

For families of children who are deafblind

Summer 2013
Issue 10

Wandsworth deafblind Service

Your newsletter

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This newsletter is for families of children with combined vision *and* hearing difficulties - which is called deafblindness or multi-sensory impairment (MSI)

This is the 10th annual 'Your newsletter'

(Apparently that's a tin anniversary...yeah!)



As reported in last year's newsletter, Wandsworth's visual and hearing impairment services have come together with Linden Lodge School to form Wandsworth Sensory Support Services. The new logos (left) for the vision (above) and hearing (below) teams are shown here. The two groups of specialists retain all their expert knowledge and skills but are working

Wandsworth Sensory Support Services

more closely together under the new 'umbrella' of the Sensory Support Service which is great for the crossover of ideas and information that so benefits our deafblind/MSI children.

Ten years ago when Jo wrote the first of these newsletters there were only a couple of handfuls of deafblind children in the borough and a couple of Intervenor (specialist 1:1 workers with deafblind children). Now there are well over 30 children in the borough supported by the deafblind service and over 20 Intervenor in four different schools (enjoying a get together - above)



24th - 30th

June is deafblind awareness

week.

deafblind awareness week is held in the week of Helen Keller's birthday. This year it is going to be BIGGER and BETTER than ever before (see Page 2)

A world 'name' in deafblindness visits borough.

In November we were host to a leading international figure in deafblindness. Prof. Jan van Dijk who is responsible for many of the ways we work with our deafblind children visited Linden Lodge. He gave lectures to staff met with many families and even squeezed in some assessments. He also opened the

new deafblind Alba Centre

This is an exciting new development in the borough. It is a new department at Linden Lodge where classes are taught in a specially adapted distraction-free environment by specialist MSI trained staff, with a high level of Intervenor support. For more information contact Mia Dodsworth at Linden Lodge.



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More Wandsworth News..... deafblind Developmental Assessments

We have had another full year of assessments of some great children. We have had children from different schools come to Linden Lodge to use the facilities in the Alba Centre and have also done assessments in other schools and in homes. The sessions involve families, teachers, Interveners, therapists, local professionals and any other key people. The reports from the assessments help when making targets for the children and contribute to their Annual Reviews.



Usher Syndrome

Oak Lodge has had visits from the Sense Usher team who brought their dog with them and talked to the students about the challenges that vision changes can bring to young Deaf people with Usher.



..and at Greenmead

The staff have adapted the curriculum to suit the needs of the children better - so two new teaching approaches in the borough; with the Alba Centre using the Victoria MSI one too!

deafblind Awareness Week Event

A group of parents at Linden Lodge have organised an awareness raising (and fun!) morning of simulation activities, talks and learning on 28th June (in deafblind Awareness Week). Local MPs, the mayor, key members of the council, local education and many other interested parties are coming along. The theme of the morning is the importance of Interveners. HUGE thanks to the organisers!



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Brothers and Sisters - Siblings

Having a brother or sister who has very special needs like deafblindness is likely to be life-changing. It is not easy as a parent spreading your attention and coping with any addition to the family - but when the new addition has many hospital trips or medical procedures or needs a very high level of support the situation can be far more difficult.

There are obviously some positive things about having a sibling who is very 'special' such as a deafblind child - for example one 14yr old 'big sister' said that living with her deafblind sister gave her 'a greater understanding of other people's differences', AND she's learnt how to sign - which is useful when she volunteers at the Additional Needs Cub Pack - because she found she 'knew more signs than the cub leaders!'



The not so good thing she said was that it could take longer to do things as her sister needed time to have things explained and 'get herself sorted'.

There are some good new resources for siblings...

~ Contact a Family has a good new booklet guide about siblings available at http://www.cafamily.org.uk/media/629582/siblingscurrentlastupdatedjan13_low_res_for_web.pdf or Jo can give you a copy.

~ There is also a charity supporting siblings of disabled people, which is called Sibs and has just launched the first ever UK-wide online support service. The site at <http://sibs.org.uk> has a section called YoungSibs. It includes information about disability, dealing with feelings and family life, and tips for coping



with difficult situations. One 12 year old who has a deafblind little brother who we asked to have a look at it said "It's very welcoming, It's easy and simple and also very helpful if you've got questions to ask. It's also very friendly".

~ Also - Shooting Star Chase hospice do a lot of work with siblings and have just started a new teenage siblings group (their first trip out was Go-karting).

~ Sense have a very supportive sibling network. They have a Newsletter three times a year and run sibling weekends.

Also - while we are looking at the needs of members of the family who may sometimes feel a little bit forgotten -

how about Grandparents? There is a support network, help, information and advice on <http://www.grandparentsplus.org.uk/advice>

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Some useful bits and pieces!

Contact a Family guides Contact a Family have updated some of their guides one called Understanding your child's behaviour is very good and can be found at http://www.cafamily.org.uk/media/629551/behaviour_current-last_updated_january_2013_final.pdf - or from Jo

The Government published the **Children and Families Bill** in February 2013. It suggests some changes to support provided to children and young people with special needs including replacing the Statement of Special Educational Needs with a broader Education, Health and Care Plan (EHC) which will apply up to the age of 25, requiring local authorities to set out a 'local offer' of support and giving parents and young people the option of a personal budget to purchase specialist support. Sense have more information about how this may affect deafblind children on their website - or ask Jo

California deafblind Services have some great resources

There are lots of excellent articles at <http://www.cadbs.org/articles-by-subject/>

Complex support group

Don't forget - there is a support group for families of children with complex needs run through the Acorn Family Centre - and a thriving Father's group - for details 8673 7564

Early Support Developmental Journal for Multiple Needs now available

This Developmental Journal has been produced to help families and professionals support children with complex needs and visual impairment. It is based on a series of 'Can Do' cards which are really practical. The Journals are only available to download at <http://www.ncb.org.uk/earlysupport> (but if that's a problem - ask Jo!)

Children with visual impairment and autism

RNIB has a new microsite offering guidance about children who have both visual impairment and an autism spectrum disorder. Visit the website at: www.rnib.org.uk/autism

And don't forget Sense is the biggest deafblind charity in the country and organise great holidays for deafblind children - <http://www.sense.org.uk/content/summer-holidays>

If you want to see back-copies of this Newsletter ask Jo/Jane. Some have pull out and keep pages (Issue 3 - about the effects of deafblindness, Issue 6 -Audiology, Issue 7 - the role of the Intervenor).

Wishing you all a happy and healthy
summer - if the sun ever arrives!

