



Charity No: 1066691

# AIMING for Disabled Children



**NHS**  
Brent

December 2009

## Brent Carers Centre

Wembley Centre For Health & Care  
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Welcome to the fourth edition of Brent's 'Aiming High for Disabled Children' Newsletter. Since the last newsletter, we have been working hard to develop a commissioning strategy with our health partners to agree the priority areas on which Aiming High funds can be spent.

Maureen Donoher, our Short Breaks co-ordinator, has given a brief overview of this strategy in the newsletter. If you have any comments about this strategy, please let me know. You can write to me at Chesterfield House 9, Park Lane Wembley HA9 7RW or email disabledchildrenteam@brent.gov.uk. The full strategy can be found at [www.brent.gov.uk/health](http://www.brent.gov.uk/health) and social

care/children with disabilities.

Another feature in the newsletter is a 'Focus on Direct Payments'. I hope under Aiming High that we will be able to significantly increase the number of parents and young people in receipt of a Direct Payment. If you are interested in changing the current care plan you receive into a Direct Payment, please contact the duty social worker on 0208 0374689

I hope you find this newsletter helpful and informative. If you have any suggestion for future articles, please let me know!

**Marion Rodin** – Head of Integrated SEN & Disability Services

## AIMING HIGH – updates

### Aiming High – on short breaks

Short breaks can be provided through a carer coming into your home to look after your child so as a parent you can get on with doing other things around the home. The carer may even be able to take your child out to a leisure activity in the local community. At the moment these carers are mainly provided through contract by an agency called Personnel and Care Bank. The contract will end in July 2010 and we will be advertising for all interested agencies to bid for this new contract. The difference with the new contract is that we have identified 2 groups of disabled children who need carers with specific skills that the agency will have to provide – these are children with complex health needs and children with a learning disability or on the autistic spectrum. Further news on the progress of the bids we receive for this contract will be given in the next newsletter.

### Aiming High on transition

Improving the way young disabled people make their transition into adulthood is an important part of Aiming High. Parents have said that having access to information on what support key agencies such as Children's and Adult Social Care, Connexions, schools, and local health services provide around transition, is crucial to them and their son or daughter. We have therefore awarded a contract to Prospects (who work with Connexions to provide Personal Advisors to young people) to develop a multi media Transition Information Pack which will hopefully answer most of the questions parents have around transition. Both parents and young people will be consulted in the making of the pack, which should be available by April 2010.

We are also committed to developing person centred support to young people in transition. We plan to offer a small group of young people and their parents the opportunity for their annual educational review to be carried out as a person centred review. The review will be facilitated by a trained worker and the young person will be given all the support they need to take part in their review and make sure their views and hopes for their future are

heard and plans made to try and meet them. This is a new way of working with young people in Brent and we want to make sure we get this model right before extending person centred reviews to more young people

### Aiming High to involve young people

We have also decided to recruit a Young Persons Participation Officer from next April to work more closely with young people to ensure that they have a say on the way services are provided. Setting up a Youth Forum will be a top priority for this person as will linking up with the Brent Youth Parliament which is already attended by two young disabled people.

### Aiming High on play provision

This summer, thanks to Aiming High funds and the hard work of our play providers, we offered more play scheme places for more children than ever before. Brent Play Service in cooperation with Brent Play Association arranged for several playschemes to take place at a number of sites around Brent. In addition, Brent Mencap and Resources for Autism were also commissioned to provide play schemes this summer. In total over 150 children had access to one or two weeks play activities and a further 50 young disabled people also attended courses and activities provided by Brent Youth Services Summer University scheme.

Plans are already being put in place to develop play provision for next year as well as to award a contract for the provision of play services from September 2010.

### Aiming High on parent participation –

The active involvement of parents in shaping the future delivery of services for them and their disabled child is vital to the success of Aiming High. I very much welcome the launch in Brent of the first parent led forum for parents of disabled children called '1Voice'. An article on this forum provided by a parent appears in this Newsletter. I urge you to join this forum so your voice can be added to those of other parents who want a better deal for their children.

