

NEWSLETTER



March – April 2009

FULL of LIFE

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3 Exmoor Street, London W106BE

AIMING HIGH FOR DISABLED CHILDREN...GOOD NEWS FOR FULL OF LIFE

The Together for Disabled Children partnership, which is made up of Serco and Contact a Family has been selected by the Department for Children, Schools and Families to support the Aiming High for Disabled Children short breaks and parent participation programmes. Aiming High for Disabled Children programmes are backed by significant extra funding from 2008 to 2011. This includes £370m for short breaks, £19m for transition support, £35m for accessible childcare pilots and £5m for parent participation. Aiming High will also ensure that Local Authorities and Primary Care Trusts measure the experiences of parents of disabled children who use their services. Hopefully this will help improve support and health services for our families. The government is also keen to ensure that the families of disabled children have an opportunity to have a say in the way services are developed and run and have created the 'Parent Participation Fund'. Full of Life have been successful in our bid, this initial funding will enable us to print our Newsletter in colour, upload it to our website and also provide training for parents to enable them to be part of any service development groups. We hope that this will enable our families, now and in the future, **so...here is more information about the parent participation training offered to parents. Please contact the office as soon as possible to book your place 0208 962 9994**

Parent Participation Training

MAKING YOUR VOICE HEARD! Trainer Lucy Seifert.

Training will enable you to contribute confidently and effectively on Borough committees and consultations and so help steer changes for disabled children and their families.



The programme will be held over three sessions and includes requesting information and feedback assertively, showing confidence through your body language, handling meetings assertively, being a brilliant listener and dealing with an opposing view, presenting information and ideas clearly and powerfully.

When: Wednesdays 18th March, 25 March and the 1st April

Times: 10.30-1pm

Where: Full of Life, 3 Exmoor Street, W10 6BE

About Lucy:

Lucy Seifert is a leading UK authority on assertive communication and author of four books published by Gower Publishing,

including Training for Assertiveness and Training for Self-empowerment& contributor to Understand Body Language. She has worked with commercial, public sector and voluntary organisations, including Disability Action (WF) parent training for Sure Start (Westminster and University of Oxford.



**ROS OUR FAMILY
SUPPORT WORKER
IS RETIRING, COME
ALONG ON THE 25TH
MARCH TO SAY
GOODBYE**

Ros has been part of the Full of Life family for 8 years now. No words can really describe the amount of support and love that Ros has given our families, Full of Life trustees and staff. Ros has supported some of the most vulnerable and isolated families in the Borough in both practical and emotional ways. She has sourced furniture, bedding, clothes, helped families deal with debt problems, filled in endless Disability Living Allowance Forms, Carers Allowance Forms and supported families in hospitals and with housing issues. In the eight years Ros has worked for us she has raised approximately **£2 million pounds**, ensuring families have accessed relevant financial support and benefits, this has all been done on a part time two days per week post! Her counselling has literally been a lifeline for parents and has been crucial in supporting some parents who have sadly lost their child. Ros is a truly wonderful person, and we will all really miss her.

Ros's last day will be Wednesday 25th March 2009. It would be really lovely to see you for tea and cakes. Please let us know as soon as possible if you can come, so that we can provide the right amount of catering.

**FULL OF LIFE WAITROSE'S CHARITY
OF THE MONTH**



We are thrilled to say that as part of their Waitrose's 'Community Matters' initiative Full of Life was chosen to be one of their Charities of the month. The 'Community Matters' initiative allocates £1,000 a month to each of Waitrose's 190 branches, to distribute amongst three local community projects. Shoppers then get to help decide how the sum is divided amongst the three selected organizations. A huge thank you to everyone who supported Full of Life and raised a **GRAND TOTAL OF £358.**

**UPDATE ON THE NEW
CHILDREN WITH
DISABILITIES CENTRE.**



We are in a unique position as dare we say it...everything seems to be going according to schedule! Funding for the outside play areas of the New Children with Disabilities Centre has been secured via the Play Pathfinder Funding which is great, it will be fully accessible, with a wheelchair accessible swing, trampoline as well as sensory equipment, and outdoor space for children to play, garden or simply relax! Parents and staff have worked together in the development of this whole project right from the start and we at Full of Life are really proud of what has been achieved. A huge thanks to all the parents who have given up their precious time to take part in this development, it will ensure that the needs of all disabled children are catered for now and in the future.

**FULL OF LIFE YOUNG PEOPLE AND
RBKC APOLLO AWARDS**

Young people with complex needs who attend Full of Life After School and Summer Holiday Provision were shortlisted for the RBKC Apollo Awards. This scheme is to recognise

the hard work and new heights that young people have reached. Young people were nominated for their summer production of the Wizard of Oz (photo's on our website under gallery (www.fulloflifekc.com)). Our Boccia Team's hard work and determination managed to help the Boroughs Youth Teams come third in the London Youth Games. Although we didn't get an actual award we were shortlisted out of 300 nominations...which was great news. Well done to everyone who took part.

