meets the criteria and more and to have it there and not make use of it correctly would be just be a total waste of the effort already put into it. It would not make sense to have such a place and not put it to use.

Many parents like us need some respite to enable us to do the job we do the best we can. Carers save the government and local authorities millions each year by caring for their loved ones, and if we could not do it then what would happen?

Having respite facilities is a vital part of an authorities budget and as a carer is an absolute life saver for us. Giving us a short break and for many of us time to spend with our other children whose lives are also severely affected by having a sibling with special needs.

3. Direct Payments -

A good 80% of parents in the meeting were not happy with this scheme at all. There is a huge amount of confusion around it and it is not something that I personally would want to engage with in its present state. For many of us our lives are so busy that having the time to

organise a budget like this would be extremely difficult. There are also going to be a number of people who would not be able to manage the direct payment scheme. For many people if they are or their partner's are self employed it affects their tax etc. The most confusing part of this scheme is having to be an employer and sort out the tax element and holiday entitlement etc and the liability aspect. In it's current format this scheme is just too complicated and long drawn out for the majority of people to be included in. I think it needs to be hugely simplified before it can be rolled out a wider basis.

4. The role of social workers -

This is another confusing aspect we all have to go through. There is a real difference it seems regarding the level of quality here. One issue is the actual name, I think the word social worker should be changed to perhaps family liaison officer or something similar. I did not request a social worker for years as like many parents do not purely because you feel a stigma attached to having a social worker, it feels like something you shouldn't need to have. But obviously to access any of the schemes you need to be assessed so it's a necessary part of many lives.

Many of us felt that we were not being offered the services available and had to go down a long route of constant pushing to be taken seriously. And that as we were clearly in control of our lives and homes etc that we were penalised and not given the options required.

Now obviously if a family are in desperate need they should be helped, no one would be contesting that at all, but equally if like many of us we work hard to ensure everything is as smooth as possible that should not mean that we are not given any help.

It seems that the experiences many of us had is that we were pushed into not requesting respite.

When I first saw a social worker I was told that any night respite was only offered to people who were completely desperate, and really made to feel like I was asking for the impossible and it made me feel I should not be doing so. I took it no further at that stage as I felt quite uncomfortable about it and felt like I was perhaps being unreasonable with my request.

Two years on, I saw another social worker who was extremely pleasant and helpful and the total opposite experience of the previous time. I was taken seriously and put forward for overnight respite care. The process then took over 4 months to be arranged which I feel is rather excessive. Apparently the social worker compiled her report which then had to be put before a panel of people, what people I do not know? Surely that whole process could be far more simplified and cost effective?

Many of us feel the system is still very old fashioned and I expect has a vast amount of financial wastage and should be reviewed to become simplified, more cost effective and family friendly.

5. Future budgets -

The fact is for whatever reason, possibly due to higher survival rates of premature babies is that each year more children are requiring a statement of special needs. This trend will no doubt carry on and in 5 years time there will be a greater need for these facilities and schemes and even more in 10 years etc. SEN schools will need to grow and even more built over the future years. And importantly, all of these children will one day become adults but still require very similar care they have now. The structure has to be in place to deal with this and continue investment in facilities and opportunities for disabled children/adults is paramount for the future of all boroughs. It is not something that can be ignored and put to one side, it is vital for everyone's sake that education and opportunities are made for those

among the spectrum of all needs.

We all know that budgets are being squeezed but this is one area that will need investment, the key is to run this area as effectively as possible and not take away vital services but avoid wastage regarding unnecessary procedures and red tape. It can be done and I suspect to a great effect but at present there does appear to be a great deal of long drawn out practices that no doubt create a great deal of wasted budget.

I do apologise for the length of this email but I really wanted to give an outline as to the discussions that took place and points that us parents feel are extremely important to address.

I would be grateful to hear what your views are regarding the current services and what changes may be taking place. I hope that the powers in the authority will be able to continue with the good quality services that are offered and our children do not have to miss out on the care they currently receive whilst at their holiday clubs.

([councillors name](#)) - I am copying you in on this as I understand you have had dealings with these type of issues before and members of the Parent Voice highly recommend your opinion, so I hope this is okay.

Many thanks for taking the time to read through my notes and I hope to hear from you both in the future regarding this extremely important subject.