# Day Trips

During the summer, three day trips for parents and carers and their families were organised by Brent Carers Centre using funds provided by Aiming High. The idea was that families were treated to a subsidised day out. Our first trip was to Legoland. This location was chosen as some parents following a brief consultation decided that Legoland was the most accessible theme park. It was also chosen as being a suitable venue for the young children as there is plenty on offer for the little ones. The day was very successful in a many ways. Firstly, we were able to take a total of 74 carers, parents and children; secondly, our transport was very accommodating to all our needs and finally, the sun shone all day for us which made it a great day out.

We were also blessed with the sunshine on both the trips to Brighton. Once again, parents, carers and children enjoyed a great day out. Some enjoyed eating fish and chips and candy floss, some even braved the sea and had a dip. For the bravest, a ride on one of the hair raising

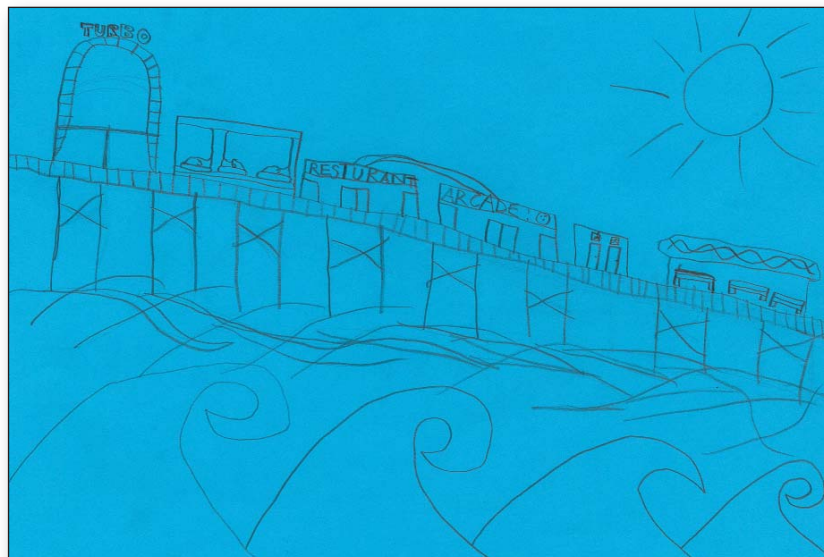
rides at the end of the pier was in order. For the majority, watching these rides was plenty to get hearts racing.

The day trips were subsidised with Aiming High funds for which we are all extremely grateful for. In total over 130 people benefitted from the trips and are looking positively to some more in the future so that families can enjoy stress-free days out together.

*“Thank you for organising the trip to Legoland. We had a nice time”.*

*“Thank you and the team for the trip to Legoland. The children had the most enjoyable day and the weather really held out for us”.*

*“Thank you for inviting us to Brighton. We were really pleased we came as it was so well organised”.*



by Jett Coleman

# Day Trips

## Parent/Carers Trip to Chessington, World of Adventures

Following many requests from parents, we went on a day trip to Chessington, World of Adventures on Halloween. Although, fancy dress was not compulsory, some of our children made a superb effort. The fancy dress theme continued when we arrived and the array of costumes were very impressive to say the least – the family of green witches were particularly eye catching if not a touch spooky!

The day proved to be very successful and yet again, the sun shone for us after a dismal and grey start. Many of our families had not been on a trip with Brent Carers previously so it was lovely to welcome new families. Once again, having the trip on a Saturday enabled all members to attend which was the focus of the trip during planning stages – it was lucky that Halloween itself was on a Saturday.

Below are a few comments parents and children said on their evaluation sheets:

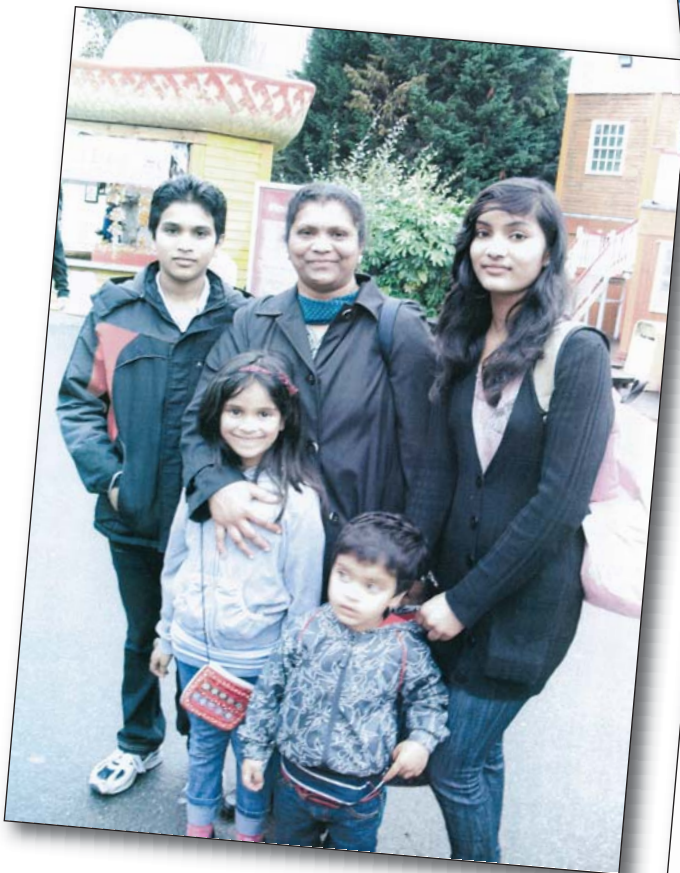
*“The best part of the day is that my whole family could be together”*

*“These trips make such a difference to our family in a really good way”.*

*“Having fun with all the kids is great”.*

*“Please organise more family trips as it is the only time we can get out together”.*

When asked for suggestions for future trips, families came up with a wide array of places to visit, including; Thorpe Park, London Zoo, country parks and the ever popular seaside. We are hoping to plan and organise more trips in the spring and summer to enable more families to join in the fun.



by Jack O'Donnell

# 1 Clement Close

So much has happened at Clement Close since our last article in aiming high.



Children and young people at Clement Close celebrated the opening of some new play equipment – thanks to the grant awarded by the Youth Opportunity Fund. The play equipment including an accessible swing and a round about was installed at the Short break unit at Clement Close in Willesden and was officially opened by the Mayor, Councillor Jim O'Sullivan on the

31 July 2009. Young people at Clement Close were able to show their appreciation to the grant makers for making a positive contribution to their project.

It was a very successful day with a large number of parent's, families and professionals in attendance. Brent steel pan band came to play, which the young people very much enjoyed and took a shine to and made the day even more memorable. Parents also brought lots of food which everybody enjoyed.

The new facilities also include a sensory room, vegetable and herb garden, which young people really enjoy whether that be helping water the garden or just relaxing and listening to music and stories or play sports from our qualified disability sports instructor.

Having access to the equipment has made a significant difference to children and young people who have profound disabilities, and has created a better social environment for parents, families professionals and young people.

The funding given in May 2009, from Aiming High has been an asset to the staff and young people in that it provided much needed training and support for the staff in story telling, intensive interaction work, group story sessions, music and song sessions. This has really taken off at Clement Close and 'Getting Desmond out of bed and off to school' the sensory story is very popular with the young people.

The Ofsted have seen the benefits and enjoyment for young people in these areas and some parent s are taking these skills and knowledge home. The Ofsted inspection report rating in June 2009 was 'Good' and gave recognition for the progress made at Clement Close.

For two of the young people who were instrumental in helping us gain the Youth Opportunity Capital Grant, there has been positive change in their lives particularly attending meetings to give progress reports of the project.

At the Respect Festival on 4 July this year, Clement Close was able to distribute the new leaflets, to promote the service and the new facilities. Young people, parents and staff played a key role at the festival.

As a result of becoming involved in the project one young person has also attended Brent Youth Parliament meetings, actively involved in 'Voice in Care' and has recently joined a panel that is a voice for Brent young people in care led by Brent called 'Care in Action'. One young person's social net work has increased considerably having an individualised communication book which helps to be more involved and have a greater say in choices, not only in Clement Close matters but in friendship and social networks.

One young person was successful in applying for a Whizz kids new outdoor electric wheelchair. Eagerly waiting for it's delivery before Christmas.

In July, we received visitors from as far away as Jordan and more recently in neighbouring boroughs to look at how our service operates and to try and emulate what has been achieved at Clement Close.

We continually strive to improve the service and value the feedback we receive. We sent a satisfaction survey out in October to parents and professionals involved in the service. We will use the feedback to develop the service.