FULL OF LIFE NEW INFORMATION SERVICE

We have been successful in our bid to develop and deliver a new information service. This service will act as a hub for parents and professionals to feed information they think will be helpful to families who have a disabled child. We want to include as much information as possible covering issues such as health, education, play, respite, leisure, other voluntary organisations, as well as how to access various services, including contact details of relevant people. The new service will be available on our website, over the phone and via information surgeries at Full of Life as well as the New Children with Disabilities Centre. We hope to develop a directory of services and other practical information products. The development of this information service will also help us to see where there are gaps in either information or service delivery for children with disabilities and their families and so help us to work for change. We will let you know when the service is up and running, which should be quite soon.



EMAIL ADDRESSES PLEASE

In order to save on postage and to keep you updated with events quickly, can you please send a blank email to office@fulloflifekc.com.

FOL COMMUNICATION PASSPORTS

Many of you will know about our communication passports which were developed to ensure the needs of disabled children were met on play sites. Over 60 children and young people currently have one, and we are about to go to print again. Parents, children and staff have found these really practical and have used them in various settings such as overnight respite, play centre, afterschool provision etc. They ensure that you don't have to explain your child's needs numerous times to staff and they can get on with the most important thing of having fun! **If you would like a passport for your child, please contact the office on 0208 962 9994 so that we can reserve one for you before half term and summer holidays start!**



THE MUIR MAXWELL TRUST, AND LIFE SAVING EPILEPSY ALARMS

The Muir Maxwell Trust is a paediatric epilepsy charity founded in 2003 by Ann and Jonny Maxwell, whose son Muir has had severe epilepsy since he was four months old. As parents who have a child with epilepsy knows, caring for a child with complex epilepsy is challenging, requiring twenty four hour care, with parents often sleeping with their child or checking them throughout the night. The loss of sleep and the stress for the whole family is immense. From small beginnings in Ann's study in their Edinburgh home, the Trust has emerged as one of the UK's leading charities supporting paediatric epilepsy. The Trust

provides much needed practical support to children and their parents/carers, whilst raising awareness and understanding of childhood epilepsy.

The Muir Maxwell Trust provides epilepsy alarms, as well as other items of equipment needed by parents for the home. Parents can apply directly to the Muir Maxwell Trust for an **epilepsy alarm**, or go through their health visitor, community nurse, epilepsy nurse, GP or consultant. They will receive a voucher from the Trust, which requires to be countersigned by a medical professional who can confirm the diagnosis of epilepsy. The voucher is then sent directly to the manufacturer and the alarm will be delivered within a week. The Trust does not means test for movement alarms, but donations are gratefully received.

How the epilepsy alarm works – the life saving wireless epilepsy alarm sits under the mattress of the child’s bed and alerts the parent or carer to a seizure while sleeping. The alarm makes a loud noise if a sensor detects violent movement in bed, enabling parents to act quickly, and put their child in the recovery position and administer medication as necessary. The epilepsy alarm provides peace of mind and allows many families to have a proper night’s sleep for the first time in years.

For further information about the epilepsy alarm, please contact Ann-Marie Nelson at the Trust Office on **0131 273 5256**, or email info@muirmaxwelltrust.com. **For further information about the Muir Maxwell Trust please see their website on www.muirmaxwell.com**

CHANGING PLACES

For thousands of people including 40,000 people with profound and multiple learning disabilities standard accessible toilets do not meet their needs. Changing Places consortium

have been campaigning for a number of years, to make sure that disabled toilets, have height adjustable changing benches, hoist systems and plenty of space. As part of its Inclusive Design Strategy, the Olympic Delivery Authority has announced that it will include accessible Changing Places toilets in each of the Olympic Park’s venues. As a further result of their lobbying, the Community and Local Government Committee has called for all local authorities to provide consistent and evenly distributed public toilets, recommending that there should be more disabled facilities. **We hope to see more locally in Kensington and Chelsea too.**

DEBT ADVICE FOR FAMILIES WHO HAVE A DISABLED CHILD.

It has been well documented over the years that families who have a disabled child, live below the poverty line. New research unveils extreme hardship among the nation’s carers. The number of carers struggling to make ends meet has risen dramatically since 2007. Two thirds are in fuel poverty, over half are in debt and are cutting back on essentials like food or heating to make ends meet. Nine out of ten carers say their financial position is worse than 12 months ago. Yet parents/carers provide vital support for their child, elderly sick or disabled relatives making a contribution worth £87 billion a year to the UK economy. We know that all of this causes extreme anxiety, **here is something you can do about it.** Contact a Family has entered into a pilot project with Citizens Advice Bureau to improve the supply of face to face debt advice to families with disabled children. The Greater London area is one of the pilot areas in which the new service has started. There are seven workers based in Camden CAB who offer advice and help for



families with disabled children anywhere in the Greater London area. They will arrange to visit you at home anywhere in London. If you would like to make an appointment, please call the **Contact a Family helpline on 0808 808 3555** and they will arrange an appointment for you.