Letter Three

I thought I'd send you some of my thoughts about short breaks. Eligibility Criteria needs to be clear. I was thinking something along the lines of you need to be qualifying for middle to high rate disability living allowance and therefore able to claim carers allowance.

If you want Holly bank you need to be on high rate to show a need for night time respite. Once you qualify in principle then there needs to be an assessment of some sort. This will be very personal. Things to include should be: - Family set up, for example singles parent, siblings, locality of family members as well as the child's needs and disability.

Provisions that need to be in place in Bromley must include a suitable environment equal to Riverside which has all the equipment needed for children with physical disabilities. There appears to be so much disparity with regard to this provision. Is it over subscribed or not, are there places or not, are people not turning up or is this a myth.

This, in my opinion shows just how inefficient the social care team is and they really need to start to provide hard evidence to show what is actually going on. I know there is strong evidence that Riverside may be closing but it is very important that something should be in place to continue giving a similar service. Clear guidelines need to be drawn up so families are aware of the rules with regard to accessing this service and there should be more flexibility so that families are given times and dates suitable to their families needs. This isn't rocket science and is extremely easy to implement.

I also think local universal providers should be encouraged to include children with disabilities if they are deemed suitable with extra support. I think what would be useful would be for someone who was very passionate and knowledgeable were to go and visit some of these places and give a hard sell reassuring them that it could work. The type of provisions I am talking about are places like drama academies, sports clubs or holiday clubs. I do think that if this were to happen there would have to be realistic costs and families would need to be aware that they would have to pay for these provisions as they would for any typical child but they could use direct payments to pay for any additional support that they needed which could come from either the provider or someone known to the family.

I have also thought about some of the local leisure centres opening up their facilities to children with additional needs and this again needs a good hard seller to speak to the manager at somewhere like the Pavilion to see if a few times over the holiday period the facilities could be used exclusively for these children for a few hours.

The other thing I would like to see is more coach trips for families in the

holidays. I think these would be a great success and be a good source of support as well as a good day out. Mencap do these but I think there should be more. The autistic cinema days are also very good.

To be honest the social care team just doesn't seem to be passionate about what they are doing. They just seem to be a bunch of pen pushing people who do this work purely to make a living and have no interest at all in the children. I know this seems harsh and I am generalizing a bit but this area has been inefficient for a long time and goes way before austerity kicked in! [Note: this illustrates the frustration and strength of feeling some parents feel. When parents seek support from SB team, they are often already overwrought so any obstacle to receiving support can appear insurmountable.](#)

Letter Four

I am writing as part of the response for Short Breaks consultation.

We are in receipt of Direct Payments for our child and really appreciate these. They enable us to access provisions targeted to suit our child's needs.

There is a concern that suitable provisions are thin on the ground and as our child develops even less will be available.

In the early days we could access universal with one on one or high level of support. Granted out child was the largest in the crèche but their behaviour didn't 'stick out'.

Our child has grown and is now six, with the strength and size of a nine year old coupled with the behaviours of a toddler. Our child suffers greatly from anxiety and if things become too much they will become violent.

Our child can no longer access the art club run by Maypole as the staff need to maintain the safety of others. This is not a reflection on Maypole in any way, they provide excellent services. I have found my child to be out of control even if I attend as one to one support.

I aspire to returning to work however, with my child's outbursts it has been almost impossible to find appropriate childcare. I do currently perform contract work during school term times but am very limited with hours that I can accept. On occasions where such work has gone over school collection times, my husband has been the only capable & willing childcare. This has an impact upon our family as my husband has to take a day off from his own job to facilitate this. The reason for the day off is that he works over sixty miles from home.

Extended family are not able to help, indeed it is likely that our surviving elderly parents will increase the caring 'burden'. All this and I haven't even mentioned sleep issues or that I haven't had an evening out with my husband for over a year!

I appreciate our circumstances are extreme. My only reason for explaining them is to illustrate just how difficult everyday life can be. We welcome the Direct Payments but money is only a very small part of Short Break provision.

At a meeting hosted by BPV we learnt that Vibrance are setting up a PA register. This is a great idea and it would be even more appreciated if a similar register could be set up for childcare, especially adhoc care. A list of suitably vetted people showing their experience/training would be fantastic.

Adhoc child care is very difficult to secure and almost impossible to seek out when you are in the midst of day to day issues like ours. I know of a number of other parents who would want to use such a list. Please consider setting up such as part of your Short Break offer.

A tired mum.