Clement Close has been delighted with the nomination for an achievement award for equality and diversity from Brent Council to be given out later this year.



# Transforming Short Break Services

Aiming High for Disabled Children steering group is leading the transformation of short break services. The joint commissioning strategy is at the final stages before formalisation and the following lists our intentions for Short Break Services over the next two years.

Anyone wishing to know more about this should contact Maureen Donoher, Short Break project manager 0208 937 4700 or email [maureen.donoher@brent.gov.uk](mailto:maureen.donoher@brent.gov.uk)

## Universal

1. We intend to make small grants available for local community based social, leisure and sports clubs and events that are targeted at, or promote inclusion of, disabled children and young people.
2. We will work with the Early Years Service and have developed a Childminding steering group with the scope of developing skilled and trained childminders to care for disabled children in the childminders home.

## Targeted

3. We will tender for providers or award grants for a variety of short break services, which will address all levels of support required. This will enable children or young people who need a higher level of complex support and those who need a lower level of support to access universal or specialist services. This will also enable us to provide overnight breaks in the home for those requiring home support.
4. We will make available small grants to support the development of local specialist and targeted social, leisure and sports provision, including clubs and one off events. We intend closer working with the Brent Council Sports Services, Brent Youth Services and Ability Youth Project; as well as other service and third sector providers.
5. Services will be commissioned and grants awarded to providers of individual and group care to enable children and young people across the autism spectrum to access targeted and universal services.
6. Young people want to have a voice and have more of an influence about services available to them. We will appoint a Child Young Person Participation Officer to assist children and young people develop skills to influence services and delivery.
7. We will support disabled teenagers who want to enjoy short breaks in a way that promotes their independence and their access to a wide range of activities, according to their needs and preferences.
8. We want to improve the provision of relevant information to disabled children and their families about services available to them. This could be in the form of booklet, electronic or on the council's website.
9. Information relating to services allocated to children and young people or and their families is recorded on different systems which do not inter-relate with each other. A detailed breakdown of the planned short break

services to disabled children, which are funded by social and health services will be developed.

10. We will re-launch the voluntary Children's Disability Register.
11. We are developing a new state of the art multipurpose eight bed Short Break Resource Centre on the site of Hay Lane and Grove Park School to replace the existing two Short Break Units.  
This Resource Centre will provide services for ASD children and young people and those with complex health needs as well as those with other and additional disabilities. The Resource Centre will work in partnership with Health and Education and have access to the facilities of the specialist school also to be built on the same site.
12. We will introduce the Early Support Programme in Brent for newly diagnosed children with disabilities. This national government used in local authorities, hospitals and community-based health services across England will achieve better coordinated, family focused services for young disabled children and their families.
13. We will build further upon the recent expansion in holiday play schemes, after school clubs and holiday and half-term provision and leisure activities.
14. We will increase the take up of direct payments. This is council payments for families with disabled children and young people who have been assessed as needing help from social care, and who would like to arrange and pay for their own care and support.
15. We want to develop the Family Links service and have appointed a worker to assess and supervise Family Links Carers to enable this.
16. To want to appoint a part time worker to monitor the quality of the Short Break Services (Domiciliary) provided. This person will also assist families who may need some additional support managing their Direct Payments.

## Specialist

17. We will commission through CAHMS an intensive package of outreach support and intervention to those children or young people with severe challenging behaviour; where there is serious risk of family breakdown and where with this intervention those behaviours may be reduced in frequency, severity and level of risk.
18. We will commission services for children and young people with complex health needs that can deliver the necessary high level of care in the child or young person's family home. Expertise and training will be provided to care workers. This commissioned service will also include provision for overnight care.
19. We will establish a workforce development strategy which will address healthcare, training and nursing support to universal and targeted short breaks settings, and clear pathways for statutory, voluntary and private providers to access this when and where the need arises.

## Focus on Direct Payments

Direct Payments are a way of arranging social care services for disabled children and young people and their families. A person with parental responsibility for a disabled child is given money to pay for the service instead of Brent council arranging that service on their behalf. A disabled child will be eligible for direct payments if he/she is eligible for a social care service. Disabled Children Services will decide whether a child is eligible by carrying out an assessment of the needs of the child and their family.