DIFFICULTIES ACCESSING HEALTH CARE?

The lack of health provision for people with learning disabilities has been highlighted in



MENCAP'S 'Death by Indifference' report in 2008 and also more recently in Sir Jonathan Michaels Independent Inquiry 'Healthcare for All'. These reports have led to Secretary of State for Health Alan Johnson saying that he accepts the recommendations of Sir Jonathan Michael's report and so will set up a confidential inquiry to investigate premature deaths of people with learning disabilities, along with Public Health Observatory to provide data on services. The hope is that this will help improve NHS commissioning of services. Full of Life are concerned that this inquiry is to be a confidential inquiry, we think it should be a public inquiry, and have written to the Minister to voice our concerns that yet again that the health needs of people with learning disabilities will be swept under the carpet. Councillor Judith Blakeman's report into the local health inequalities (available on the RBKC website www.rbkc.gov.uk) have also highlighted clear gaps in health services in Kensington and Chelsea for people with learning disabilities. One of these being dentistry for people with complex needs who need general anesthetic to be treated which continues to be an issue.

Please contact us on 0208 962 9994 if you have had trouble accessing health services

for your son/daughter or the person you care for.

PLAY PATHFINDER ACCESSIBLE... FREE... INCLUSIVE PLAYGROUNDS

Kensington and Chelsea have been chosen as a Play Pathfinder. This funding will upgrade and build innovative adventurous playgrounds for children and young people across the Borough.

The Borough have been working with children and young people to develop innovative play sites with challenging equipment and natural landscapes, which will give all children the opportunity to play actively outdoors. The play sites will also be accessible for disabled children, many will have specialised and sensory play equipment. The New Children with Disabilities Centre at St Quintins and Little Wormwood Scrubs will be among the first play sites ready for children to play. Full of Life are also part of the Play Pathfinder steering group. Over time as part of the Full of Life Information Service, we hope to also develop a map of free play sites including accessible play equipment. If there is specific play equipment that you think should be on a play site near you please contact us to let us know. **0208 962 9994**

Did you know!!

Lady Allen of Hurtwood founded the first Adventure Playground for children with disabilities on a site in Old Church Street Kensington. It was probably the first in the world! On the **10th of March 11am BBC Radio 4**, Alan Dein discovers the surprising history of the adventure playground and the role Lady Allen played in promoting adventure play.



YOUR FAMILIES DETAILS BEING 'SHARED'... CONTACTPOINT

Parents and Carers in Kensington and Chelsea are being urged to contact the Council if you want to keep information about you and your child from officials using a new government database.

This year the Government is launching ContactPoint, a new database designed to give social workers and other professional's access to a range of information about every child in England up to the age of 18 and their parents/carers. The data held on ContactPoint will be gathered from existing databases and the cooperation of councils and other organizations is **compulsory**. The Council will seek to use its discretion under the Act to limit the information held on ContactPoint but reserves the right to put information on the database where it considers children to be vulnerable or at risk. ContactPoint will contain every child's name, address, and date of birth, together with the names of their parents/carers, the services they access such as their school and GP and the names of other professionals involved with that child. Again the Council will use its discretion regarding access to the system. The Government has proposed a process called 'shielding'. Shielding means hiding details about a child, young person or family member's whereabouts because some family members may be at risk if their whereabouts become known. Criteria which the Government proposes are used to determine whether a record should be shielded are where not doing so would:

- Place the child at risk of significant harm.
- Place an adult at risk of serious harm
- Put a child's adoption placement at risk.

- Prejudice the prevention of detection of a serious crime.

However there are other criteria which the Council believes need to be taken into consideration where:

- Children or parents believe that this information puts them at risk of 'grooming'
- Children and parents believe that their security is compromised.
- Children or parents have concerns about identity theft.
- Children or parents are concerned about the consequences of the loss of their data.

Whilst Full of Life **totally** agrees that the protection of vulnerable children is paramount. ContactPoint will cost nearly £240million nationally. Surely this money would be better spent on practical support services for vulnerable children and their families?

Parents or carers who want to request that the Council exercises its discretion in respect of their data should contact the Council as soon as possible, as it is proposed that the nations system will go live in March 2009. For Further information please contact the ContactPoint Team on 0207 534 4694 email contactpoint@rbkc.gov.uk or see the Governments website www.ecm.gov.uk/contactpoint

Thanks to the Together for Disabled Children's, Parent Participation Grant which has funded the printing of this quarterly newsletter.