



## FULL OF LIFE NEWSLETTER FEBRUARY-MAY 2011

### **CUTS, STAYING TOGETHER AND KNOWING YOUR RIGHTS!**

We are bracing ourselves for cuts, although we haven't heard of anything yet! But we feel sadly that there is no doubt, we will have to return to our lobbying which we can now do with even more vigour as we now know the law! In the meantime we are keen to ensure you know your rights and the rights of your child and so Professor Luke Clements is back! Thanks to Together for Disabled Children we have booked two training sessions with Luke. Further information is available on the flyer sent with this Newsletter. Luke has also published a fantastic new book which is available free to download from our website [www.fulloflifekc.com](http://www.fulloflifekc.com)

### **FULL OF LIFE AT ST CHARLES**



At the recent opening of the first stage of the redevelopment of St Charles Centre for Health and Wellbeing, Young People and staff from Full of Life were asked to perform their production of Grease the musical. This was our first truly public performance, everyone had a fantastic time and we rocked the place! It was really great for our local community to see what our young people can do with the right support.

## FULL OF LIFE GIRAFFE AWARD 2010



This year's award has been given to the community dental service at St Charles Centre for Health and Wellbeing. As you will have seen for our previous newsletters we have been really impressed by the staff team, they work with our children, young people and adults in a calm, understanding and respectful way, and they have a great sense of humour! If you are having problems getting your child seen by a dentist for preventative treatment or if you need further information about the service please contact them on **0208 962 4470**

## VACANCIES FULL OF LIFE AFTERSCHOOL/COLLEGE CLUB



We have been told by parents that they have not been offered Full of Life afterschool/holiday provision as an option for their respite care package. So here is some information about what happens in our services for young people with complex needs which we hope will allow you to make an informed choice about your respite provision. Full of Life afterschool/college club supports young people with complex needs who need one to one support. The service operates three afterschool club sessions per week 3.30-6pm Tuesdays, Wednesdays and Fridays term time only, a Saturday Club and Half term Holiday provision which operates 5 days per week 10-4pm. The service provides opportunities to learn work and play with others in an atmosphere of mutual care and respect. One to one provision offers an array of individualised opportunities both in our centre and in our local community. Young people are encouraged to make choices and develop skills through a range of activities and shared experiences. Through individualised communication aids young people are able to exercise their right to make choices and shape their own futures through the use of person centre planning. Our partnership work with parents, schools and colleges and other services helps us ensure that young people retain personal, social and independence skills as they reach adulthood. For further information please contact Jenna Fashola on 0208 962 9994 or email [jenna@fulloflifekc.com](mailto:jenna@fulloflifekc.com) or check out the photographs of the services in action on the main Full of Life website [www.fulloflifekc.com](http://www.fulloflifekc.com) then click Photos.

## TRYING TO SAVE MONEY!!



We have been looking at ways of saving money, one of our first ideas was to stop posting our newsletter as it costs us £200 each time we post it! Not only will we save money, we will also help

the environment! So please let us email it to you! Send your email address to our Information Officer Adrian Graham [info@fulloflifekc.com](mailto:info@fulloflifekc.com) . We will also make it available on our website [www.fulloflifekc.com](http://www.fulloflifekc.com), but if you don't have any way of printing it off and you would like a copy, you can contact us on 0208 962 9994 and we can print off a copy for you.

## SEN TRAINING:

It was great to see so many parents benefit from our SEN training run by ASSET, if you didn't manage to make the sessions you can still contact us for support from Allison Ambrogi our Parent Partnership Officer on 0208 962 9994, email [ppo@fulloflifekc.com](mailto:ppo@fulloflifekc.com) or visit ASSET's website on [www.asset\\_gb.org.uk](http://www.asset_gb.org.uk)

## FULL OF LIFE INFORMATION SERVICE



We have been lucky that we have received funding for this service for another year. It turns out our service is unique! As other local authorities are having difficulty developing a similar service! We are also being contacted quite regularly by parents and professionals from neighbouring boroughs, and as far away as Scotland and North Yorkshire! The website has over 600 hits per month and is being used mainly between Tuesdays and Fridays which we know is a 'parent pattern'! We are developing our email database to keep you up to date quickly with information that will be helpful to you. Thank you for the positive feedback from parents and professionals, it's great to know that yet again we have developed a service that is helping families in practical, enabling ways!