As a parent you can use direct payments to employ a person – called a personal assistant - to support and care for your child as an overnight or day carer, a sitter or to support your child at a community activity, for example a youth club. Or you can use direct payments to buy into a local service, for example a residential short breaks unit, a children's hospice, a sitter service, a placement at a day nursery or after school club. You cannot however buy into a service run by Brent council. You may also use a direct payment to purchase equipment needed by your child.

If your child is assessed to need a service, the amount of money that you will be given through your direct payments will be an amount that the council estimate is reasonable in order to buy a service of an equivalent standard to that run by Brent. Currently, the hourly rate for a Direct Payment is £11.65 per hour. This is not the rate the personal assistant will receive as a direct payment should cover not only the payment to the person you employ but also recruitment costs, holiday pay, sick leave, insurance and training costs.

Using direct payments may appear daunting and as a parent, you may be put off by the amount of work that is involved. However, it is important to remember direct payments offers a parent and their child much more control and flexibility over how, when and where support services are arranged.

In providing a Direct Payment, the welfare and safety of the child must come first. A parent will not be given a Direct Payment if the Council thinks their child is being placed in a risky situation.

As children grow older, parents need to give more weight to what they want. Once they are 16 years of age, parents will be expected to give them more control over the whole process of direct payments, in situations where they have the ability to take on this control. Direct payments given directly to 16 and 17 years olds are aimed to help young people become more independent and prepare them for adult life. It can be the stepping stone to using adult direct payment schemes and ensuring that as far as possible young disabled people are supported to lead an independent life.

If you are in receipt of a social care service from the Council for your son or daughter and are interested in

receiving a Direct Payment, please speak to your allocated social worker or key worker or contact the duty worker in the Disabled Children Service on 0208 937 4689.

(Extracts from 'A Parents Guide to Direct Payments' DFS 2006)

## Christmas Activities in Brent's Libraries

On Saturday 19 December

**Making Christmas Hats** at 2.30 pm – 4.00 pm at Kilburn Library

**Making 3D Christmas Trees** at 2.30 pm – 3.30pm at Ealing Road Library and Barham Park Library

**Making 3D Tags** at 2.30pm – 3.30 pm at Tokyngton Library

### Christmas Crafts

At 11 am – 12 noon at Preston Library and at 2.30 pm – 3.30 pm at Kingsbury Library Plus, Willesden Green Library and Neasden Library Plus.

For children aged 5 years and over. Children under eight years must be accompanied by a parent/carer.

**No booking required.**

## PANTOMIME

The Chameleons Amateur Dramatic Society *present*

### 'Jack and the Beanstalk'

on 14th – 17th January 2010 at Paul Daisley Hall, Brent Town Hall, Wembley.

**Book online at [www.thechameleons.co.uk](http://www.thechameleons.co.uk)**

Tickets cost £9.50 each – there are concession rates.

10% off for groups of 10 and more.

All Thursday night tickets cost £7.50.

# 1 Voice

Hello everyone, my name is Kieran O'Donnell. I am the Chair of 1 Voice, a newly formed parent forum for Brent. I would like to take this opportunity to look at in more depth as why it is important for a parent led forum to be a recognised voice in Brent. I would also like to give you a little background on myself and the reasons why I got involved.

I have lived in Brent for over 40 years and have been married to Linda for 17. Linda has also been born and brought up in Brent. We have 3 children, Ryan, 15, Luke, 12 and Jack, 6.

Jack was born prematurely at 30 weeks in Northwick Park Hospital. At 7 weeks, he was diagnosed with Periventricular Lucomalacia (Cerebral Palsy). He is unable to walk unaided but uses a Kayewalker to whizz around. We have also just taken delivery of his first wheelchair. At 2 years old, Jack went to Anansi nursery and then onto Willow's Children's Centre. Whilst at Willow's, Jack was statemented and we all agreed that it would be in his best interest to send him to a mainstream school. Jack is now in Year 1 and has fitted in really well and has been voted as the class representative on the school council.

My first encounter to parent forums was being invited to attend a parent participation conference at Brent Town Hall. I had no idea what this meant or what would be involved, but from the very start I was taken in by the concept of parents being actively involved with decisions that affect their children. I had not thought about it before, but it all made total sense, as who knows their child better than their parents.

