

For families of children who are deafblind

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Issue 11

Wandsworth deafblind Service

# Your newsletter

Jo Franklin (deafblind Service Coordinator) and Jane Broadbent (specialist facilitator for deafblind children) are contactable via Wandsworth Sensory Support Services (Hearing Support) 020 8673 7564 or (Vision Support) 020 8780 1801 or [franklin@wandsworthhis.org.uk](mailto:franklin@wandsworthhis.org.uk)



## Wandsworth Sensory Support Services

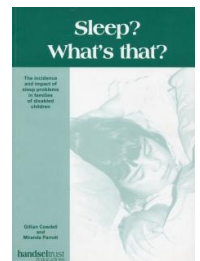
This newsletter is for families of children with combined vision *and* hearing difficulties - which is called deafblindness dual or multi-sensory impairment (MSI)



This is the 11<sup>th</sup> annual 'Your newsletter' which is coming out a little earlier than usual (all will become clearer on page 4). So, some Useful Bits to start with...



We have been thinking a lot about sleep - or lack of it - in the Borough. At the end of last school year we had a really useful day of training from the Handsel Project on Sleep. The results from a questionnaire many of you helped with suggested that lack of sleep was a really big problem for many families (their report 'Sleep? What's that?' suggests that you are not alone). On 18<sup>th</sup> March the Family Information Service organised a really good Sleep seminar run by Sleep Practitioners from 2Sleep - their website has loads of good info [www.2Sleep.org](http://www.2Sleep.org)



23<sup>rd</sup> - 29<sup>th</sup>

June is deafblind awareness week.

deafblind awareness week is held in the week of Helen Keller's birthday. This year the theme is.... Pom-poms!!!



If you are a Wandsworth resident - have you heard about **the Wand Card**? It is a card that gives you some great concessions - including at Battersea Zoo (to mention only one of a long list) and free parking at St George's and Queen Mary's Hospitals. Call Eleanor or Lucia from the Family Information Service on 020 8871 7899, or email [fis@wandsworth.gov.uk](mailto:fis@wandsworth.gov.uk)



Sense have created a giant piece of sensory art called the Tapestry of Touch with 6,000 pompoms, which will be travelling the country to raise awareness of deafblindness and Sense until the end of June.

A quick word about 2 syndromes..

For young people with USHER Syndrome don't forget to look at the [www.usherlife.co.uk](http://www.usherlife.co.uk) website.

And there is a brilliant new publication about working with children with CHARGE Syndrome which can be downloaded at [www.sense.org.uk/content/charge-information-pack-practitioners](http://www.sense.org.uk/content/charge-information-pack-practitioners)



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## June 2013 - A wonderful deafblind awareness week.



Last year's deafblind Awareness Week was the biggest and best we have ever had in the Borough. Ashling Barve led a team of other parents; Sue and Douglas Coster, Myriam Lantrade, Sally Wadman, Eleanor Fiske and Nick Barve, to create a truly memorable event. They worked so

hard to organise a day that would really help people to understand the impact of deafblindness and promote the children's needs. They were helped in this by the team of professionals who work with deafblind children in the Borough.



We had activities using simulation glasses, sleep shades and earplugs to try to help us imagine a little of what the world might be like for the deafblind child. The



activities on offer looked at experiencing signing, mobility, eating and touch - all with simulated hearing and visual difficulties.



We had representatives from Sense with us and a wealth of information available. The people who came also watched the new Intervenor DVD and left with a better understanding of why Intervenor is so vital in enabling deafblind children to access the world. We had an MP, the Mayor, a wealth of professionals from across the Borough and beyond and even one deafblind young woman who was further encouraged in her desire to work in this field herself.

It was a really wonderful team effort. Huge thanks to everyone who worked so hard to make it such a success