## SPORTS PROVISION FOR DISABLED CHILDREN/YOUNG PEOPLE



There is a new programme of sports activities for children and young people with disabilities, these include swimming, athletics, and Boccia, for further information please contact Lene Smith on 0207 351 2346 or email her on [sports.development@rbkc.gov.uk](mailto:sports.development@rbkc.gov.uk)

## LOCAL CHANGING PLACES:

Changing Places Consortium has been campaigning on behalf of people who cannot use standard accessible toilets. This includes people with profound and multiple learning disabilities and their carers as well as many other disabled people. A Changing Places toilet has enough space and the right equipment including a height adjustable changing bed and a hoist. For more information about the changing places campaign or to find a changing place close to where you may be visiting, please see their website [www.changing-places.org](http://www.changing-places.org). Full of Life have been working with the Borough for quite a while now to develop local Changing Places and so it's great to see that this year some will be developed at Kensington Leisure Centre, Little Wormwood Scrubs and some Youth Clubs. But the Borough is looking at developing more, particularly in the Centre and South of the Borough and so would like to tap in on your expertise! Please email Peter McDonnell [Peter.McDonnell@rbkc.gov.uk](mailto:Peter.McDonnell@rbkc.gov.uk) with your ideas and comments on the following questions.

1. What can you **NOT** do because of a lack of local changing places?
2. Where do you think we need a changing place in the Borough and why?
3. Are there any other barriers to not having a changing place?
4. Any other comments?

## DISABLED PARKING... BAYWATCH...UPDATE



Disability Now's 'Baywatch' campaign which has been operating since 2005 has been raising the awareness of Disabled bays and badges being abused. More people are being prosecuted for using badges illegally or for having fraudulent badges. **Please remember** that if your child has been allocated a blue or purple badge you can only use these to park if your child is with you. In Kensington and Chelsea you will also need a residents permit to park.

Some parents have reported to Full of Life that people are parking in their child's allocated bay. If this does happen and there is a blue badge in the car, please write down the number of the badge and the car registration number, then report it to the accessible transport department in the town hall **0207 937 5464**. Our reason for suggesting this, is that we know that people awarded a blue badge know **not** to park in an allocated bay and therefore the badge may

be fraudulent. If you need a car removed from your bay you can call parking enforcement at Lots Road **07793 697 439 OR 0207 351 1203.**

## SHORT BREAKS AND DEVELOPING SERVICES



It is great to see that so much has been done locally for short breaks services because of the partnership work with parents. This has meant that funding has been spent on what matters most to our families. But this doesn't mean that the work has finished, especially at a time of financial climate change!! Parents need to be at the centre of services that support them best, otherwise we will return to the past with services developed for us rather than by us. Please let us know if you need support and let us have feedback on the services you currently receive, good as well as the things you find difficult and we will do our best to sort things out!

One piece of good news is that the government announced that there is £800 million investment into short breaks over the next five years. This is a very public commitment by the government to short break provision for disabled children and their families. But the worrying thing is that it has not been ring fenced, so it could be merged into the council's main budgets. Full of Life will try to find out how much the council has received and what it is being used for, as we want to continue to help shape services especially at times such as these.

## CAMPAIGNING SINCE 1994: DON'T CUT US OUT!



Since 1994, Full of Life have fought hard to keep our children and families on the local Agenda. We have made sure you know about services that can support you, have developed our own services when no one else would and supported parents and professionals to develop future services. A recent message from a parent on our answer phone has been that in spite of speaking to lots of people....all roads lead to Full of Life! Sometimes some people have found this campaigning difficult... not only the council officers but also us as parents...as we still have the stress and worry of caring for our children, which

we will do for the rest of our lives! And so it was good to see MENCAP'S 'Don't Cut Us Out' booklets on how to campaign to stop cuts, this has verified that how we campaign is the right way....the only thing we haven't done so far is to contact the local papers as we have always thought we would get there in the end. Let us know any of your ideas of campaigning to keep our support services.

### **KEEP IT SIMPLE.... GOOD FOR EVERYONE!**

***Cemented to the floor by law: Respecting legal duties in a time of cuts!*** This paper written by Steve Broad Barrister for Doughty Street Chambers and endorsed by Council for Disabled Children is not only essential reading for local authorities but for parents too! The paper outlines the central legal duties in relation to disabled children and their families which public bodies must comply.

[http://www.ncb.org.uk/cdc/resources/cemented to the floor by law.aspx](http://www.ncb.org.uk/cdc/resources/cemented%20to%20the%20floor%20by%20law.aspx)

### **DISABILITY LIVING ALLOWANCE WHAT IT ACTUALLY MEANS!**



There are growing concerns about the changes to Disability Living Allowance and the significance and impact on disabled children and families. We know that it's the benefit you claim for your miracle baby who survived, despite being born far too soon but now has special needs; the benefit you claim if your child has complex behavioural or health problems, all are scenarios that can be pushed firmly away by those they haven't happened to. Maybe that's why the Financial Times cleverly commented last year that cuts to disability benefits were "the easiest bits of welfare reform to sell", as people don't understand that these benefits are for them, only needed when they are most vulnerable and least able to fight for themselves. We feel the impact of DLA on the lives of disabled children and adults is completely misunderstood and due to tabloid 'scrounger stories' the assumption is that people who claim Disability Living Allowance are living a lifestyle choice of state sponsored comfort. In fact the following is a list of some of the 'luxury' items that the majority of our families use Disability Living Allowance for, clothes, shoes, nappies, wipes, bed pads in fact for some families receiving Disability Living

Allowance can mean they have enough food on their table for their children...this happens...even in Kensington and Chelsea!