As a parent group, we started slowly with various open meetings to discuss matters such as do we need a parent forum? What is the aim of the forum? Who would like to be on the Committee? Agreed terms of reference, a name and logo for the forum. Since these early days, progress has been made at a remarkable speed; committee members have been decided, logo and name of forum agreed; representation on local authority steering groups including transition support and Aiming High. Representation is vital on these steering groups as officers in attendance do make decisions on disability services that your child may be eligible for.

1 Voice hold regular open meetings that all parents and carers of children and young people with additional needs are invited to attend. In addition to these monthly meetings, there are specialist in house steering groups that include the following: the launch day (planned for March 2010); newsletter; fundraising; website.

Your participation in joining 1 Voice is key to its future success. If you have any experience in any of the above, we would welcome your support and interest.

As a 1 Voice member, you will receive regular newsletters with updates on achievements and successes, outings and details of meetings. Enclosed with this newsletter is a 1 Voice flyers including a registration slip and contact details.

Take this opportunity to have an influence on decisions that affect your child.

I look forward to seeing you soon.

**Kieran O'Donnell**

*Chair 1 Voice*

## Update on Together for Disabled Children (TDC) Grant

In April, Brent Carers Centre successfully bid for a grant of £10,000 to formalise parent participation in Brent. This followed on from the grant awarded to Brent Carers Centre to host a conference to highlight the need for formal parent participation which was held in March 2009. The second award for £10,000 is to enable Brent to have an effective parent's forum offering parents who have children with special needs the platform necessary to voice thoughts, opinions, facts and real life experiences with their children who have additional needs. In essence, this grant enabled Brent to form 1 Voice, the Brent parent forum, working together for children and young adults with additional needs. To date, 1 Voice have held monthly meetings, formed a committee, established a website ([www.1voicebrent.com](http://www.1voicebrent.com)), and attended London-wide events, accessed training and planning a launch in the spring.

The grant was a one-off to kick start parent participation in Brent thus 1 Voice are looking at ways to fundraise in order to be a sustainable forum in order to take their work forward. To date, funds have been spent on buying a laptop, software, projector and training in assertion facilitated by Lucy Serfiet, a life coach and published author.

Monies have been set aside for publicity and leaflets, childcare, website maintenance.

We are extremely grateful to Together for Disabled Children for giving Brent the valued opportunity to develop parent participation in the borough, particularly Claire Harding, the parent participation advisor whose advice and input has been invaluable and greatly appreciated. We hope to continue working in a positive manner with outcomes that will benefit our children and carers.



## Useful contacts:

Many of the listed contacts can put you in touch with other organisations that also may be able to offer information and support to you.

Children with Disabilities Team.....	020 8937 4483
Children and Families Information Service.....	020 8937 3001
Special Educational Needs Assessment Service.....	020 8937 3229
Brent Parent Partnership Service .....	020 8937 3434
Brent Connexions Service.....	020 8438 1650
Brent Youth Service (Ability Youth Club) .....	020 8937 3760
Brent Youth Service – Learning for Life 16+ .....	020 8937 3676
Brent Play Service.....	020 8810 9126
BOAT – Brent Outreach Autism Team.....	020 8838 0513
Brent Mencap.....	020 8451 5278
Brent Carers Centre .....	020 8795 6240
Contact a Family.....	020 7608 8700
Brent Young Carers Project.....	020 8795 6249
Parentline Plus.....	020 7284 5536
Brent One Stop Shop (for all council enquiries) .....	020 8937 1200
1 Voice.....	07765 362 877

If you no longer wish to receive this newsletter, please complete the slip below and return it to Brent Carers Centre or email to [disabledteam@brent.gov.uk](mailto:disabledteam@brent.gov.uk)

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Telephone details: \_\_\_\_\_

**Disclaimer:** Every effort has been made to ensure that the information in this newsletter is correct. Brent Carers Centre and partners can accept no liability for errors and cannot recommend products or services. Views and opinions expressed in this newsletter are not necessarily those of Brent Carers Centre and partners.

## How can you help?

- Join the editorial board
- Be involved in helping to plan future events
- Write articles for the newsletter
- Volunteer to distribute the newsletter
- Look at joining steering groups, especially joining sub-groups, for example, Early Years.