**Thank-you all!**

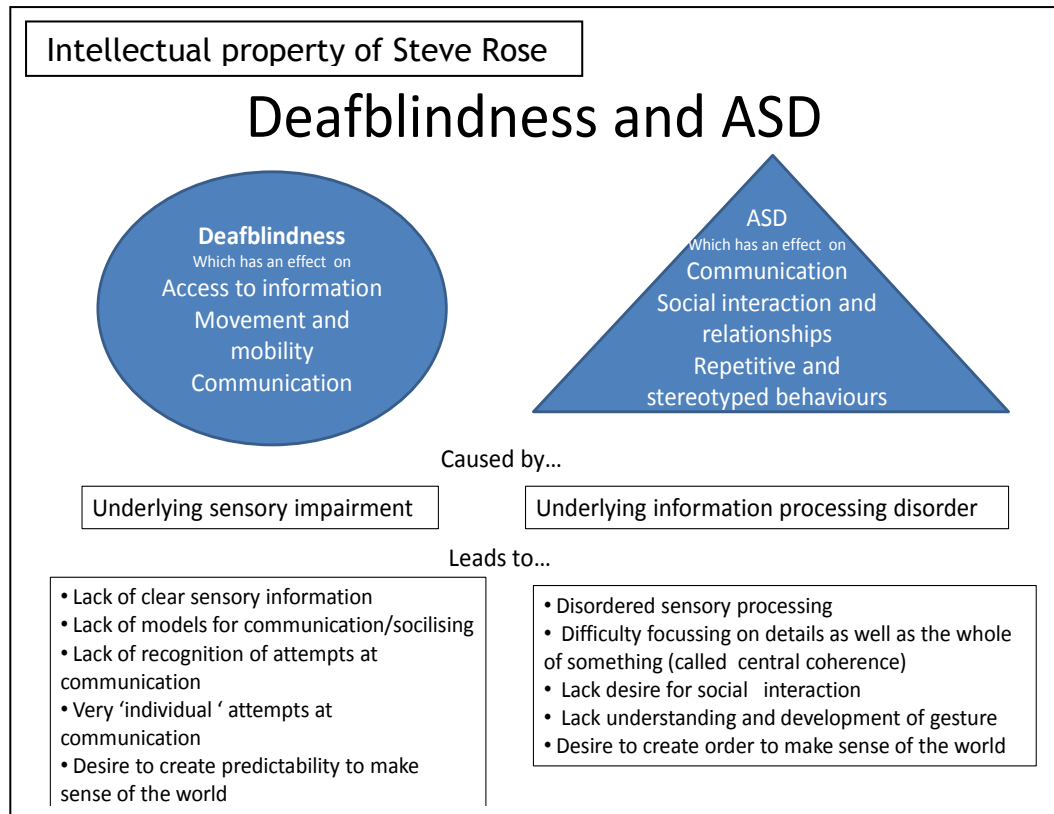
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In Your Newsletter we try to have one page that covers some useful topic that the 'professionals' are talking about that might be of interest to you...

This time it is

## The differences between deafblindness and ASD (Autism)

Steve Rose Head of Children's Specialist Services at Sense did some work on this for his recent Masters dissertation. This is really useful because deafblind children can often do things that get mistaken for ASD. He looked at all the things written in this area and came up with a long list of things that seemed the same but had different causes or were similar or different. He has put his thoughts 'in a nutshell' into a diagram like the one here.



If we look at something like the way that the two groups differ when they are both looking at something (joint attention), deafblind children may show joint attention in an unusual way and it may be a sort of series of 'joining' someone in looking (or feeling) something together, but a child who has ASD might have what Steve calls 'disordered' joint attention..... It is a really complicated area - but it is good to know that someone has been having a really good look at it

MANY THANKS to Steve for letting us share this work

And something everyone in special educational needs (SEN) is also talking about.... **The Government's SEN reforms**

The Government has just passed the Children and Families Act. In it single education, health and care (EHC) plans have been suggested which should bring better partnership working between these groups as well as some other new things like Individual Budgets. Local authorities will have to produce a Local Offer which sets out the support it expects to be available to children with SEN, The statutory Deafblind Guidance will continue to be in force saying that deafblind children should be assessed by someone who is qualified to do so to ensure that they have access to services. See <http://www.sense.org.uk/content/governments-proposals-england> for more info.

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## Some other news

### 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

### Are you a member of Sense?

As well as a great source of information and publishing Talking Sense, Sense are a great advocates for the families of deafblind children. They organise Summer holidays and short breaks for children up to the age of 19.

<http://www.sense.org.uk/content/holidays-and-short-breaks> They also have some really useful new information on welfare benefits, including the 'Bedroom Tax' and Personal Independence Payment (PIP) .

Sense will also be having its Big Event again on 27 September 2014 in Birmingham. It will be 'a chance for people to share ideas, to find out about new opportunities, learn from one another and Sense professionals, and have a social!' Keep an eye on the Sense website for details soon

Don't forget there is some brilliant info at <http://www.cadbs.org/articles-by-subject/>

Have you heard...**Transport for London (TfL)** has launched a new 'Turn up and Go' assistance service for mobility and sight impaired customers at all London Overground stations. Staff will provide assistance without the need to book in advance

### And finally...

The reason this newsletter is coming to you a little early is that I will be leaving Wandsworth in April after 14 years. I have worked with some inspirational professionals, met some wonderful families and been privileged to work with some truly exceptional children. I will carry such wonderful memories with me and will **always** want to hear news of 'your' children.

Wishing you all health and happiness - Jo



Not much change in 14 years...well OK - the photos are small so you can't see the grey hairs and wrinkles!



# ..and a very happy Easter !