Despite the official fraud rate for DLA being only 0.5%, what is odd is that the plan is to scrap DLA altogether and replace it with the personal independence payment (PIP), which will require expensive rebranding to ensure that even fewer people are eligible for it. The proposal to remove the mobility component of DLA from people who live full time in care homes whose local authorities' fund their places shows how ruthless the attack on benefits really is. If these changes take place, families who have a child or adult in residential schools or care homes but who do actually come home to visit their family may no longer be able to do. Some young people who are in this type of residential placements cannot use public transport due to behaviour issues, or cannot access public transport as its inaccessible! Ultimately our children and families would face further isolation and crucially not have the same opportunities for family life as other people. It also completely demonstrates that the government simply doesn't understand what DLA does for the most vulnerable children and families in our society. This is causing huge anxieties in the lives of local families who are already nearly at breaking point. **If you need support with DLA forms please contact us on 0208 962 9994**

## SEN AND DISABILITY REVIEW

The Governments Green Paper on Special Education Needs and Disability is expected to be published soon. There will be a 12 week consultation period on the green paper and we will put a link to the consultation on our website. [www.fulloflifekc.com](http://www.fulloflifekc.com). This was brought about by the realisation that too many children and young people with special educational needs and disabilities are failed by services designed to help them (Source: Dept of Education Consultation Document). In the report Children's Minister Sarah Teather said that 'parents should be in control of their child's education and future'. They must be involved in discussions and decisions about the support they need rather than feel that they have to battle the system'. Whilst a thorough review of the SEN system is welcome and it is commendable that the government is consulting families, agencies and service users. What is ultimately going to determine the amount of support, resources and choice is money! In all policy documents the existing statutory instruments are usually overlooked- in fact the existing legislation already guarantees each child the right education. In the eyes of the law, our most vulnerable children are guaranteed an education that is appropriate to their needs (Education Act 1996 section IV) unfortunately in many cases parents and the LEA can't quite agree what appropriate means.

The problem is not that the existing legislation is wrong, it's just not being enforced. 94% of appeals involving content of statements (parts 2 and 3) were upheld and went in favour of parents according to SENDIST annual review 2008- 2009.

**If you need help with anything to do with SEN please contact Allison Ambrogi our parent partnership officer on 0208 962 9994**



**AND FINALLY.....A LITTLE GOOD NEWS.....NO CHANGE TO CARERS ALLOWANCE ... BUT WE ARE STILL NOT OUT OF THE WOODS!**

We are pleased to see that Carer's Allowance will remain a non means-tested benefit. It is clear that the Government were considering drawing Carer's Allowance into the new system and if this had been the case, hundreds of thousands of parents/carers would have faced a means-test and the risk of losing their Carer's Allowance and a key recognition of their contribution to society. We are pleased that the Government has listened to parents and carers and preserved this important right - recognising that carers have a unique place in the benefits system.

The Government is still making major changes to the welfare system which will affect carers. Carers who already receive means-tested benefits will be moved onto the Universal Credit and families are facing major reforms and, in some cases, reductions to disability benefits. We will do our best to scrutinise all of the Government's plans for the benefits system and work hard to fight ensure that families, who are saving the **UK £87 billion every year** with the care they provide, get the support and recognition they need."

**All of our staff can be contacted by calling: 0208 962 9994 or emailing them direct at the following email addresses**

1. Debbie Cummins Family Support Worker [Debbie@fulloflifekc.com](mailto:Debbie@fulloflifekc.com)
2. Allison Ambrogi Parent Partnership Officer [ppo@fulloflifekc.com](mailto:ppo@fulloflifekc.com)
3. Adrian Graham Information Officer [info@fulloflifekc.com](mailto:info@fulloflifekc.com)
4. Jenna Fashola Service Manager Afterschool, Saturday and Holiday for Young People with Complex Needs [jenna@fulloflifekc.com](mailto:jenna@fulloflifekc.com)
5. Patricia Torres Carers Advocate [patricia@fulloflifekc.com](mailto:patricia@fulloflifekc.com)
6. Gill Fashola Learning Centre Manager for Adults with Complex Needs [gill@fulloflifekc.com](mailto:gill@fulloflifekc.com)